

LEADERS IN care

STORIES OF THE MOST AMAZING CARE ANYWHERE

WINTER 2023

Shriners Children's ski camps
give kids much more than a day
on the slopes

Winter Wonderland



Shriners
Children's™

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 healthcare professionals.



WHO DO WE TREAT?



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

WHAT ARE OUR PEDIATRIC SPECIALTIES?



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

GROUNDBREAKING RESEARCH



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

CONTINUING EDUCATION



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



THE SHRINERS FRATERNITY

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

COMMUNITY CONVERSATIONS

Dear Readers,

As the end of the year rolls around, I notice a key change. People are as



busy as ever, but the light is lower, warmer, and there's an undertone of something that's sometimes missing during other times of the year. Hope.

This issue contains stories of medical odysseys: journeys that started in uncertainty but led to a place of hope and healing. At Shriners Children's, our clinicians find a way to say yes. With experience, expertise and compassion, they create custom care plans and encourage their patients to articulate their goals and reach for their dreams.

You'll meet a boy with a rare genetic condition that causes devastating effects on the bones and internal organs. You'll meet a girl who received a terrible injury

during an artillery strike in her home country of Ukraine. You'll meet a young woman born with a knee condition so painful, despite years of treatment and surgeries, that she was about to give up on her dreams.

The connection they share? Finding answers – and renewed hope – here at Shriners Children's.

Our clinicians work here because they want to help children with the most challenging of cases. In doing so, they become among the best in the world. Their dedication to providing care that changes lives is truly inspiring to me.

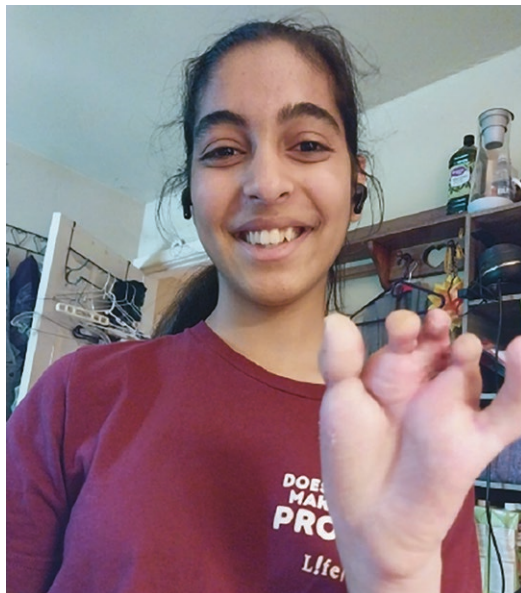
I wish you and yours a season of inspiration and hope.

Sincerely,
Mel Bower
*Chief Marketing & Communication Officer,
Shriners Children's*

PATIENT PERSPECTIVES

Clara was born with amniotic band syndrome – she was missing the lower part of her leg, and her hands and fingers were affected as well. She recently underwent a hand surgery that transformed the look and functionality of her hand. Her mom, Joleigh, had this to say:

"I am constantly blown away by the entire team at Shriners Children's and all you do every day ... Thanks for all you have done over the last 11 years to make Clara's life better, and especially for your patience during her toddler and pre-school years ... We are always so grateful."



LEADERS IN CARE AWARDS 2020-23



WINTER 2023

Contents

ANNOUNCEMENTS

- 4 An Epic Investment in Patient Care



PIONEERS IN PEDIATRICS

- 5 Treating Rare Diseases from A to Z
8 The Latest in Burn First Aid



CHAMPIONS IN HEALING

- 11 Paving a Path to the Stars
15 Winter Wonderland



PARTNERS IN SERVICE

- 17 A Rare Connection
19 Legacy of Love

OUR COMMUNITY

- 23 A Journey of Hope

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

ON THE COVER: Campers celebrate their success on the slopes at Un-Limb-ited Camp in Salt Lake City.

An Epic Investment in Patient Care

Electronic health records system puts patients first

Morgan Smith, a registered nurse and specialty clinics coordinator at Shriners Children's Greenville, is meeting with an orthopedic patient.

She enters the room, and the patient's journey begins with Epic, the most utilized and popular electronic medical records system in the U.S. It all starts with checking vitals and collecting basic information. Height, weight, blood pressure – check. But it's more than that.

"We make sure their medications are correct, check if they have any allergies – and we input all of their history into Epic," she said. "Then, they're ready to see the provider, who will have all of that information at their fingertips."

It's the start of collaboration that will extend through the patient's entire care journey.

Efficiency and personalized care

Part of Shriners Children's commitment to providing the highest quality of care is investing in the latest technology and tools. The goal of the Epic electronic medical record system is to ensure more personalized, ever-higher quality care. A user-friendly tool, Epic has many features that allow for higher accuracy and increased collaboration and efficiency.

"It really revolutionizes the care of the children, to have the medical information available the same day for much better coordinated care and efficient care in the clinic," said Fran Farley, M.D., Shriners Children's Chief Medical Officer.

Smith, who just started using Epic, sees its value. "It has cut down on time and improved the workflow," she said.

As a workflow tool, Epic helps drive each step in the care process, explained Shriners Children's Chief Information Officer John McFarland. For example, the system automatically updates as a medical assistant, nurse and physician each do their part.

Through the system, the provider informs Smith if the patient needs labs or any other follow-ups, and she updates the chart and schedules future appointments.

"So we not only have the capability of ensuring the clinical documentation is accurate, but also awareness of their journey that day," McFarland said. "It helps drive people to take the next steps, so the visit in its entirety is the most efficient it can be."

By the end of the day, any of the child's medical providers can see the updated records, not just within Shriners Children's, but, through secure links, the child's pediatrician and any of their other specialists.



Fran Farley, M.D.,
Chief Medical Officer

Have MyChart?

Sign up now for MyChart
Connect online with your Shriners Children's care team conveniently and securely.

Shriners Children's

Ask about MyChart and sign up today.
For assistance with MyChart call 1-800-237-5055, option 8 or email mychartquestions@shrinersnet.org

Download on the App Store | Get it on Google play

MyChart is a registered trademark of Epic Systems Corporation.

A systemwide effort

To boost accuracy and efficiency, Epic recordkeeping is streamlined across the healthcare system.

"If you're a nurse, your documentation is going to be the same if you're in Shriners Children's Hawai'i or if you're in Shriners Children's Boston," said Shriners Children's Chief Nursing Officer Beverly Bokovitz, DNP, RN, NEA-BC, FAAN. "Whether you have a patient with burns or a child in orthopedics, the documentation is standardized across our system."



Beverly Bokovitz, Chief
Nursing Officer

What it means for patients

It's all part of the positive experience that Shriners Children's is dedicated to providing.

"Both patients and their caregivers think the appointments are faster," Smith said. "Patients and families love MyChart, the patient portal connected to Epic. So, if they leave the visit and they forgot to ask the provider a question, they can just message the provider directly through MyChart, or they can schedule their appointments through MyChart. They can also access their health records securely through the tool."

"With Epic, we improve the quality of care, and we improve the relationship between the patient and the nurses," Bokovitz said. "Having a customized plan is very much key to the wrap-around care that we deliver at Shriners Children's." 📱

Treating Rare Diseases from

A to Z

*Providing
extraordinary care
for extraordinary
conditions*

*Mohammed, who
has spina bifida,
is one of the many
patients who
come to Shriners
Children's for
treatment of
rare diseases and
conditions.*

There are more than 7,000 rare diseases affecting patients in the United States. From arthrogryposis to Zellweger syndrome, they are each so uncommon, most of us will never encounter any of them. The same is true for most pediatricians and adult physicians. But there's a place where rare diseases aren't so extraordinary: Shriners Children's.

In the last 10 years, Shriners Children's has treated more than 27,000 patients with rare diseases. In addition, clinicians and researchers associated with Shriners Children's have published more than 250 studies examining several dozen rare diseases. >>

Rare Conditions Treated at Shriners Children's

We are always working to identify the range of rare conditions treated at Shriners Children's. While this list is not a complete catalog, it offers a look at our extensive reach in this field.

Number of patients (since 2012)	Number of patients (since 2012)
Achondroplasia 758	Klippel-Trenaunay Syndrome 58
Acute Respiratory Distress Syndrome 136	Larsen Syndrome 32
Adams-Oliver Syndrome 6	Loeys-Dietz Syndrome 10
Amniotic Band Syndrome 1646	Marfan Syndrome 846
Arthrogryposis Multiplex Congenita 3340	Marinesco-Sjögren Syndrome 10
Bruck Camurati-Engelmann Syndrome 13	Melorheostosis 7
Cauda Equina Syndrome 173	Moebius Syndrome 38
Charcot-Marie-Tooth Disease 383	Morquio Syndrome 88
Coffin-Lowry Syndrome 4	Multicentric Carpotarsal Multiple Pterygium Syndrome 4
Cole-Carpenter Syndrome 1	Osteolytic Syndrome 8
Compartment Syndrome 547	Nail Patella Syndrome 6
Congenital Insensitivity to Pain 6	Osteogenesis Imperfecta 3004
Cubital Tunnel Syndrome 573	Pfeiffer Syndrome 9
Duchenne Muscular Dystrophy 899	Pierre-Robin Syndrome 61
Dysautonomia 140	Poland Syndrome 115
Ehlers-Danlos Syndrome 1444	Postural Orthostatic Tachycardia Syndrome 11
Epidermolysis Bullosa 40	Prader-Willi Syndrome 444
Escobar Syndrome 25	Rett Syndrome 400
Fragile X Syndrome 126	Spina Bifida 7066
Freeman-Sheldon Syndrome 25	Spinal Muscular Atrophy 730
Goldenhar Disease 79	Spondyloepimetaphyseal Dysplasia 8
Hadju-Cheney Syndrome 6	Staphylococcal Scalded Skin Syndrome 84
Hereditary Multiple Osteochondroma 1360	Stevens-Johnson Syndrome 140
Holt-Oram Syndrome 22	Superior Mesenteric Artery Syndrome 3
Hypophosphatasia/X-linked Hypophosphatemia 1540	Tethered Cord Syndrome 168
Juvenile Dermatomyositis 79	Thrombocytopenia Absent Radius Syndrome 141
Juvenile Paget/Paget Disease 3	Williams Syndrome 89
Klinefelter Syndrome 164	Zellweger Syndrome 13

While Rare Disease Day is marked February 28 on the calendar, Shriners Children's provides care to children with rare medical conditions every day of the year. We're often told that patients don't feel different at Shriners Children's because they see so many others like themselves when they are here.

Special kids finding their way to Shriners Children's

Children with rare diseases find their way to Shriners Children's in many ways. Some already know their diagnosis and seek out our well-known care providers to treat their uncommon conditions. Others come because their condition has specific symptoms that our providers can help with.

"We see a good number of children who don't come to Shriners Children's for their primary diagnosis," said Marc Lalande, Ph.D., Shriners Children's Vice President of Research Programs. "They might have a syndrome that isn't considered an orthopedic disorder, but rather is neurodevelopmental, such as Rett syndrome or Prader-Willi syndrome. They come to us at Shriners Children's because there are secondary skeletal issues, often involving the spine, that we can treat."

Others, like Nathan, come to us seeking answers they can't find elsewhere. When Nathan was 9, he started having pain in his knee. In addition, because one of his legs was shorter than the other, he had problems walking. That sparked Nathan's mother, Blanca, to go on a year-long journey to figure out the cause of Nathan's trouble.

Nathan was first seen at a Chicago hospital, where doctors could not diagnose or treat his condition. As his pain and walking difficulties worsened, Blanca wasn't sure where to go. Eventually, the family landed at Shriners Children's Chicago.



After four months of testing, the medical team there was able to pinpoint the root of Nathan's problems: He was diagnosed with Morquio syndrome.

Morquio syndrome is a rare, genetic metabolic disorder that affects about 5,000 children nationwide. People who have this condition are unable to process certain types of sugar molecules, which affects the growth and development of the spine, bones and organs.

Now 14, Nathan is doing well. To treat his condition and prevent the disorder from progressing, he receives an IV infusion weekly. The care and answers they found at Shriners Children's convince Blanca and Nathan that he has a bright future ahead.

Specialists providing world-class care

Spina bifida is a birth defect in which an area of the spinal column doesn't form properly, leaving a section of the spinal cord and spinal nerves exposed, which often results in damage to the spinal cord and nerves. Only 1,400 babies are born in the U.S. each year with spina bifida, and there are fewer than 125,000 spina bifida patients in the country.

More than 7,000 of those patients have been seen at Shriners Children's in the last 10 years. Mohammed is one of them.

Fleeing war and family tragedy in their native Iraq and then Syria, Mohammed and his family arrived in the U.S. when he was 4. Habitat for Humanity helped the family settle in Sacramento, California. They didn't know Shriners Children's Northern California was there, or that it has one of the top spina bifida programs in the country, led by Maya Evans, M.D.

"It was meant to be that we came to Sacramento," said his father, Bassam. "It was fate."

Now 12, Mohammed loves basketball, the Sacramento Kings and hanging out with his friends. He attends middle school and uses a wheelchair to navigate his everyday life. Bassam credits Dr. Evans and the Shriners Children's team for connecting the family with every resource possible that's given him the ability to live a more independent life.

Over the years, Mohammed has undergone multiple surgeries to correct deformities in his lower leg, foot and spine. When he was 11, he underwent a spinal procedure and received a halo traction device that uses gravity and a patient's own body weight to straighten the spine.

Although Mohammed spent many long and difficult days in the hospital for his surgeries, he is someone who sees the bright side of every situation. "I always looked forward to seeing the child life specialists on the second floor and seeing other kids," said Mohammed. "We played lots of video games like NBA2K and air hockey. Not to brag, but I'm pretty good at air hockey."

That's not the only sport he excels in, though. He is the only student in his school district who plays basketball from a wheelchair. His team created a special play for him called the Mohammed Shield. The play calls for his four teammates to form a square around him, while he drives to the basket, shoots and scores.

"It's the best," said Mohammed. "I love basketball, that's all I want to do. I want to go pro one day."

Researchers forging the path for future patients

Shriners Children's clinicians and researchers are dedicated to not just treating children who have rare diseases, but to



Mohammed doesn't let his diagnosis stop him from playing the sports he loves.

conducting research to learn new knowledge about these conditions that will lead to more effective treatments and better outcomes for these patients. Because Shriners Children's sees so many patients with rare diseases, our teams are in a unique position to collaborate in research across the healthcare system.

What began as a small research effort with a budget of \$12,000 is now a sophisticated, multimillion-dollar program with international recognition. Over the years, Shriners Children's researchers have made significant breakthroughs in many of our areas of specialty care. At the Shriners Children's Genomics Institute, researchers are working to discover genetic causes for diseases and conditions and use the knowledge to create personalized therapies.

At Shriners Children's, "rare" means extraordinary. And that's how we make our patients and their families feel. Providing the most amazing care anywhere and committing to the endless search for better treatments and outcomes, we treat each patient for being as exceptional as their diagnosis. 🏀

In the United States, a rare disease is one that fewer than 200,000 people live with.

Do You Know the Latest in Burn First Aid?

New Shriners Children's research could reduce the likelihood of hospitalization

You may know that immersing a new burn in cool running water is highly effective first aid, but do you know how long to hold it under the tap? It might be much longer than you thought – 20 minutes, according to a recent research paper out of Australia co-authored by Shriners Children's Northern California burn physician Tina Palmieri, M.D. The new paper shows that cool running water on a burn provides more than pain relief. It also helps prevent some of the damage to the skin and underlying tissues. What's more, you have up to three hours to get the benefit of the running water treatment, so there is ample time to react.

A review of several studies demonstrated that 20 minutes of cool running water first aid was associated with substantial improvements.

A look at the evidence

While Dr. Palmieri's group's paper was unable to establish a statistically significant reduction on ICU admissions, it did find a strong benefit on the other outcomes investigated, including a reduction in burn depth, decreased need for skin grafting, a shorter re-epithelization (resurfacing of the wound) time and less need for any surgical treatment for wound management.

For their paper, Dr. Palmieri and the group evaluated seven studies with the requisite quality and data for a meta-analysis. Those studies had a total population of 11,383 patients, of whom 50% received cool running water first aid for 20 minutes. Among the studies, findings included the following:

- One study reported a 31% decrease in the likelihood of pediatric hospitalization.
- One pediatric study reported a 63% decrease in the likelihood of a full thickness wound depth at the first dressing change.
- Pooled results from three studies showed a 46% decrease in the likelihood of the need for skin grafting.
- In two studies, the likelihood of needing any kind of surgical treatment, including grafting, debridement, etc., was 36% lower.
- Taken all together, the studies suggested that the average re-epithelization time was reduced from 14 days to 13 days. (Shriners Children's burn surgeons suggest that when a burn re-epithelizes within 14 days, it won't scar, but any longer than that, it will.)

"The review demonstrated that 20 minutes of cool running water first aid was associated with substantial improvements to patient morbidity, including significant reductions in burn wound temperature and depth, hospital admissions, skin grafting or other surgical intervention requirements and infection rates," the study conclusion said. "Moreover, from a practical sense, cool running water first aid is mostly accessible, simple and can be applied by conscious patients, bystanders and pre-hospital responders."

While it is not definitively known why the water helps, it is thought the coolness alleviates pain somewhat and reduces the temperature of the wound, which >>

Do's and Don'ts of Burn First Aid

Reacting quickly and appropriately to a burn injury can make a significant impact in the recovery process and extent of the skin damage. Here's what to keep in mind for first aid best practices, according to guidance from the American Burn Association and Shriners Children's Dr. Palmieri.



Do
Immediately run the burned area under **cool water**. Dr. Palmieri recommends running it under water **for up to 20 minutes** within three hours of the injury.



Remove all jewelry and clothing around the area.



For small burns, apply **soothing lotions** intended for burns, such as aloe, every four hours.



Drink plenty of **fluids**.



Seek **medical attention** for severe burns or those affecting an area of the body larger than the palm of the hand. According to Dr. Palmieri, if the burn is larger than five hand prints in size, seek medical attention without delay – don't stop to run it under water. This is due to the risk of the patient going into shock.



Take ibuprofen or acetaminophen for **pain control**.



Cover the area loosely with a bandage.

Don't

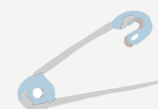
✗ **Do not place ice on the injury** – it could cause further skin damage.



✗ **Do not use any household substance** on the burn, such as butter, tomato or toothpaste – it could trap the heat as well as introduce bacteria to the wound that could cause infection.



✗ **Do not pop burn blisters** – they help protect the injured area from infection.



“Twenty minutes can seem an eternity when you need to stay under the water and not move. You have to actually time it.”

– DR. PALMIERI

may suppress some histamine release, a triggering factor in causing inflammation and swelling.

Are there occasions you shouldn’t take the time to run under cool water? Yes, Dr. Palmieri said.

“If a burn is more than roughly five palm prints in size, you should seek immediate medical attention,” said Dr. Palmieri. “But, if it is less than that, keep the burn under cool running water for 20 minutes” and then seek additional treatment as necessary.

Moving past barriers

While this recommendation is practical and feasible almost anywhere, it’s not especially easy. “Twenty minutes can seem an eternity when you need to stay under the water and not move. Twenty minutes is hard to do,” Dr. Palmieri said. “You have to actually time it.”

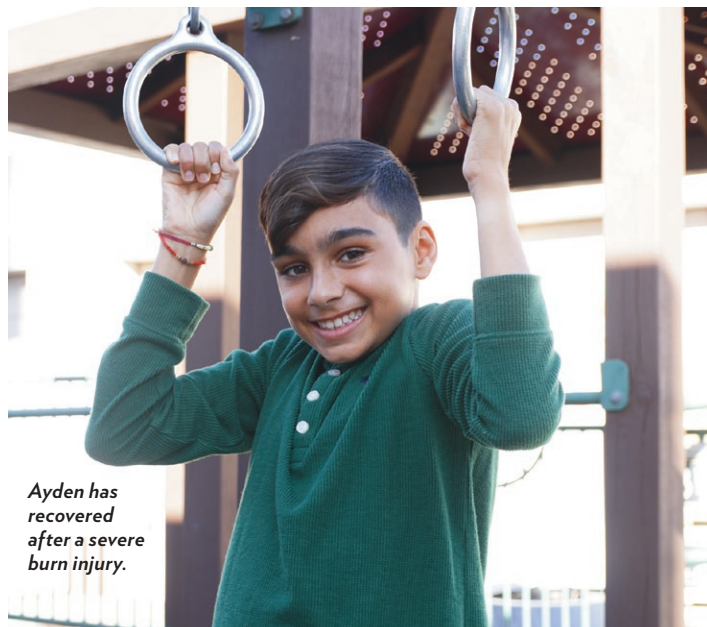
The American Burn Association (ABA) has recommended running burns under cool water for five minutes, but neither the ABA nor the Centers for Disease Control and Prevention (CDC) have adjusted their recommendation to 20 minutes. Dr. Palmieri says the groups have been reticent because there hasn’t been a definitive, randomized, prospective trial – only case-report studies. Dr. Palmieri thinks both organizations should begin to recommend running for the faucet or hose based on the accumulating evidence. 🚰

FOR MORE INFORMATION

about fire safety and burn prevention, visit beburnaware.org.



Tina Palmieri, M.D.



Ayden has recovered after a severe burn injury.

After First-aid Action, Firefighters Recommend Shriners Children’s

Ayden, who was 10 at the time, was standing next to his father, Ravin, a chef, in a makeshift kitchen at an outdoor event. Suddenly, a gust of wind blew a tent into the cooking station and sent boiling water and hot food onto Ayden’s legs and feet.

Luckily for Ayden, four off-duty firefighters had arrived at the event just minutes earlier. The firefighters immediately sprang into action. One quickly disinfected the large kitchen sink so they could treat Ayden’s burns with water, another called for help, and the others grabbed their first-aid supplies. The team worked quickly to triage Ayden’s burns with bandages and water.

In that moment, Ayden’s parents faced a difficult choice. They could transport Ayden by ambulance to the nearest emergency room or they could bring him themselves to UC Davis, close to Shriners Children’s Northern California.

“The firefighters strongly recommended that Ayden go to Shriners Children’s,” said Ayden’s mom, Ashlee. “They all told us we must go there.”

Ashlee and Ravin put Ayden in the car and raced to UC Davis, where he was later transferred to Shriners Children’s. Ayden was treated for second- and third-degree burns for several days. He had follow-up care for months following his injury, including skin graft surgery.

“Everyone from the doctors, nurses and child life specialists did everything they could to make Ayden feel as comfortable as possible,” said Ashlee.

Today, Ayden is a typical 12-year-old boy and is back to doing what he loves: playing drums, competing in sports and hanging with his friends. Ashlee credits Shriners Children’s, and the amazing firefighters who sent him there, for his recovery.

champions

IN HEALING

A FAMILY-CENTERED APPROACH TO COMPASSIONATE CARE

Paving a Path to the Stars

*Our patients' inspirational
journeys to a bright future*

“Follow your dreams!”
“What do you want to
be when you grow up?”
“You can do anything you set your
mind to!” These messages are as
common to childhood as popsicles
and PB&Js. But for children fac-
ing a complex medical diagnosis
or serious injury, these aspirations
can seem out of reach.

For more than 100 years,
Shriners Children's has provided
transformational care that helps
children along their journey to a
bright future. Our patients dream
big and accomplish great things.
They become business owners,
teachers, doctors and pilots. They
are professional athletes and moti-
vational speakers.

For every patient facing what
feels like an uncertain road ahead,
there's another out there paving
the path to greatness. Here are just
a few stories of these remarkable
young adults. >>



*Emmy once feared she
would never be able to
dance again due to her
rare knee condition.*



Steven was treated for burns and now competes in Strongman competitions.

“We started small by tossing a ball. They knew playing sports was really important to me, so it felt like we were accomplishing something together.”

– STEVEN

Steven faces the fire

Steven wears his life on his skin. Ink from more than 14 tattoos can be found beside raised lines, bumps and swirls. Every scar is like a map you can trace to the accident that changed his body forever.

When he was 14, Steven sustained second- and third-degree burns over most of his body after a gas leak triggered an explosion at his home in West Virginia. For three months, he received treatment at Shriners Children’s Ohio.

“It was really frustrating,” he recalled. “I remembered how to walk, eat and lift things, but my body wouldn’t cooperate.”

Steven credits his family and care team for finding the right motivation: sports. “We started small by tossing a ball,” he said. “They knew playing sports was really important to me, so it felt like we were accomplishing something together.”

After he was discharged, Steven wanted an activity that was both physically and mentally challenging. He found that in Strongman competitions and has spent the last six years competing and succeeding in these events. He placed second in West Virginia’s 2020 Strongman competition and was named “Miami’s Baddest Man” in 2021.



Steven is now a firefighter, 17 years after his accident.

This strongman can lift a 330-pound stone over his head and carry an 800-pound yoke for 50 feet. “Just because I look different doesn’t mean anyone should underestimate what my body and mind are capable of,” said Steven.

Now 31, Steven has a new challenge: firefighting. “Fire may have won round one with me when I was a kid, but I’ll win round two,” he said.

Emmy leaves it all on the dance floor

Emmy, 19, had debilitating knee pain that she suffered throughout her early childhood. She was born with discoid meniscus, a rare condition where the C-shaped pad of cartilage in the knee that acts as a shock absorber is instead oval or disc-shaped.

By the time she was 12, Emmy had undergone five knee surgeries, yet the pain became unbearable. She feared she would never



Emmy was once a patient, and now spends time visiting with current patients and volunteering with Shriners Children’s.

FOR MORE
stories about how
Shriners Children's
changes lives, visit
myleadersincare.com.

again be able to do the one thing she loved most – dance.

Emmy's parents were not ready to let their daughter give up. The sports

medicine care team at Shriners Children's Northern California help put Emmy back on the path to her passion.

"It seemed so crazy," said Emmy. "I never thought I would be dancing again!"

Not only did Emmy get back out on the floor, but she even had a stint as a professional dancer. Emmy credits her success to the two knee surgeries, hours of physical therapy and the endless encouragement she received from Shriners Children's staff. She said the team helped lead her away from pain toward dancing again.

"Shriners Children's kept telling me I could dance again," said Emmy. "They gave me my life back."



Matthew has become a successful business owner and now gives back to Shriners Children's.

"Shriners Children's kept telling me I could dance again. They gave me my life back." - EMMY



Matthew makes it his business to give back

When Matthew was 2, a horrific accident left him with third-degree burns and substantial injuries to his hand. He was rushed to Shriners Children's Boston from his home state of New Hampshire for specialized burn care. Matthew was a patient for more than 15 years. During that time, he had dozens of surgeries to reconstruct his hand, as well as intensive physical therapy to improve function.

"As I look back on my difficult start in life, I realize it's not what happens to you in life but what you do with it," he said.

With a desire to help patients like himself, Matthew reconnected with Shriners Children's Boston as an adult. He is the successful owner of a photography and videography company that services over 400 weddings a year. Matthew has donated his company's photography and photo booth services, complete with fun props, for patient parties and the hospital's signature fundraiser, the Boston Haunted Walk.

Matthew even ran the Boston Marathon to honor the burn care he received as a child, although he did it in a creative way. The COVID-19 pandemic caused a reimagining of the beloved race in 2020, with runners choosing their own 26.2-mile course. Matthew crossed his finish line at Shriners Children's Boston to raise funds and awareness for the hospital that gave him the hope and healing to achieve his dreams. >>

"As I look back on my difficult start in life, I realize it's not what happens to you in life but what you do with it."

- MATTHEW

In Their Own Words

Inspired by the incredible accomplishments of former patients, current patients tell us about their hopes and dreams for the future.



Bridget, 15 |
SHRINERS CHILDREN'S
NEW ENGLAND

“I aspire to be a Dallas Cowboys cheerleader. My passion for this sport started as a toddler, and I am dedicated to reaching that elite level of athlete, despite a knee injury. Post-surgery, I have never felt stronger or more versatile as a dancer.”

Kayson, 8 |
SHRINERS CHILDREN'S OHIO

“I want to be a pilot because I can fly people all over the world to destinations they love, and it would make them happy.”



Wen, 10 |
SHRINERS
CHILDREN'S
SHREVEPORT

“I want to be an artist. I love to draw, and I'm inspired by nature! I want to use art to encourage people.”



Grace, 15 | SHRINERS CHILDREN'S FLORIDA

“I think it would be cool to design prosthetics for animals or develop websites for blind or visually impaired users.”

Madison, 16 |
SHRINERS CHILDREN'S LEXINGTON

“I want to work in the horse industry. I enjoy training, riding and just about anything to do with horses. I cannot think of anything I'd rather do that brings so much joy to my life.”



Solomon, 16 | SHRINERS CHILDREN'S HAWAII

“I want to express myself creatively in the art of acting because I love to embody characters. Acting gives a different perspective of looking at life.”



Maria, 18 |
SHRINERS CHILDREN'S
MEXICO

“I want to dedicate myself to flower farming and help the community where I am from. I like to see how flowers grow and cultivate them. I am studying engineering in sustainable agricultural innovation.”



Dash, 8 |
SHRINERS CHILDREN'S
TWIN CITIES

“I want to design video games and even be on *BattleBots* someday.”



Sydney, 18 | SHRINERS CHILDREN'S PHILADELPHIA

“My dream job is to work as an occupational therapist at Shriners Children's. The care I have received has shown me how important it is to help others be comfortable and successful no matter their diagnosis or injury. I want to be that person for someone else like Shriners Children's was for me.”

Winter Wonderland

Shriners Children's ski camps give kids much more than a day on the slopes

Camps at Shriners Children's allow patients of all abilities the opportunity to experience the thrill of winter sports. Our Twin Cities and Salt Lake City locations offer programs that give kids the chance to have fun, make friends, build confidence and, of course, do a little shredding.

A place for kids to relate

Shriners Children's Twin Cities offers two winter camp opportunities: downhill skiing for patients with limb differences and Nordic skiing for patients of all abilities. While the camps are held in Minnesota, just south of the Twin Cities, they draw families from South Dakota, North Dakota, Iowa and Wisconsin.

"It's always amazing to me when families travel great distances so their kids can attend our camps. They recognize the importance of their child being surrounded by other kids with similar challenges, which is always by far my favorite part of camp," said Maureen Johnston, child life specialist and camp director. "After running camps for more than 20 years, I see one common theme – friendship. I'm always inspired as I watch kids come together and cheer everyone on as they master a skill or encourage each other to get up and try again if they fall. Watching kids with similar physical differences teach one another new ways

to accomplish tasks in unique ways is amazing."

Nordic Ski camp is led by BethAnn Chamberlin, a U.S. Biathlon Paralympic development coach, and is supported by Paralympic athletes. A typical day has campers going from station to station doing drills, racing and learning cross-country ski techniques.

At the 2023 session, downhill ski day brought morning temperatures of minus 20 degrees Fahrenheit, but it didn't slow down the 75 campers and volunteers on the mountain. After taking breaks to warm up, the kids were eager to return to the slopes as quickly as possible.

"The first time I was with other kids missing a limb was at Shriners Children's camps," said Adelaide, who has attended Shriners Children's Twin Cities camps since she was 5. Now 16, attending camps is still one of her favorite things to do each year. "Winter events like downhill skiing and Nordic skiing are so much fun," she added. "Shriners Children's provides these activities so we have a chance to challenge ourselves, learn new skills >>

Kids participate in snow sports at Un-Limb-ited Camp in Salt Lake City.

"Through camps, my confidence has grown, I have made new friends, and I have become a better team player. They have helped me grow as a person."

– ADELAIDE



Adelaide has attended Twin Cities camps since she was 5.



Kids form long-lasting friendships at Camp Achieve in the Twin Cities.

and, most of all, have fun. Through camps, my confidence has grown, I have made new friends, and I have become a better team player. They have helped me grow as a person.”

Living life unlimited

At Shriners Children’s Salt Lake City, patient care extends to Utah’s snow-covered mountain tops; after all, one of the best ways to provide the most amazing care anywhere is with the greatest snow on earth!

Each year, Shriners Children’s patients with limb differences from across the U.S. gather at Park City Mountain Resort for a week of skiing and snowboarding at the Salt Lake City-based Un-Limb-ited Camp.

Un-Limb-ited Camp provides a place for these teens to get out of their comfort zones and develop life-long friendships with peers who can understand them better than most.

At the 2023 camp, 19 patients took to the slopes equipped with adaptive gear such as monoskis, bi-skis, outriggers and one-on-one expert instruction from the National Abilities Center instructors at Park City Mountain Resort.

“We had several first-time skiers and snowboarders this year, and they have just

taken off; it is a real testament to how well these kids can adapt,” said Walter Durtchi, Shriners Children’s Salt Lake City care manager and Un-Limb-ited Camp staff member. “Half the kids up here are better than I am; they are incredible!”

While the thrill of skiing and snowboarding is reason enough for teens to attend camp, what happens off the snow has the biggest impact. Staff and

volunteers facilitate social activities to tackle common life-long issues, including recreation, relationships, body image, bullying and self-esteem.

“On a daily basis, I don’t get to have the opportunity to speak with other people and share my experience with other people who know how I feel and feel the exact same way,” said Tia, a Shriners Children’s Salt Lake City patient. “Being able just to text a friend I met at camp has been so helpful to me.”

Other campers described the friendships they made at Un-Limb-ited as their safe space and their own kind of support group.

“Life has thrown these kids some major curveballs, but they continue to push through and defy those odds. That’s what makes them unlimited,” said Laura Hollingshead, Shriners Children’s Salt Lake City recreational therapist and Un-Limb-ited Camp staff member.

Shriners Children’s mission is to provide kids with opportunities to reach their dreams and live without limits. For more information about camp opportunities, visit shrinerschildrens.org or contact your closest Shriners Children’s location. 📍

At the 2023 camp, 19 patients took to the slopes equipped with adaptive gear such as monoskis, bi-skis, outriggers and one-on-one expert instruction.

Campers celebrate their success on the slopes at Un-Limb-ited Camp.



“Half the kids up here are better than I am; they are incredible!”

– WALTER DURTSCHI, CAMP STAFF

A Rare Connection

Patients share the same rare condition – and so much more

Madelyn and Keira, who found each other over social media, share the same limb difference.

Keira and Madelyn were both born with the same rare condition, congenital absence of the left arm. Treated at different Shriners Children's locations – Keira in Philadelphia and Madelyn in St. Louis – and with 15 years between them, it wasn't likely that the two would ever cross paths. And yet seven years ago, the unlikely happened. Thanks to the power of social media, their mothers Jessica and Melissa connected, and a special bond between the pair began. The connection is an example of how Shriners Children's patients find much more than amazing care within our walls. >>

Finding your match

Despite their age difference, the girls share many similarities. Keira, 8, is often described as 23-year-old Madelyn's mini-me. Those similarities have allowed them to find someone who can relate to their daily experiences. Over the years, the girls and their moms found support in each other, but only through messages and video calls. Until recently. The fated friends were finally able to meet in person through Shriners Children's and the Lucky Fin Project, an educational resource and support network for families of children with limb differences.

"Meeting Keira in person was one of those moments that was incredibly hard to put into words because there is genuinely an immense amount of joy in meeting someone who looks just like you, after knowing each other for years but being separated by distance," said Madelyn. Keira said she was excited when she saw Madelyn and happy that they could meet in person.

Spreading the word

The most special part of the visit was their opportunity to speak together at Keira's school. During the presentation, the girls shared their stories and educated students about braces and prosthetics. "Keira's self-confidence was evident as she stood with Madelyn in front of the large group of students, something she never would have done before!" said Keira's mom, Jessica.

"Meeting Keira in person was one of those moments that was incredibly hard to put into words because there is genuinely an immense amount of joy in meeting someone who looks just like you."

- MADELYN



The girls meet for the first time when Madelyn makes a surprise visit to Keira's home.

The girls and their moms truly love celebrating one another, and they especially love celebrating all of their accomplishments together.

"Keira lit up when she saw Madelyn and immediately ran to her like she had known her forever. You would never know this was their first meeting in person," said Jessica. "That is a true testimony of the connection of the Shriners community."

"Not many individuals are born completely missing their left arm, and knowing that Keira is able to see someone who looks like her is a delight," said Madelyn. "There is so much valuable knowledge in the living experience that each of us has with various disabilities, and it means the world to me to pass on that information to make a positive impact." 🧡

Over the years, the girls and their moms found support in each other, but only through messages and video calls. Until recently.

Creating a Legacy of Love

The many ways you can help Shriners Children's reach more kids in more places



IMAGE: ISTOCK.COM/PCH-VECTOR

Making a difference through a charitable gift annuity

As a little boy in a big hospital in the mid-1940s, Eugene remembers that his nurse sang to him whenever he was scared. Eugene, then not quite 10, was a patient at Shriners Children's Philadelphia, recovering from surgery to fix a stiff arm, shoulder and retracted hand.

Decades later, Eugene proudly supports Shriners Hospitals for Children through his three charitable gift annuities (CGAs).

A CGA is a simple philanthropic option in which you make a gift, and in exchange, you receive fixed payments for life.

"I discovered that CGAs accomplish two

purposes," Eugene said. "They help the organization, and I receive income in return. In fact, I make more money now than when I was working!"

Eugene's support of Shriners Hospitals for Children honors the memories of all that his family and the nurses and doctors did for him when he had medical issues as a child. "To get life, you have to give," Eugene reminded us. "That's what I'm doing now for the children at Shriners Children's." >>



WANT TO LEARN MORE about which choice is right for you? A charitable gift annuity, a gift from your IRA or a gift in your will or trust? Are you ready to join Eugene, Colleen and Billy and start your legacy of love for kids? If so, contact us today to learn how you can help bring hope and healing to children for generations to come. Contact us at **813-367-2241** or **plannedgiving@shrinersnet.org**.

Annuity Interest Rates

ONE LIFE

AGE	RATE
60	4.9%
65	5.4%
70	5.9%
75	6.6%
80	7.6%
85	8.7%
90+	9.7%

TWO LIVES

AGE	RATE
60/65	4.5%
65/70	4.9%
70/75	5.5%
75/80	6.1%
80/85	7.0%
85/90	8.3%
90/95+	9.5%

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.

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.

Eugene



Honoring someone through an IRA charitable rollover

Colleen

When Colleen's father was just 2 years old in the late 1920s, his legs were so bowed he couldn't walk properly. A neighbor noticed that the toddler wasn't walking as he should and connected him with Shriners Children's St. Louis, the closest location to their southern Illinois home.

Colleen has never forgotten that story. "From what I heard, my dad had rickets," Colleen said. "He wouldn't have walked if he hadn't gotten help."

Colleen started supporting Shriners Hospitals for Children early in her career. Last year, Colleen used an IRA charitable rollover, also known as a qualified charitable distribution, for the first time to make a tax-free legacy gift. She felt overjoyed to be able to make a "big gift," and she received several helpful benefits because of her generosity.

"My dad said Shriners saved him," Colleen recalled. "This was an opportunity to give back."



IMAGE: ISTOCK.COM/PCH-VECTOR

"My dad said Shriners saved him. This was an opportunity to give back." – COLLEEN



Billy

Sharing hope through a gift that keeps giving

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 member of the fraternity for 48 years. Not only was he able to tell her all 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 Hospitals for Children 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's experience inspired him to name Shriners Hospitals for Children as a beneficiary of his estate through the endowment fund. Today, Billy is an enthusiastic member of the Dream Makers Legacy Society.

TO LEARN MORE about these or other opportunities to make a gift to Shriners Children's, call **813-367-2241** or email plannedgiving@shrinenet.org.

IMAGE: ISTOCK.COM/EKATERINA CHIZHEVSKAYA



Charitable Giving Through Real Estate

Unlock your philanthropy potential – without directly hitting your bank account – by considering a gift of real estate. A donation of real estate can include a personal residence, commercial property, undeveloped land or vacation home. If you have held the appreciated property for longer than one year, you can benefit from an income tax charitable deduction; reduce or eliminate capital gains tax; and reduce your estate administration expenses. Included among the ways you can donate real estate to Shriners Children's are:

- Make a direct gift
- Donate your home while still living in it through a retained life estate
- Give through your will or living trust
- Use a property to fund a FLIP Charitable Remainder Unitrust to receive lifetime financial benefits 📞

 **VISIT** shriners.givingproperty.org to learn more.

Gifts of Stock

It's as quick as grabbing your morning latte at the local coffee shop. Shriners Children's has partnered with **DonateStock.com** to enable supporters to make stock donations in 10 minutes or less. Through this secure portal, giving stock is fast, safe and easy. By making a gift of stock, you avoid capital gains tax, and Shriners Children's receives the full value of your contribution. The fair market value of your stock is also tax deductible. 📞




 **VISIT** lovetotherescue.org/stock-gifting to learn more or to make your gift.

IMAGE: ISTOCK.COM/FILO

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.
- If you are required to take minimum distributions, you can use this transfer to satisfy your obligation. 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.

Contact the Planned and Major Giving Office at plannedgiving@shrinenet.org or 866-954-1576 for more information.



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A JOURNEY OF HOPE

NAME: KAROLINA

CONDITION: DOUBLE AMPUTEE

LOCATIONS: SHRINERS CHILDREN'S BOSTON, SHRINERS CHILDREN'S NEW ENGLAND



“She got right up and took off walking. It surprised me how fearless she was.”

– BROCK MCCONKEY

Injured during an artillery strike in her home country of Ukraine, 7-year-old Karolina, a double amputee, arrived at Shriners Children's Boston in early 2023. Treated by a collaborative care team from the Boston hospital and Shriners Children's New England in Springfield, Massachusetts, Karolina took her first steps on new prosthetic legs just weeks later.

Led by physical therapist Hilary Smith-Chong, the Shriners Children's Boston rehabilitation team worked on strength and balance with Karolina in preparation for receiving her prosthetics. Brock McConkey, Manager of the Pediatric Orthotics and Prosthetics Services (POPS) department at Shriners Children's New England, casted Karolina for temporary prosthetic legs.

Shriners Children's worked in partnership with the Ukraine House – the foundation established by Ukraine President and First Lady Zelensky – to provide care for Karolina. Relationships with additional humanitarian and government agencies were integral to helping both Karolina and Daria, her godmother and guardian, during their time in the United States.

On the day of her initial fitting, Karolina's ability to instantly navigate her temporary prosthetics astonished everyone in the room. “Children who use bilateral prosthetics need to have even more balance and strength than those who don't,” Smith-Chong explained. “She picked up the use of her prosthetics possibly faster than any other child I have worked with.”

Karolina received her permanent prosthetics before leaving Shriners Children's Boston in late March. Her positivity and perseverance inspired everyone she met. “Karolina is truly a hero for everything she has been through,” said McConkey.



★ Small Beads, Big Victories

A colorful way to mark a burn survivor's journey

Child life specialists at Shriners Children's Ohio use a colorful method for patients to mark their milestones on their burn recovery journey.

Each child who spends significant time in the hospital receives "journey beads." Each bauble represents a different surgery, procedure or goal the child accomplished during their hospital stay.

"We wanted to honor the recovery path our patients are traveling with a visible representation of their experience," explained Michelle Smith, child life specialist. "Every patient's journey starts with the same bead: a red heart to welcome them to the Shriners Children's family."

There are dozens of different colored and shaped beads to mark each accomplishment.

The star-shaped beads represent different procedures for radiology, sutures, and facemask or pressure garment fitting. Some beads are given when a patient reaches a recovery milestone, such as a nutritional or medical goal. There are also larger beads for developmental or emotional goals. For example, a child can earn a bead for an act of courage, celebrating a birthday or holiday in the hospital,

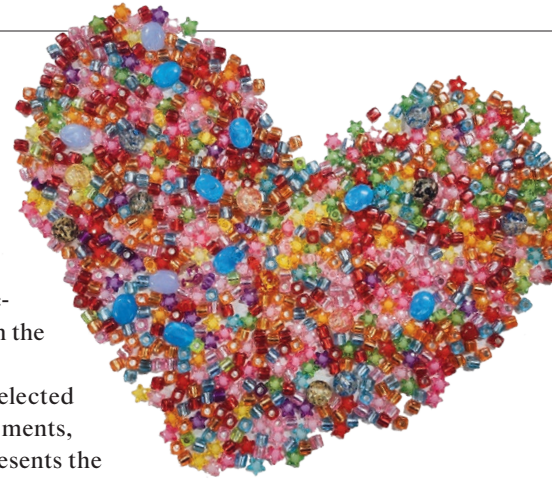
or to mark their first successful outing away from the hospital unit.

"We intentionally selected a variety of accomplishments, because that truly represents the comprehensive, multidisciplinary care patients experience during their hospital stay," said Sarah O'Neal, a child life specialist with the hospital.

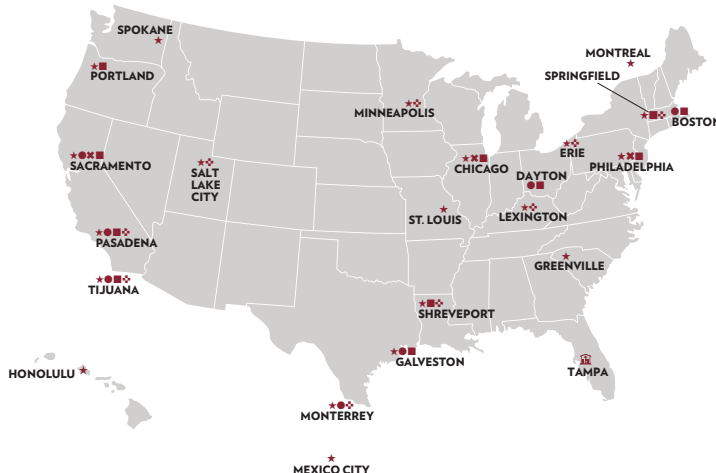
When the child is ready to be discharged from the hospital, Michelle and Sarah carefully arrange the beads into a vibrant, colorful heart before presenting them to the patient and their family.

"It's a really emotional moment when a child and their family see their collection of beads, sometimes hundreds of them, grouped together," O'Neal said.

"One surgery or dressing change by itself may seem insignificant, just as one single bead is small and easy to overlook," Smith said. "But taken together, it represents the determination, fortitude and strength of their healing story."



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