Hope for the Holidays

Shriners Children’s provides life-changing care for patients with burn injuries
ABOUT 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 health care 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 health care system with locations in three countries. The fraternity, which has nearly 200 chapters in several countries and thousands of clubs around the world, continues to support this unique health care system. To learn more, please visit shrinersinternational.org.
DEAR READERS,

I am sure we all expected that the COVID-19 crisis would be over by now. Unfortunately, that is not the case, and we all must continue to live and work in the virus’ menacing shadow. Even so, throughout this difficult year, everyone connected with Shriners Children’s remained focused on our mission of improving lives and gave their best efforts to our patients and families every day. This unwavering commitment and perseverance is, quite simply, selfless and stunning. I am intensely proud of our entire staff and honored to be part of this incredible organization.

While December is considered the season of hope, compassion, giving and gratitude, we see and celebrate these values every day in each of our locations. Our medical and clinical staffs continue to offer knowledge and options to patients living valiantly with both rare and more common conditions. Our donors continue to fund our efforts and goals, and our patients continue to inspire us with their grace, thankfulness and inner strength as they overcome one challenge after another.

Within the pages of this edition of Leaders in Care, we are pleased to share stories focused on these themes.

Shriners Children’s is honored to be able to continue our nearly 100-year tradition of offering hope, compassion and healing to children and families, and we look forward to a new year of promise and opportunity, an end to the pandemic, and continuing to share our stories with you.

Sincerely,
Mel Bower
Chief Marketing and Communications Officer
Shriners Children’s

ROBEL (AKA ROBI) was an inpatient at Shriners Children’s Philadelphia for more than six months. He sent this note of thanks.

DEAR SHRINERS,

I wish I could thank you in a way that would give you as much gratitude as you deserve, but that would be impossible. You are the reason why I’m so independent and healthy. Had it not been for you, I would not have been the person who I am today. Not only have I recovered from my injury, but also I have met incredibly amazing people with amazing personalities. You all are so considerate, selfless and diligent. I will miss you all!

Sincerely,
Robel

ON THE COVER: Ntangwe sustained bum injuries in his home country of Namibia and receives care at Shriners Children’s Texas.
Strengthening Collaborative Care

Shriners Children’s Salt Lake City is expanding its long-standing relationship with Intermountain Primary Children’s Hospital. Patients will continue to receive outpatient clinical care at Shriners Children’s, but they now receive surgical, inpatient and infusion therapy services at nearby Primary Children’s Hospital.

Physicians who treat patients at Shriners Children’s Salt Lake City will still perform patient surgeries – they will just be done at Primary Children’s Hospital. All other services remain onsite at Shriners Children’s, including multi-specialty clinics, Pediatric Orthotic and Prosthetic Services (POPS), motion analysis, therapy services, wheelchair seating and mobility, radiology, research, community outreach and care management.

This transition is a continuation of a collaborative care model that has been in place for many years for patients who receive specialized care. This collaborative care model will give surgical patients ready access to more specialists and services – and allows Shriners Children’s Salt Lake City to enhance its specialty services to better meet the community’s needs.

Service Above Self

Shriners Children’s Hawai‘i physician receives recognition

Rotary International District 5000 and Shriners Children’s Hawai‘i are proud to announce that Paul Moroz, M.D., is the recipient of the Rotarian International Service Above Self Award. The award is the highest honor given to a Rotarian and is in recognition of exemplary humanitarian service, with an emphasis on personal volunteer efforts and active involvement in helping others.

Dr. Moroz has worked for more than 20 years with various non-governmental and relief organizations in Nepal, Bhutan, Tanzania, Kenya and Haiti. He served on the board of directors of the Canadian Network for International Surgery and has been an expert consultant with the World Health Organization’s Global Initiative for Emergency and Essential Surgical Care. He was honored in 2012 as a fellow of the College of Surgeons of East, Central and Southern Africa for his work in East Africa.

He was the inaugural chair of the Canadian Orthopaedic Association Global Surgery Committee (COAGS), which seeks to reduce the worldwide burden of musculoskeletal trauma and disease. More recently, Dr. Moroz has conducted research to improve surgical relief when natural disasters hit the Pacific region and has hosted several Scoliosis Informational Nights that provided education for patients across the Pacific Basin.

Dr. Moroz is a pediatric orthopedic and spine surgeon and a clinical associate professor of surgery at the University of Hawai‘i John A. Burns School of Medicine. He joined Shriners Children’s Hawai‘i in 2015.
Clara, 4, sits comfortably watching cartoons, singing to herself and drawing princess castles in her pink, sparkly notebook. Her green T-shirt reads, “Clara Strong. Bent but never broken,” the family motto.

Clara is about to undergo another medical procedure at Shriners Children’s Lexington for infantile scoliosis, a condition causing her spine to curve into an “S” shape. She’s had more than a dozen procedures in her short lifetime. But instead of acting nervous, Clara is calm, and so is her mom, Kayla. “It was very scary at first,” said Kayla. “But Shriners Children’s has done a really great job of making me feel better and giving me a game plan.”

At Shriners Children’s, our philosophy is to consider all options for each patient. For children with scoliosis, this ranges from scoliosis-specific exercise therapy, casting and bracing, to the most advanced surgical treatments, such as growing rods, vertebral body tethering (VBT) and spinal fusion. Our multidisciplinary teams work with patients and their families to create custom treatment plans that will allow patients to return to the activities they enjoy as quickly and with as little pain as possible. >>
The goal is to reach 10 degrees or less with casting or bracing.

**Casting**
Clara is being treated with Mehta casting. The cast is applied in the operating room with the patient under anesthesia and goes from below the arms to just below the waistline (for some patients, it may also go over the shoulders). Each cast is worn for two to three months, with a brief break in between. The number of casts needed and time taken to achieve correction varies in each case.

Following the Mehta casting series, patients wear a removable brace as needed. While Mehta casting corrects spine curvature for some children, for others it may serve to delay curve correction surgery until the child is older.

“The Mehta cast attempts to harness the natural growth of the child’s spine and chest to try to correct their scoliosis,” said Vishwas Talwalkar, M.D., of Shriners Children’s Lexington. “The advantage of the casting over bracing is that you can actually gain correction rather than just maintain.”

When Clara first came to Shriners Children’s Lexington, she had a 50-degree curve. At her visit in July, it was down to 18 degrees. The goal is to reach 10 degrees or less with casting or bracing. For Clara, who also has a fluid-filled cavity at the bottom of her spine called a syrinx, the road to a straighter spine might also involve surgery.

Clara’s family has talked to Dr. Talwalkar about the possibility of MAGEC growing rods and, as her body reaches maturity, perhaps a spinal fusion. The MAGEC rods are surgically implanted to help straighten the spine and are lengthened externally as a child grows using a magnetic remote control held over the spine, reducing the need for repetitive surgeries.

**“Shriners Children’s makes you feel like you are their only patient, and your child’s treatment is the only thing they’re worried about.” – MANDII, GABBI’S MOM**

**Bracing and exercise**
For some patients with scoliosis, treatment may include wearing a brace. Sometimes bracing is combined with a special kind of physical therapy called SSE, scoliosis-specific exercises.

That’s the case for Gabbi, of West Fargo, North Dakota. Her parents first realized something was amiss when she was 11. As they watched Gabbi swim, they noticed her shoulder blades appeared to be at different heights and wondered if she had scoliosis. They downloaded the Shriners Children’s SpineScreen app and scanned Gabbi’s back. The app revealed that her spine had an abnormal curve, so they made an appointment at Shriners Children’s Twin Cities.

Gabbi was diagnosed with scoliosis and, due to the progression of the curvatures three months later, received a custom brace. In addition, Gabbi participates in SSE, using exercises, stretching and breathing to help improve her posture. Since starting treatment, Gabbi, now 14, is on her fifth brace, her curvatures are correcting, and she has grown more than 11 inches.

Gabbi considers her treatment at Shriners Children’s an awesome experience and is eager to share her story with others who may be going through similar situations. “They have a whole plan for scoliosis care, and I love that they look at every option for each kid,” said Gabbi.

Gabbi’s mom, Mandii, agrees. “Shriners Children’s makes you feel like you are their only patient, and your child’s treatment is the only thing they’re worried about,” she said.
Surgery

Sometimes a patient’s scoliosis is severe enough to require surgery.

Chloe, an artist and dancer, was diagnosed with idiopathic adolescent scoliosis when she was 11. Shriners Children’s Chicago Chief of Staff Purnendu Gupta, M.D., explained that the diagnosis is done through a clinical exam, a neurologic exam and X-rays. “Here at Shriners, we have EOS technology, which is a way to do X-rays with less radiation,” Dr. Gupta added.

Eventually, Chloe needed spinal fusion surgery, which Dr. Gupta performed, and she was officially cleared to return to dance just over a year later. “I’d like to say thank you to Dr. Gupta for fixing my spine and for putting up with me every time I asked when I could go back to dance,” Chloe said. “You’ve been so kind, and I am forever grateful for what you’ve done for me.”

Chloe’s journey with Shriners Children’s continued when she needed the Chicago hospital’s sports medicine care. About four weeks before spinal fusion surgery, she fell and dislocated her kneecap because her balance was off due to her scoliosis. Chloe saw Orthopedic Surgeon Kelsey Davidson, M.D., and had reconstruction surgery.

“I’d like to say thank you to Dr. Gupta for fixing my spine ... You’ve been so kind, and I am forever grateful for what you’ve done for me.” – CHLOE
Vertebral body tethering
For patients who meet very specific criteria, an alternative to spinal fusion called VBT may be an option.

That was the case for Trinity, now a freshman in college who has been cheerleading since she was 8. When she hurt her knee and needed to see an orthopedist, her mother, Shavonda, asked about the curve in her spine that Trinity’s pediatrician had noticed at a recent visit. That’s when Trinity was diagnosed with scoliosis.

Her parents researched the best place to go for innovative, fusion-less scoliosis procedures and discovered Joshua Pahys, M.D., and the team at Shriners Children’s Philadelphia. Trinity had VBT surgery in June 2016. Post-surgery, she felt better than she had in a long time, her lower back pain was gone, and she had a straight spine.

VBT straightens the spine using the patient’s growth process. It is a less-invasive procedure than spinal fusion and preserves mobility.

Medical staff at Shriners Children’s Philadelphia, led by Chief of Surgery Amer Samdani, M.D., developed the methods and techniques for VBT and worked closely with numerous stakeholders to bring the technology involved in VBT to approval.

Trinity was able to return to cheerleading six weeks post-surgery. She competed as an Urbana Varsity Cheerleader and a Level 6 All-star Cheerleader for the Maryland Twisters. She also has been a Rebel Athletic Model and has promoted the cheerleading athletic brand around the world.

A Rare Find
Patients with rare conditions get answers and make progress at Shriners Children’s

Shriners Children’s has been a leader in caring for orthopedic conditions since opening its first location in 1922, primarily in response to a polio epidemic. Today, most of our locations can treat virtually all pediatric orthopedic conditions – even those that are extremely complex and rare – with a team approach focused on innovation and compassion.

A care team that’s like family
Aja first visited Shriners Children’s Hawai’i when she was 5 months old, after having been diagnosed with osteogenesis imperfecta (OI, also known as brittle bone disease) before she was born. Her parents chose the hospital because of its reputation for providing excellent care for pediatric orthopedic conditions. Shriners Children’s is known for its research into developing treatments for OI.

The most common sign of OI is bones that break easily. For Aja, treatment has included a number of surgeries, casts and follow-up care. Aja’s team of doctors, nurses and other health care professionals at Shriners Children’s are part of her “ohana” (family). When she needs care, she refers to the hospital as “auntie’s house” and looks forward to seeing the physicians and staff. “Everyone is so nice, and they make me feel better because they fix my broken bones so I can walk again,” Aja said.

Now 10, Aja relishes being a big sister to her two siblings and enjoys swimming, dancing hip-hop and painting with them. Her experience with her care team has fueled her desire to help other children, and she wants to work at Shriners Children’s some day. “I have no doubt that her quiet confidence and resilience will make that a reality,” said her dad, Adam. “Shriners Children’s has been a blessing to our family, and we have the peace of mind knowing it’s never about cost; it’s about the kids.”
A goal of independence
When Deborah and Chris learned that their unborn daughter, Molly, had arthrogryposis multiplex congenita (AMC), a rare orthopedic condition, they weren’t sure what it meant. “We were told from other doctors that there wasn’t much anyone could do,” said Chris. “After we met with care providers at Shriners Children’s Portland, we had a much more positive outlook.”

AMC is characterized by tightened joints, muscles and tendons and affects approximately 1 in 3,000 individuals in the United States. The condition, which ranges in severity, can appear in hundreds of different ways and typically includes visual cues such as clenched fists or club feet.

Molly was born with club feet, causing both of her feet to turn inward and upward. She also had dislocated knees, a dislocated hip and muscle weakness in her legs. If left untreated, Molly might have had difficulty walking or sitting comfortably in a chair.

Molly had her first appointment at Shriners Children’s Portland with Ellen Raney, M.D., when she was 6 days old. Along with her care team and Molly’s parents, Dr. Raney set out to help Molly gain as much independence as possible. After four surgeries, numerous rounds of serial casting to correct the positioning of her feet and spica casting (a cast that includes one or both legs as well as the waist) to foster healing after hip surgery, Molly has gained the independence that her medical team was seeking. Now 3, she has been walking on her own for almost a year.

“Molly loves showing off how much she can bend her knees,” said Deborah. “She’s excited to learn how to jump, and she’s started to join her brother and sister on the trampoline. Molly may do certain things her own way, but there’s little that she can’t do.”

A ‘home for everything’
At 16, Nathan was losing almost complete use of his right leg and had trouble moving his arms. His condition was especially devastating because it prevented him from participating in his favorite sport – bowling. Nathan was diagnosed with acute flaccid myelitis (AFM), a condition that attacks the tissue and the myelin (the protective coating of the nerves in the spinal cord) resulting in weakness and loss of muscle function. AFM is a very rare illness, with approximately 400 cases in the United States over the last four years.

Nathan and his family first learned of Shriners Children’s Philadelphia through an AFM support group on Facebook. Once Nathan began receiving care at Shriners Children’s, he was also diagnosed with a limb length difference and scoliosis. Joshua Pahys, M.D., orthopedic surgeon, is currently treating the scoliosis with bracing.

Jay, Nathan’s dad, said, “When we first heard of Shriners Children’s, we didn’t
know that it would become our home for everything.”

Because of the care he has received for both conditions, Nathan is now able to resume participating in competitive bowling tournaments. Last summer, he competed in the “Teen Masters,” an ambitious tournament for K-12 and college students.

**A persistent search for answers**

When Jade was in kindergarten, she developed a tough spot on her leg that felt hard to the touch. Her parents thought this was odd and made an appointment with their family pediatrician, who told them not to worry.

After a few months, Jade’s parents took her back to the pediatrician. The undiagnosed spot on her leg had not gone away and appeared to be growing. Her doctor was perplexed but seemed confident that it was something Jade would outgrow. Years went by, and, eventually, it began to affect Jade’s ability to walk and participate in activities she enjoyed most: cheerleading and gymnastics.

“I was just so frustrated,” said Jade’s father, Chris. “We were referred to so many doctors who didn’t seem interested in investigating this further. They didn’t know what it was, and they would just refer us somewhere else. Before we knew it, we were being referred back to the original doctors we first met with. We were quite literally going in circles.”

Jade’s pediatrician ultimately referred her to Shriners Children’s Northern California, where her family met Orthopedic Surgeon Debra Templeton, M.D. Dr. Templeton diagnosed Jade with linear scleroderma, an extremely rare autoimmune disease characterized by an overproduction of abnormal collagen that causes normal tissue to be replaced with thick, dense scar tissue. It can affect underlying bones and muscles if left untreated. Dr. Templeton explained to Jade’s parents that she would do everything in her power to build a team of doctors and specialists who would find answers and an appropriate course of treatment.

Jade, now 13, is currently being treated by Assistant Chief of Staff and Orthopedic Surgeon Jon R. Davids, M.D. He analyzed Jade’s gait using high-tech motion analysis – an integral piece of the comprehensive treatment plan for her rare medical condition.

“TO LEARN MORE, visit shrinerschildrens.org.”
It was Dec. 25, 2017, and Kristin wasn’t where she had thought she would be – at home with her family, exchanging gifts and preparing a holiday meal. Instead, the Tennessee woman was huddled in a van, nervous and scared, as strangers drove her and her young son to a hospital six hours away. Braxton, 3, had an open burn wound from weeks before that was getting worse.
Two weeks earlier, at his grandmother’s house, Braxton had reached for a pot of boiling water. The scalding spill left second- and third-degree burns on nearly 70% of his body, including his scalp.

The next few days were a blur. At the local hospital, Braxton was sedated. “He could not open his eyes or sit up,” his mother recalled. “His wounds would stick to the bed linens overnight, and each morning they had to unstick him.”

Kristin received support and thousands of messages through a prayer chain. One stranger’s words stood out. “She said she thought Shriners Children’s could help him, and we needed to get there,” Kristin said.

So, on that Christmas Day, two “Roadrunners” appeared to bring Braxton and his mother to Shriners Children’s Ohio, hundreds of miles from their home in Tennessee. Members of the Shriner fraternity, Roadrunners are dedicated to helping transport patients to Shriner’s Children’s facilities for medical care.

“They left their families on Christmas to take care of my son and me,” Kristin said. “I can’t describe how heartwarming that is. There are really good people in this world.”

The drive was just the start of the support the organizations provided, Kristin said. She left home unprepared for the colder Ohio weather, so the Shriners and hospital staff found her a winter jacket and

Safety in the Kitchen

Cooking is the leading cause of home fires, and scald burns are the second leading cause of burn injuries. Hot liquids, including coffee, soup and microwaved items, can cause devastating injuries. Help protect your family by remembering these tips:

• Keep a close eye on what you’re cooking; never leave the stove or oven unattended.
• Cook with pots on back burners and turn handles inward.
• Do not cook or carry hot items while holding a child.
• Keep hot items away from edges of counters or tables.
• Be aware of things that can catch fire—oven mitts, wooden utensils, food packaging, towels or curtains—and keep them at least 3 feet away from your stovetop.
• Be careful when heating foods in the microwave oven and use the minimum cooking time. Serious burns can result when packaging melts.
• Never allow young kids to use the stove, oven or microwave. When you are ready to teach children how to use these appliances, also consider whether they are able to safely reach.
• Teach children how to handle hot foods safely. Many scalds happen when kids reach up and hot liquids spill.
• Use placemats instead of tablecloths, which young children may pull on, spilling hot foods or drinks.

FOR MORE INFORMATION, visit beburnaware.org.
gloves. They made sure Kristin could stay by Braxton’s bed but also provided a private room so she could sleep.

The biggest impact was on Braxton.

“He was a completely different child the next day,” Kristin said. “They bandaged his burns correctly so they wouldn’t stick. He was looking and acting so much better, more like himself.”

Braxton doesn’t remember much about the bandages, needles or doctors. But he remembers how the staff made him feel. In a word: special. “I got ice cream and hot dogs whenever I wanted,” Braxton exclaimed.

After a month, Braxton went home. But he was never gone long, returning for skin grafts and other surgeries.

Kristin said she had the staff’s support, even when not at the hospital. “I would get worried about how something was healing,” she said. “So I would call and send pictures and ask a lot of questions, and they always helped and never made me feel bad.”

The strength of that support system was tested when Braxton started elementary school, and other children were quick to notice the scar and thin hair on his head.

“He would come home crying,” Kristin said. “He started dreading going to school. Other kids would tease him. The teachers kept asking him what happened, and he didn’t want to talk.”

Shriners Children’s Ohio helped Braxton get fitted with a custom hairpiece. Funding for such hairpieces is made possible through the generosity of donors, particularly the Dr. James Russell Myers Fund. Kristin said she sees the impact of that donation every day in Braxton.

“I have seen his confidence really change,” Kristin said. “He talks more and is more outgoing.”

Braxton agreed, saying he likes to show off his hair and that it comes with an added bonus. “I can take it off when I get too hot,” he said.

Care Across Miles

Ntangwe was 18 months old when he fell into a scalding pot of hot water his mother used for cooking in his Namibian village. Having no knowledge of Shriners Children’s, or any connection to the United States, she treated his wounds the best she could. But given the severity of his burns and the lack of access to proper care, this resulted in horrible scarring on Ntangwe’s legs.

Erik, who traveled to Ntangwe’s village to help build houses and run water pipes, met Ntangwe when he was 3. Ntangwe’s mother showed Erik his severe burns and asked him for help.

A chance meeting on a flight home with a retired nurse led Erik to Shriners Children’s in Galveston, Texas. After months of red tape, Ntangwe made his first trip with Erik to the U.S. in June of 2018, and he had his first surgery to remedy his scarring and improve his mobility last summer.

Ntangwe is now 9 and enjoys being the newest member of the Shriners Children’s Texas ambassador family. As for Erik, he loves being Ntangwe’s medical guardian in the U.S.

Hot Soup: An Overlooked Risk

Nobody knows exactly how many scald burns happen because of soup and noodles, but care providers in burn units and emergency departments across the country agree that these injuries are among the most common burns they see in children. “There continues to be a steady rate of hot soup burns in children,” said Sally Martens, FPN, a member of the burn team at Shriners Children’s Northern California. “We see at least two to three noodle soup burns each week.”

Often these burns affect the lap and genitals, Martens said, when children who are sitting down knock over a container onto themselves. Other dangers that can cause kids to drop hot items in their laps include hot cups that burn their hands and flimsy containers that bend in their hands.
Making the Climb Toward Progress

Therapies offered at Shriners Children’s improve physical abilities, psychosocial health and more

Therapy is a critical element in the recovery and rehabilitation process for patients of Shriners Children’s.

The goals of therapy are to reduce the impact of injuries, disease or developmental delay on a child’s ability to function, and help them perform daily living skills and participate in community activities. Therapists work to improve physical abilities, including motor skills, balance, coordination, strength and endurance. In addition, recreational therapy uses sports, games and activities to provide experiences that improve physical and psychosocial health and the overall well-being of the patients.

Here, we share how therapy has made a difference for some of our patients.

Occupational therapy

Christian was born with a left arm that was much shorter than his right. He began receiving care at Shriners Children’s in Erie, Pennsylvania, when he was a baby and had the first of many arm-lengthening surgeries when he was 4. Surgeries were followed by occupational therapy, primarily focused on self-care.

Christian, now 14, recently returned to the medical center to be seen by the Pediatric Orthotic and Prosthetic Services (POPS) staff and get fitted for a prosthesis. His tennis coach suggested it might improve his game by allowing him to better serve the ball and have more power behind his serve. They designed a device that allows him to toss the ball up with his left arm and hit it with his right.
“They knew what to do right away,” said Christian. “They fix problems. If a kid says, ‘I can’t do that,’ they find a way to make it work. They are amazing and encouraging.”

As he follows his therapy plan and begins to build strength and coordination in both arms, Christian’s serve will only get better.

“I always want to improve,” he said. “I don’t feel good when I don’t. I also want to prove to people that I can be just as good as them.”

**Physical therapy**

Logan, 11, was in a car accident that left him with two broken legs: two broken tibias, two broken fibulas and two broken femurs. Three months later, Bassem, 15, was out for a bike ride when he was hit by a truck and dragged for 50 yards. His neck, back, scapula, femur, tibia and fibula were fractured. Both boys underwent multiple emergency and follow-up surgeries at UC Davis Children’s Hospital, performed by Brian Haus, M.D., pediatric orthopedic surgeon and co-director of pediatric sports medicine and joint preservation at Shriners Children’s Northern California. The two boys were later transferred to Shriners Children’s Northern California for physical therapy and rehabilitation, where their friendship ignited. Suddenly, they were no longer alone in their recovery.

“The collaboration between Shriners Children’s Northern California and UC Davis Children’s Hospital allows us to deliver the best pediatric care possible for kids,” said Dr. Haus. “UC Davis is a level one trauma center, and we have some of the most complicated cases that can be addressed over there. The rehabilitation that exists at Shriners Children’s is something that’s truly unique and special. The fact that we can take care of kids at both facilities and give them the best possible care that they need makes us incredibly unique.”

Dr. Haus works closely with Bassem and Logan’s physical therapy teams and ensured the boys were scheduled for physical therapy together from the start. Dr. Haus knew their experiences were similar and that a bond between them would contribute to a faster road to recovery for both of them.

“I think we’re good friends because we’ve had similar experiences,” said Logan. “And, he’s a cool kid.”

Logan and Bassem have been able to motivate each other during physical therapy sessions and comfort each other during times of shared frustration.

“Logan is the one who is really keeping me going,” said Bassem. “I see him walking in physical therapy now, and that’s where I’m trying to get to. He’s my inspiration.”
Recreational therapy
As part of Shriners Children’s Portland’s recreational therapy initiative, the Adaptive Ski & Snowboard program allows patients of all abilities to have fun on the local mountain, Mount Hood. Until this program, for many of the children, skiing and snowboarding had never been an option. Barriers that patients had experienced may have included their physical condition, the need to use mobility devices like walkers and wheelchairs, the cost of adaptive equipment, a limited number of instructors who are familiar with adaptive equipment and transportation to the mountain.

“They are often told that they can’t do things,” said Caroline Scott, CTRS, recreational therapist. “This is an opportunity for everyone to be told, ‘yes.’”

Lucy and her mom, Stacy, are particularly grateful for the program. Lucy, who has permanent brain damage as a result of a bacterial infection, uses a wheelchair in her everyday life. But on the mountain, she’s easily able to keep up with her peers with the help of adaptive skis and trained volunteers.

“She is elated,” said Stacy. “On the way up here, she was shrieking, she was so happy. It breaks my heart with happiness because it’s awesome to have something like this that makes her feel so included. There are no words.”

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“A True Partner
Travis has neurofibromatosis, a rare disorder that has caused tumors to fill his leg for most of his life. A patient of Shriners Children’s Salt Lake City since he was 3, Travis has gained the ability and confidence to navigate things many people take for granted, like walking up the stairs.

Physical Therapist Mark Lange has been a constant throughout this journey. Over many years, therapy sessions helped Travis learn that he could use his left leg to support himself and make his muscles stronger, even though the tumor completely invaded his left thigh and hip.

That all changed earlier this year, when his femur broke from just 9 pounds of pressure. So, at the age of 14, Travis made the decision to have his leg amputated. His therapy appointments are now focused on strength and recovery.

As his physical therapist, Lange is always on Travis’ side and, while helping Travis become more independent and confident, has witnessed him face many difficulties most people will never experience. “He’s a really brave young man,” said Lange. “I’m always impressed with how he pushes himself through the things he doesn’t believe he can do. And that allows him to achieve his goals and continue making progress.”

“This is an opportunity for everyone to be told, ‘yes.’”
- CAROLINE SCOTT, CTRS

“I’m always impressed with how he pushes himself through the things he doesn’t believe he can do.”
- MARK LANGE, PHYSICAL THERAPIST
Our patients learn to live with grace and strength in the face of adversity – to face life with determination while overcoming physical challenges. They also want to share that sense of hope and healing with others – often by giving to the health care system that has meant so much to them.

Here are the stories of three young people who have done just that, making a difference in the lives of children and families around the world.

Providing a source of comfort
Anna, 17, is one of many patients who has spine issues in connection with other conditions. She has several diagnoses, including diplegic cerebral palsy and kyphoscoliosis, a spinal deformity that causes the spine to curve both sideways and forward. In December 2019, Anna became a patient of Shriners Children’s Chicago, where she had a complex surgery to help reduce pain and restore function.
The generous teen coordinated a fundraising drive with Higgy Bears, a company that makes stuffed animals customized with spine rods or other medical devices. The bears will go to children with spine conditions who are patients of Shriners Children’s Chicago. “I wanted to donate Higgy Bears to Shriners Children’s because of how much my Higgy Bears helped me while I was recovering from surgery,” said Anna. “I’m excited to give back to the hospital that has given me and many other patients the opportunity to live a healthy and happy life.”

Rallying communities for charity events
Sebastian was diagnosed with osteogenesis imperfecta (OI, also known as brittle bone disease) when he was an infant. He has received treatment at Shriners Children’s locations in Salt Lake City, Utah, and Pasadena, California.

Sebastian started “Born 4 Fast,” a charity organization that brings local car communities together to give back to Shriners Children’s. He has organized car rallies to collect toys and school supplies and raised money for both Shriners Children’s locations. “I just want to help make kids’ lives better,” said Sebastian.

He recently celebrated his 12th birthday, and instead of a party with his friends, he organized a car rally and raised $7,000 for the health care system.

Making every step count
Step by step, 8-year-old Emma completed a lofty goal: walking more than 5 miles as part of her Fundraise for LOVE initiative supporting Shriners Children’s Spokane.

Emma planned to collect monetary pledges and donations based upon miles she walked up until her 8th birthday last spring. In addition, she sold popcorn at her local church to add to her gift.

She exceeded her goal of $500, making a $2,753 donation to the hospital.

“She was very proud of herself and overwhelmed by peoples’ generosity,” said Emma’s mother, Billie Jo.

Billie Jo said they created the fundraiser as a way for Emma to stay motivated during her medical journey. Emma was diagnosed with infantile idiopathic scoliosis at the age of 3. Since then, she and her family have made the three-hour drive to Spokane several times a year to see specialists at Shriners Children’s, where she is fitted with customized braces to combat the scoliosis curve.

Shriners Children’s is grateful for all donations – large and small – and for all our generous donors who give so others can have a better life. We especially thank our young donors for their selflessness and compassion.

Leigh, 21, is a nursing student at the University of Tampa and has been a patient of Shriners Children’s Florida, where she has received treatment for osteogenesis imperfecta – also known as brittle bone disease – for most of her life. Her bones can break very easily, and they have. She’s had 45 fractures and 14 surgeries at the health care facility.

At the young age of 3, Leigh approached life with gratitude. When people asked what she wanted for her birthday, she was quick to say she wanted people to donate money to Shriners Children’s Florida instead of gifts. She also said she wanted to raise $1 million for the health care facility. What started as a small backyard barbecue turned into a spectacular event widely supported by Shriners and the community. Crucial to the success of this annual event was Leigh’s ability to connect with community leaders, sports figures and donors. In the fall of 2015, she reached her goal! She is the youngest donor to have a plaque on the Philanthropic Society Wall at the hospital, honoring her contributions and commitment to Shriners Children’s.

Although Leigh is close to transitioning to adult care, she is determined to continue her lifelong relationship with the Shriners community. She intends to continue to bring awareness to the greater community about the health care system and its mission, as she did as a National Patient Ambassador in 2007. She also plans to pass on the compassionate care she learned from her nurses at Shriners Children’s to her patients throughout her future career.
A Vitality for Life Becomes a Lifetime Gift

Shriner makes giving part of his legacy

Each spring, Franklin Estes plants nearly 75 salvia plants in his yard. He still lives in his own home and drives his car. Last year, he bought a new car. Not long ago, he flew across the country on his own to see his granddaughter. His get-up-and-go amazes those who are half his age.

Estes is 105. He became a Mason in 1946 and a Shriner in 1957. Perhaps it’s his cherished Shriner memories that motivate him to continue to get the most out of life – and create a meaningful legacy with his estate gift.

“I had good, close friends,” he said of his Shriner days. He’s proud of the work he did as a member of Melha Shriners in Springfield, Massachusetts, especially as a drummer and secretary in the band.

Estes speaks fondly of his younger days and of his mother, who encouraged him to become a Mason. Decades after making the decision, he still gets emotional when talking about the gift he made in his will to support Shriners Children’s New England. He made it in honor of his mother and for his time as a Shriner – and because of the work they do for children.

“I want to be sure that we can continue to enhance the life-changing care we provide for them,” said Estes.

A gift like Estes’ can make a positive impact on generations of kids at Shriners Children’s.

A Lesson in Charitable Giving

California teacher uses her social media following to raise money for Shriners Children’s

McKenzie Sutherd had an idea for a fun learning opportunity for her fourth-grade class. After her social media account gained some traction, she used her popularity to challenge celebrities to give shout-outs to her students. Actor Jack Black accepted her offer, and within 24 hours, Sutherd had more than 1 million followers.

Sutherd decided to use this attention for good and came up with a new challenge to raise money for charity.

“All of these people are giving so much positivity to you, it’s important we give that back to the world,” Sutherd told her students. After some research, the class decided that they wanted Shriners Children’s Northern California as their beneficiary, and they raised more than $50,000 for the health care facility.

These efforts landed Sutherd a spot on the Ellen DeGeneres Show. Although she was expecting to only be a part of the virtual audiences, she was surprised by a shout-out and interview with the show’s host and star.

Now, Sutherd and her friends are challenging both individuals and organizations to race against another person to retrieve an item of significance from the bottom of a giant bowl of Jell-O in 30 seconds. It’s wacky fun for both adults and kids, and it benefits Shriners Children’s. Learn more about the #SHCJelloChallenge at donate.lovetotherescue.org/fundraiser/3194586.

TO WATCH the video of the interview with Ellen DeGeneres, visit youtu.be/watch?v=DJJRP7q9gQg

L to R: Fezzy, Jonathan Duley (Past Potentate, Saladin Shriners), Ms. Sutherd, Bill Wells, Potentate, Ben Ali Shriners, and Alan Anderson, Development Officer, Shriners Children’s Northern California. Saladin Shriners in Michigan made a significant donation to help the students reach their goal. The photo was taken just before Ms. Sutherd was slimed by her students.
What’s the Perfect Gift This Season?
A Gift That Gives Back

When you start a charitable gift annuity at Shriners Hospitals for Children®, you’ll help children’s dreams come true – and enjoy these lifetime benefits:

- Fixed, regular income for life
- Possible charitable tax deduction
- Partially income tax-free payments throughout your life expectancy

How does it work? Make a gift to Shriners Hospitals for Children. In return, you (or you and someone you choose) will receive steady income for life. What’s left of your gift supports the amazing patients and care at Shriners Hospitals for Children. You can also establish a charitable gift annuity in someone else’s name. It’s a meaningful way to provide for their future and a thoughtful gesture of love.

And the greatest benefit? The joy you’ll feel knowing that you’re helping to make dreams come true for generations of patients at Shriners Hospitals for Children.

Find Your Gift Annuity Rate

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These rates are subject to change. Please contact us for a personalized illustration. If you reside in New York, please contact us directly as your rates may vary slightly.

See Your Benefits
Contact us today for a personal example of your lifetime income and benefits:
Shriners Hospitals for Children
Planned and Major Giving Office
866-954-1576
plannedgiving@shrinenet.org

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California residents: Annuities are subject to regulation by the State of California. Payments under such agreements, however, are not protected or otherwise guaranteed by any government agency or the California Life and Health Insurance Guarantee Association. Oklahoma residents: A charitable gift annuity is not regulated by the Oklahoma Insurance Department and is not protected by a guaranty association affiliated with the Oklahoma Insurance Department. South Dakota residents: Charitable gift annuities are not regulated by and are not under the jurisdiction of the South Dakota Division of Insurance.
Sharing Blessings With the Community

Church volunteers raise funds

Last June, participants in the Vacation Bible School program at Grace Home Church in Grand Cane, Louisiana, wanted to help a local organization. They chose Shriners Children’s Shreveport because it helps so many children, said Pastor Tommy McMellon. More than 50 children and approximately 20 adult volunteers participated in a “heavy money” challenge, meaning all donations needed to be coins, and those with heaviest donation won the challenge. The children raided their piggy banks and asked friends and relatives to contribute their change. Combined, the children raised $1,000, which the church matched for a total donation of $2,000 to Shriners Children’s Shreveport.

McMellon said they were blessed to be able to help and are hopeful that other churches and groups will consider taking up the challenge as well. The children are looking forward to a tour of the hospital in the future.

Why I Give

Words from our supporters

We receive many letters of thanks and gratitude from families who have received care at Shriners Children’s and were inspired to give back. These are just some of the sentiments from our donors.* We are honored by their words and support.

1. My daughter was born with clubfoot. I brought her to Shriners Children’s, and you made an amazing difference in her life. Thank you for all that you do!

2. You offered help to my brother’s child.

3. I cannot think of a better recipient of a contribution than one I can make to Shriners Children’s to make children’s lives better.

4. Many years ago, my friend received care at one of your hospitals. She had many operations, and I know her family could never have paid for this. The Shriners took care of everything. So, in gratitude for all you do, I’m sending this small donation. God bless.

5. Our grandson, whom you helped so much in his early years of life, is now thriving as a college student.

6. My daughter was a patient when she was 13, and she has been a nurse at one of the hospitals for 21 years. Thanks for all you do!

*Edited to protect donor privacy.
The Feel-Good Way to Use Your IRA

Transform the Lives of Patients at Shriners Hospitals for Children

Your individual retirement account (IRA) is a smart way to ensure your dreams for retirement come true. But did you know your IRA can also provide for the dreams of patients at Shriners Hospitals for Children?

Here’s how it works:

• If you’re 70½ or older, you can use the IRA charitable rollover (also known as a qualified charitable distribution) to make a tax-free gift to Shriners Hospitals for Children. Transfer any amount up to $100,000 per year, and you’ll provide kids with complex medical needs the care they deserve—regardless of the families’ ability to pay.
• Beginning the year you turn 72, you can use your gift to satisfy all or part of your required minimum distribution. It’s a win for you and for young patients.

How you benefit:

• You’ll feel good seeing your gift transform the lives of children.
• You’ll pay no income taxes on the gift. The transfer doesn’t generate taxable income or a tax deduction, so you benefit even if you do not itemize your tax deductions.

Not 70½ yet?

When you reach the age of 59½, you may withdraw funds from your IRA without penalty. You’ll pay income tax on the amount you withdraw, but if you itemize your tax deductions, you are eligible to take an income tax charitable deduction for the full value of the gift.

Make Your Gift Today

Contact us to learn the many ways your IRA can make a difference for kids.
Shriners Hospitals for Children
Planned and Major Giving Office
866-954-1576
plannedgiving@shrinenet.org
"If it weren’t for [his doctors], he wouldn’t be walking today. I fully believe that.”

Skylar, 6, was born with club feet. Both feet turned inward and upward toward his thighs.

When Skylar was a baby, his parents sought medical care for him, but what was provided did not improve the situation. Ultimately, a friend referred the family to Shriners Children’s Lexington, where they met Orthopedic Surgeon Ryan Muchow, M.D. The family regularly makes a three-hour trip to the medical center for his treatment but says the miles are worth it.

“Shriners Children’s does a wonderful job,” Skylar’s mom, Heather, said. “He has great doctors, and if it weren’t for them, he wouldn’t be walking today. I fully believe that.”

Skylar’s treatment has included numerous surgeries and bracing. He was also treated with the Ponseti method, which involves a series of casts, changed weekly, that turn the feet out. “With this method, we can get the foot fully corrected,” Dr. Muchow said. “It’s a pretty powerful situation to go from a foot that appears angled in the wrong direction to one that is flat. The patient is able to achieve whatever they desire, and the clubfoot doesn’t limit them in any way.”

Today, Skylar is free of any braces or casts, and he not only walks, but also travels the region as a tiny celebrity impersonator – dancing, singing and imitating the likes of Elvis Presley and Michael Jackson.

“We never thought he’d be able to do anything like this,” Heather said. “To see him out there performing, when for so long we didn’t even know if he’d walk well, is a blessing. It feels like a miracle.”

THE SKY’S THE LIMIT

NAME: SKYLAR
CONDITION: CLUB FEET
LOCATION: SHRINERS CHILDREN’S LEXINGTON
Navigating the Journey

Kids’ passport program makes outpatient care feel like an adventure

For patients and families first visiting Shriners Children’s, the initial outpatient visit represents the start of their health care journey. But as with any adventure, heading off into the unknown can be daunting.

To help families navigate the uncharted territory of their outpatient experience, Shriners Children’s Shreveport created a special passport. Featuring Shriners Children’s mascot, Fezzy (a plush bear), the passport helps guide them through the clinic while also offering fun activities.

During registration, hospital staff marks the passport with each location the child needs to visit that day. For each stop along the family’s journey, the child gets a stamp in the passport. In between stops, Fezzy offers puzzles, games and fun facts to help keep patients occupied and engaged.

The Shreveport team hopes the passport program equips families with a resource that both reassures and informs during vital initial patient assessments.

“Families are often surprised at the number of locations and time commitment required during an initial visit,” Colette Murray, director of outpatient services, said. “With our passport program, we hope to show that while the beginning of a patient journey can be lengthy and involved, each stop serves a vital purpose in planning the absolute best course of care for a child.”

Patients and their families use passports to help guide the way through the outpatient clinic.