

# LEADERS IN *Care*

**STORIES OF THE MOST AMAZING CARE ANYWHERE**

**WINTER 2020**

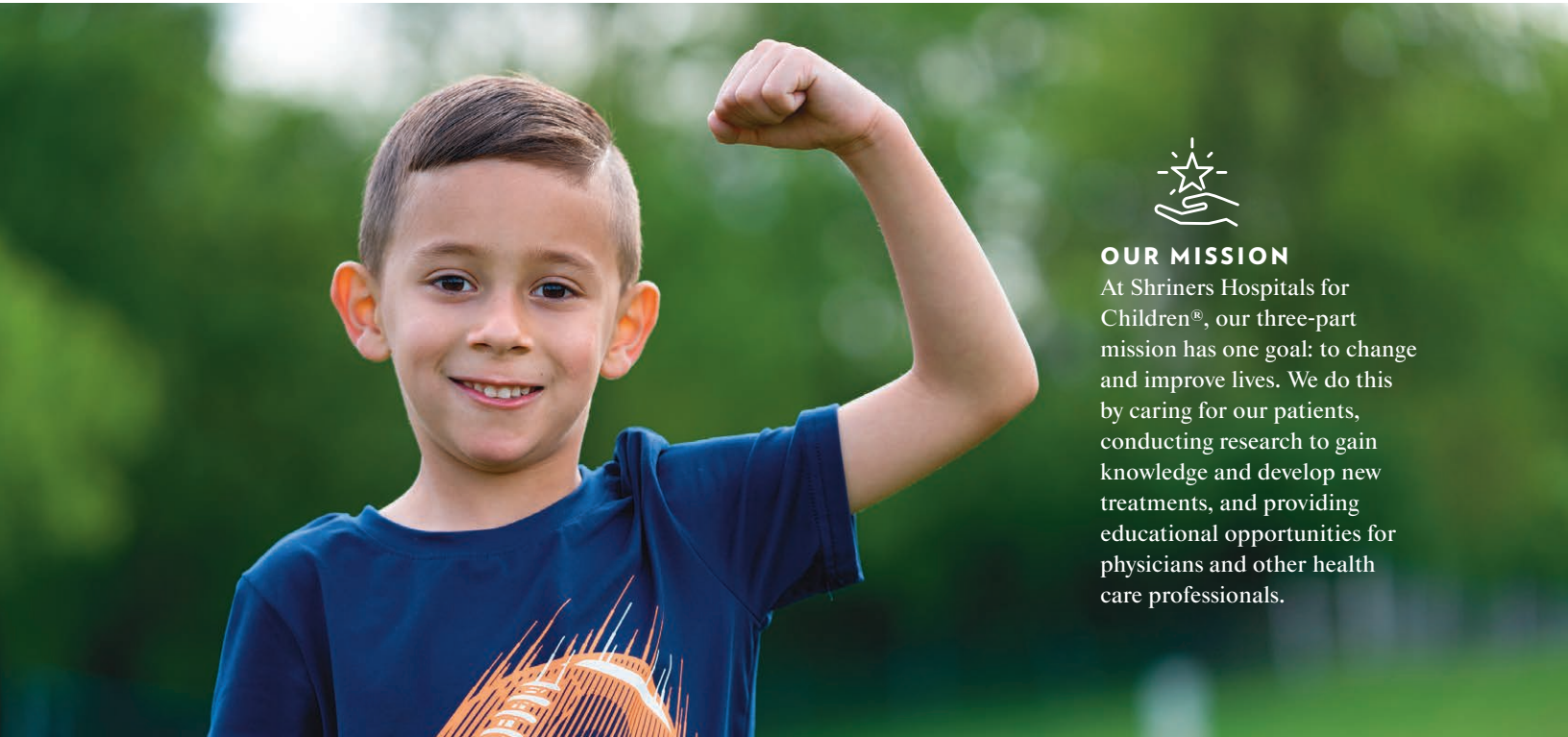
## Heroes of Hope

**Patients of Shriners Hospitals  
for Children face challenges  
with superhero strength**



**Shriners Hospitals**  
for Children®





### OUR MISSION

At Shriners Hospitals for Children®, 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.



### WHAT ARE OUR PEDIATRIC SPECIALTIES?

- + Treatment for orthopaedic 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 Hospitals for Children 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](http://shrinersinternational.org).



## COMMUNITY CONVERSATIONS

Dear Readers,

Although this year brought unexpected difficulties and challenges in the form of a global pandemic, the world is still turning and the seasons are still changing as



consistently as ever, giving us a sense of normalcy. December continues to be a season of giving, gratitude, and, especially, hope and compassion. Within the pages of this edition

of *Leaders in Care*, we are pleased to share stories focused on these themes.

Shriners Hospitals for Children are places of hope. Hope may be intangible, but it can be seen throughout our hospitals and clinics, as children with complex medical conditions and physical challenges discover they can accomplish their goals and believe in their dreams. Hope defies limits and adversity, builds confidence and fuels perseverance. We stand back in appreciation and awe as we watch children take first steps, speak clearly for the first time,

sing and laugh with joy, or even tie their shoes or write their name for the first time. We watch our patients prepare to take their places in the world and in their communities with hope, grace and confidence.

We are also people of hope. Hope encourages the researchers' painstakingly slow, meticulous work that one day may lead to answers and cures, and it fulfills the physicians' promise to improve children's lives.

Shriners Hospitals for Children is pleased to be able to continue our nearly 100-year tradition of offering hope, compassion and healing to children and families. We look forward to a new year of promise and opportunity, and to continuing to share our stories with you.

Sincerely,  
Mel Bower  
Chief Marketing and Communications Officer  
Shriners Hospitals for Children

## PATIENT PERSPECTIVES

### EDGAR PAYS TRIBUTE TO THE WOMEN WHO CARE FOR HIM

Edgar has been coming to Shriners Hospitals for Children — Salt Lake City since 2011. Last March, when he heard that International Women's Day was coming up, he wanted to honor two women who have made an impact on his life with a heartfelt note. Here is an excerpt from his letter.

*The women who work at Shriners Hospitals for Children — Salt Lake City have been the greatest thing that I could ever ask for and much, much more.*

*Let me start with the amazing Kristen Carroll, M.D. She is one of the most caring and loving people I have ever met. Dr. Carroll is always there for me. I remember when she wanted me to try a new walker and braces on my legs. I asked her, "What if I fall?" She responded, "Oh, you*



*won't fall, and even if you do, I will be here to pick you up because I believe in you."*

*Another woman I am very thankful for is my physical therapist, Crystal. She and I go way back to 2011 when I had my last leg and hip surgery. I was scared because I was casted for eight long weeks. When I finally got up from my bed at the hospital, I was in pain and couldn't walk. Crystal came up to my room and said, "All right buddy, it's time to get up and get moving. We have to get your legs back on track!" She always smiled at me and said, "I will make it my personal goal to see you walking again, because I care too much about you to not help you."*

 **TO READ** Edgar's entire letter, please visit [bit.ly/EdgarsLetter](https://bit.ly/EdgarsLetter).

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 **VISIT US ONLINE** to find more stories like these at [myleadersincare.com](https://myleadersincare.com).

**ON THE COVER:** Liam poses in his custom brace, designed by his mom, Sarah, who is also his photographer.

# Clinical Researcher Named President of Internationally Recognized Association



Susan Sienko, Ph.D.

Susan Sienko, Ph.D., a member of the clinical research team at Shriners Hospitals for Children — Portland, became president of the American Academy of Cerebral Palsy Developmental Medicine (AACPDM) during a virtual meeting in September.

The AACPDM is an internationally recognized organization that is a leader in providing education for professionals involved with the treatment of cerebral palsy and developmental disabilities in children. Members are united by a common goal to advance care options for cerebral palsy and other childhood-onset disabilities.

“The society has been involved with many groundbreaking changes, including the development of care pathways, which provide professionals with evidence-based guidelines to inform practice,” said Dr. Sienko. “Becoming president is a distinct honor. What we do and how we support research and education makes us better physicians, researchers and clinicians.”

## Our Texas Locations Are Coming Together

Move allows for more effective and efficient care

The Shriners Hospitals for Children locations in Houston and Galveston are merging their world-renowned pediatric specialty services at the Galveston location. The move is expected to take place in early 2021.

“This strategic vision marks a commitment to transforming how our health care is delivered, while maintaining our mission of providing the highest quality care to children with orthopaedic conditions, burn injuries, spinal cord injuries, and cleft lip and palate. This is an energizing journey – to grow and to treat more children as we look toward the future,” said Jerry G. Gantt, chairman of the Board of Trustees of Shriners Hospitals for Children.

While planning the move, the health care teams at both the Houston and Galveston locations will continue to provide compassionate care for their patients.

“We are dedicated to taking care of these kids,” Gantt said. “Their treatment and care is at the core of what we do every single day.”



## Two Hospital Systems Join Forces

Shriners Children’s Twin Cities and Blank Children’s Hospital, a premier pediatric hospital in Des Moines, Iowa, have joined together to provide high-quality pediatric orthopaedic care to the children of Iowa.

The new clinic opened in October 2020 on the Blank Children’s Hospital campus in Des Moines. The Blank Children’s Pediatric Orthopaedic Clinic, with physicians provided by Shriners Children’s, is a full-time clinic within a hospital setting, providing a wide range of quality pediatric orthopaedic care 24/7.

**TO LEARN** more about this affiliation and the pediatric orthopaedic service line in Des Moines, please visit either Shriners Children’s Twin Cities or Blank Children’s Hospital websites.



# pioneers IN PEDIATRICS

EVERYDAY EXCELLENCE IN SPECIALTY TREATMENTS AND RESEARCH

## IN PURSUIT OF THEIR PASSIONS

*Patients with spinal cord injuries can reach their dreams, thanks in part to innovative treatment and research*

*Alyssa, who has a spinal cord injury, tears up the skate park in her wheelchair.*

**A**s of 2020, an estimated 17,800 new cases of spinal cord injury (SCI) occur annually in the U.S., excluding those who die at the site of incidence, according to the National Spinal Cord Injury Statistical Center. Approximately 20% of these injuries occur in children and adolescents. Shriners Hospitals for Children provides exceptional rehabilitation programs and conducts groundbreaking research to help these children adapt, discover all they can achieve and accomplish, and become as independent as possible. >>

**“[Outcomes demonstrate] that nerve and tendon transfer surgery is an effective intervention for SCI patients that improves both physical ability and quality of life.”**

– DR. KOZIN

### A program to promote independence

The primary goal of the SCI program at Shriners Hospitals for Children is to assure that kids with SCI participate fully in their communities, attain independence and live satisfying lives while avoiding medical complications. To achieve this task, the program provides a wide range of rehabilitative services and therapies that build strength and stamina, increase social interaction and build confidence and self-esteem.

Our innovative approach also incorporates groundbreaking procedures, such as surgical implants that allow severely injured children to breathe without a ventilator, and advanced tendon and nerve transfer surgery, which can restore function and sensation.

### Benefiting from intricate surgery

When she was in high school four years ago, Maddie was in a car crash that resulted in a spinal cord injury. Her family learned about the SCI program at Shriners Hospitals for



Maddie's artwork, titled "American Flag"

Children — Philadelphia through a news story about a patient who had undergone tendon and nerve transfer surgeries there. The procedures were performed by Scott Kozin, M.D., chief of staff of the hospital. Dr. Kozin is a recognized leader in upper extremity surgery and is known for his work with nerve and tendon transfers for patients with SCI.

Maddie and her family met with Dr. Kozin and established a care plan, which included surgery. Maddie hoped the surgery would increase her ability to pinch and grasp with her hands and fingers, so she could return to her passion – drawing.

After a few surgeries and hours of intense occupational therapy provided by therapists at Shriners Hospitals for Children, focused on re-learning movements and re-engaging muscles, Maddie re-gained meaningful mobility in her hands.

Following treatment, she was better able to use her iPad and software to create designs that have been incorporated into both clothing and tattoos by friends and family.

“These outcomes are important and noteworthy, as they demonstrate that nerve and tendon surgery is an effective intervention for SCI patients that improves both physical ability and quality of life,” said Dr. Kozin.

### Skating through life

In Sacramento, California, 14-year-old Alyssa was tearing up the skate park. She launched herself into a 12-foot vertical drop, shot straight down the concrete bowl lined with chipped pool tiles, and raced full speed to the other side, where she spun back around with a look of fierce determination. Alyssa uses a wheelchair.



After tendon and nerve release surgery, Maddie has been able to return to her true passion – creating art.



"I've seen her do a lot of tricks, and I have to admit, that was the first time I've been a little nervous for her," said Alyssa's mother, Anna.

Alyssa took first place in the women's division (her coach regularly registers her for adult-level competitions) at the WCMX – the BMX for wheelchair riders – and Adaptive Skate World Competition in April 2020.

Alyssa was diagnosed with leukemia at age 2. A year later, she developed a spinal infection that left her partially paralyzed.

"The doctors just kept telling me she would be confined to a chair for the rest of her life, and I would have to learn to deal with

it," said Anna. "And that was the end of the discussion. I refused to let that be my daughter's life."

Anna brought Alyssa to Shriners Hospitals for Children — Northern California when she was 4, and from the very first appointment, doctors provided Alyssa and her family with therapy options, treatments and additional surgeries to improve Alyssa's overall well-being.

Over the years, Alyssa has been cared for by a multidisciplinary team at the hospital, including orthopaedic surgeons, spine surgeons, physical therapists, urologists, bowel management specialists and more. She has been fitted for various assistive mobility devices as she has grown.

"Shriners Hospitals has been there for us through the years in every possible way, whether it's help getting a new wheelchair faster, or help talking to our insurance company about Alyssa's needs, or even just getting a doctor's note for school," said Anna. "Shriners Hospitals is always there."

## Research efforts driving the future of SCI treatments

Shriners Hospitals for Children conducts innovative research to learn more about and improve the lives of those with SCI. Here are just a couple of examples:

**Quality of life study:** At Shriners Hospitals for Children — Chicago, the research

*Alyssa has won first place in women's skating competitions.*



team is creating the PedsQL™ SCI module, the first health-related quality-of-life questionnaire specifically for children and young adults with SCI, from ages 2 to 25. The project is sponsored by the Craig H. Neilsen Foundation.

"Because their daily lives are so different, children with SCI should not be compared on the same health-related quality-of-life measurement tool as children without physical disabilities," said Kathy Zebracki, Ph.D., chief of psychology at the hospital. "The new questionnaire covers health issues of individuals with SCI over time, including mobility, bladder/bowel functioning, participation and SCI-specific worries. The availability of this information will help Shriners Hospitals for Children improve this patient population's quality of life and overall well-being."

**Sleep study:** Sleep problems that occur in the general population are more common in those with spinal cord injuries. Alicia January, Ph.D., research psychologist at Shriners Hospitals for Children — Chicago, is conducting research on sleep, activity and health behaviors in young adults with SCI in comparison to their peers without SCI. The goal is to develop interventions to improve their sleep and ultimate well-being.

"Having SCI can make it more difficult to fall asleep and stay asleep. There are >>

**"Shriners Hospitals has been there for us through the years in every possible way, whether it's help getting a new wheelchair faster, or help talking to our insurance company about Alyssa's needs, or even just getting a doctor's note for school."**

– ANNA, ALYSSA'S MOM



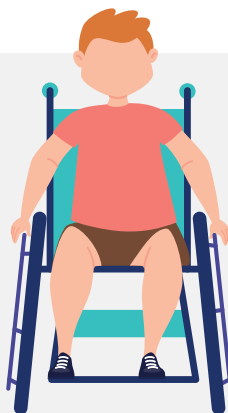
#### +Online Exclusive

To learn about Reveca, a former patient at Shriners Hospitals for Children — Chicago with SCI, who was recently awarded \$1 million for her advocacy work, please visit [bit.ly/Reveca](https://bit.ly/Reveca).

other secondary conditions like spasticity, or the requirement of nighttime catheterization. There are hormone changes that can occur after spinal cord injury that make it more difficult to fall asleep and stay asleep,” said Dr. January.

“Because we know that sleep is essential for good physical, emotional and psychological health, we wanted to investigate sleep patterns in individuals with spinal cord injury, compared to their peers without spinal cord injury, to determine if patients with SCI had more problems with sleep,” said Dr. January. “Once that is determined, we want to have people with SCI paired up with a health coach to determine if they can identify a change in their sleep regimen to improve their physical health and well-being. That change might be sleep, but it could also be changing physical activity, or being actively involved in their community.”

Combining excellent care with innovative research allows Shriners Hospitals for Children to help our patients with SCI achieve amazing things. SCI care and management is available at our locations in Chicago, Illinois; Philadelphia, Pennsylvania; and Sacramento, California. 🍷



## Spinal Cord Injuries: What You Need to Know

Approximately  
**20%**  
of SCI occur  
in children and  
adolescents.<sup>1</sup>

### Common causes

The most common cause of a pediatric SCI is **motor vehicle crashes**, followed by falls.<sup>1</sup>

Other common causes include:<sup>2</sup>

- › Injury during birth
- › Sports injury
- › Trampoline injury
- › Infection on the spinal cord

An estimated **1,455** children are admitted to U.S. hospitals annually for SCI treatment.<sup>1</sup>

Of children who sustain SCI prior to the onset of puberty, more than **90%** develop scoliosis.<sup>1</sup>

Properly restraining children in **booster seats** has decreased the incidence of pediatric SCI.<sup>1</sup>

<sup>1</sup> <https://asia-spinalinjury.org/committees/pediatric/pediatric-committee-news-and-resources/pediatric-spinal-cord-injury-facts>

<sup>2</sup> <https://www.stanfordchildrens.org/en/topic/default?id=acute-spinal-cord-injury-in-children-90-P02590>



# champions IN HEALING

A FAMILY-CENTERED APPROACH TO COMPASSIONATE CARE

## HEROES OF HOPE

*Stories like Liam's share the ways in which our patients and staff bring light into the world each day*

*Liam models a custom brace designed by his mom. It's one of many in a series of superhero-themed braces he has worn throughout his treatment for scoliosis.*

**L**iam, a patient of Shriners Hospitals for Children — Portland, was diagnosed with early-onset scoliosis when he was 2 and wears braces to help correct the curve in his spine. As part of his treatment plan, Liam is fitted for a new brace every nine to 12 months. Liam and his mom, Sarah, who is a professional photographer, have learned to embrace his scoliosis treatment by turning his braces into superhero costumes and using them in fantastical photoshoots. Every time he gets a new brace, the transformation begins.

"Liam loves the photoshoots," said Sarah. "I'm trying to teach him that through hard times come good moments – that if you look hard enough at the hard road in front of you, you will see a positive path. My hope is that when he looks back at this time in his life, it will make him smile." 🦸

### +Online Exclusive

To see the full article and a photo gallery of Liam and his braces, please visit [bit.ly/LiamHero](https://bit.ly/LiamHero).

# Putting Wheels in Motion

*An invention could open countless possibilities for the youngest of patients*

**Before it can be offered to patients, the Baby Bug will undergo a rigorous study.**

The latest invention from the Shriners Hospitals for Children — Salt Lake City wheelchair, seating and mobility department is more than just a way for our youngest patients to learn to get around. It's also a groundbreaking tool that encourages their overall development. The "Baby Bug," a two-motor power mobility chair for infants, was created by Ken Kozole, BSME, OTR/L, and his team to help babies who are missing crucial developmental milestones because they are unable to crawl or walk independently.

## A reason to move

In the first two years of life, a child's development is a complex series of events that are critical in forming the framework for growth into adulthood. Research shows typically developing children have accelerated developmental achievements when they acquire the ability to crawl, creep and walk. These early movements are responsible for rapid growth, social relationships, receptive and expressive speech, and spatial awareness. Children

unable to move independently are at risk for delays in these areas, and when they're really young, they're too small for wheelchairs.

Scott Jerome, MPT, a physical therapist in the wheelchair, seating and mobility department, explained: "Kids with special needs who don't have independent mobility miss out on exploring the world around them and the benefits that come with it. Possible social and cognitive milestones are missed."

That's why Kozole, a longtime Shriners Hospitals for Children — Salt Lake City wheelchair seating and mobility clinician, worked with his team and the Open Wheelchair Foundation to develop the prototype of the Baby Bug.

## The journey of the Baby Bug

The Baby Bug is made with a low-profile base on sturdy wheels, electronically powered and programmable, with a joystick for control. The seat is made from the commercially available Sit-Me-Up baby seat.

Before it can be offered to patients, the Baby Bug must undergo a rigorous study. As part of that research, staff recruited babies of Shriners Hospitals staff and community members to determine the optimal age for babies to use the Baby Bug, and to assess how children are able to use the joystick. Several employees were eager to enroll their children, including Physical Therapist Crystal Haakenson, DPT.

"I support all the research we do here at Shriners Hospitals," said Haakenson. "We need to gather a lot of information on how kids respond, so we know how to help kids who need more assistance and give them the greatest chance to learn."

Haakenson brought her 7-month-old daughter, Jovie, to the hospital's motion analysis center. The sessions start with a one-hour assessment of the child's motor skills before using the Baby Bug. The parent is also asked to fill out a questionnaire about the child's development.

When Haakenson placed her baby in the device, Jovie took to it right away, expertly maneuvering the joystick as she traveled the length of the motion

*Jovie is using the Baby Bug to get around.*



**"We need to gather a lot of information on how kids respond, so we know how to help kids who need more assistance and give them the greatest chance to learn."**

— CRYSTAL HAAKENSON, DPT





As Jovie uses the Baby Bug, cameras record her movements.

analysis center with ease – with the staff and her mom cheering her on. As Jovie used the Baby Bug, cameras captured and recorded her movements and interactions to determine how often she was looking at the joystick and driving the device independently, and when she needed her mother’s help.

The next step in the study is to test the prototype with a patient. A child diagnosed with arthrogryposis will take a device home for use and monitoring over a six-month period. Staff will follow up with the family on a monthly basis to record the child’s progress and monitor mobility skills.

## Mobility for life

The mobility team at the Salt Lake City hospital strives to help patients with mobility needs throughout their lives. “The Baby Bug helps us bridge the early gap in developing power mobility for children with mobility impairments, from infancy into adulthood,” said Jerome.

Once babies outgrow the Baby Bug, they will begin to use a modified Go Chair customized by hospital staff for children as young as 17 months. The Go Chair is small, contains a simple power base with joystick controls and is easy to transport and operate. Shriners Hospitals for Children — Salt Lake City’s wheelchair, seating and mobility department has delivered more than 420 of these modified Go Chairs to children throughout Utah, the Western states and parts of Mexico.

## Mobility for all

While there are currently other pediatric mobility apparatuses available, they’re expensive and difficult to obtain. Shriners Hospitals for Children plans to work with foundations and corporations to make the relatively inexpensive Baby Bug readily available to patients regardless of their family’s ability to pay.

“What’s happening here is revolutionary, cutting-edge information that needs to be shared,” said Jerome. To this end, the Salt Lake City team is already working with Shriners Hospitals for Children — Chicago physician Sue Mukherjee, M.D., to potentially duplicate this study at that hospital.

For more information on this program, call 801-536-3500. 📞

# Shriners Hospitals Surgeon Joins the COVID-19 Fight

Boston surgeon helps field hospital provide emergency care

When the pandemic hit and all nonemergency surgeries were suddenly postponed, Richard Ehrlichman, M.D., a plastic surgeon at Shriners Hospitals for Children — Boston and Massachusetts General Hospital, found his clinical schedule shifting dramatically. Dr. Ehrlichman, who is also a colonel in the



Richard Ehrlichman, M.D.

U.S. Army Medical Corps, became a key player in establishing and operating Boston Hope, a field hospital set up in the Boston Convention and Exhibition Center for patients with COVID-19. Boston Hope opened its doors in just nine days with 1,000 beds for recovering patients. Staff members also cared for those who are homeless and had tested positive for the virus.

“During this experience, we learned two important things: Some patients can have a relapse, and others who recover can be very weak and need rehabilitative care,” Dr. Ehrlichman said. “This was a different experience for me. I have set up 20-bed hospitals, but nothing this big. We learned a lot about what our patients needed, which was certainly more than we thought at the beginning.”

Over two months, almost 800 patients were admitted to the field hospital. While it’s not currently needed, officials stand ready to reactivate Boston Hope with two days’ notice to accept patients.

During this especially difficult time, we thank all of our amazing staff who have reached out to assist in their communities. 🙏

**Boston Hope opened its doors in just nine days with 1,000 beds for recovering patients.**

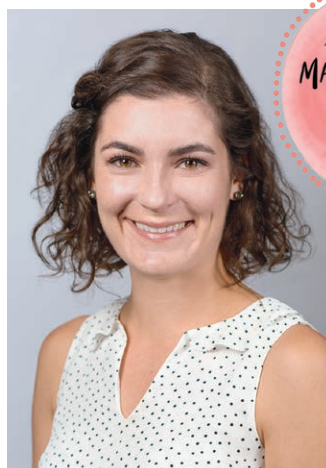
# Solving Mask Shortages



*Generous staff members and volunteers lead mask-making efforts to help cover non-clinical staff and visitors during the pandemic*

Image: iStock.com/Let7

When coronavirus cases increased rapidly in the U.S., many hospitals were left without enough masks for their staff, which put them at higher risk for contracting the virus. In addition, the recommendation from the Centers for Disease Control and Prevention (CDC) to wear face coverings in public settings led to unprecedented demand for homemade cloth face coverings. Many people stepped in to help address the shortage, including dedicated staff members at Shriners Hospitals for Children.



*Margaret Pedicini, LCSW, ACM-SW, launched "Margaret's Mask Project."*



## Taking on the role of seamstress

As patient volumes decreased at Shriners Hospitals for Children — Salt Lake City in the wake of the COVID-19 pandemic, Margaret Pedicini, LCSW, ACM-SW, a board-certified pediatric medical social worker at the hospital, used her time to fill a huge need at the hospital by sewing homemade cloth face coverings.

"Social work is a naturally and intentionally helpful profession," said Pedicini. "I like to keep busy, and since I have a lot of friends in residencies spread out across the country in various hospitals on the front lines, I decided to start making masks." Pedicini said she is trying to spread as much light and joy as possible at a time when you never know who just might need a pick-me-up.

Pedicini's diligent efforts produced more than 500 homemade masks, with 100 donated to the Salt Lake City Shriners Hospital. The rest were shipped to friends, family and personal contacts in 15 different states. Her efforts have grown from a nice idea to a huge undertaking, complete with a logo and a name — Margaret's Mask Project.



*Sarah Durgin, PA, shows off her creations.*

At Shriners Hospitals for Children — Springfield, Physician Assistant Sarah Durgin was saddened that her patients could not see her smiling at them through her mask. She worked with the staff medical photographer, who created friendly photo badges for each member of the medical staff. They wear them so patients and their families can instantly feel more comfortable and familiarize themselves with care providers (and their smiles). Durgin also made child-sized masks in fun patterns for patients. "I think kids are more likely to wear a mask if it's fun, which will help keep everyone safe," she said.



Masks created by Chicago Mask Makers.



### A community effort

In Chicago, amateur sewers of all kinds came together around the city to make masks for health care providers. They connected using the Facebook group Chicago



Lydia Barhight, Ph.D.

Mask Makers. Lydia Barhight, Ph.D., a clinical psychologist at Shriners Hospitals for Children — Chicago, joined the effort when a fellow staff member told her about it. Dr. Barhight said her husband is an ICU physician, which made her feel particularly stressed about the availability of personal protective equipment for health care workers. “I hadn’t sewed since seventh grade, but it came back to me quickly. I ended up sewing about 300 masks. As a group we donated more than 17,000.”

### Volunteers make masks, and a difference

There were even more efforts to provide masks for Shriners Hospitals for Children — Salt Lake City. More than 30 people collectively donated at least 2,500 hand-sewn masks. The generous donors included Aline Smith and her sister, Denice Vernieuw, members of the local chapter of Daughters of the Nile, a ladies’

organization that supports our health care system. “It was our pleasure to serve,” said Smith.



organization that supports our health care system. “It was our pleasure to serve,” said Smith.

Janet Welsh, one of the Salt Lake City hospital’s volunteer pet therapy dog handlers, also donated masks. “I was inspired to make masks because I am a seamstress and had the time to do so. So few people know how to sew nowadays, so I started making masks at the very beginning of the shutdown,” said Welsh. “I started sewing with the intention of making them for my family and friends, but then I got connected to an organization that was coordinating seamstresses to make masks and donate them to local hospitals. Then when Shriners Hospitals put out the call, I dropped off the two or three dozen that I had made.”

### Help from across Canada

Nearly 100 ladies representing women’s organizations across Canada that support the work of Shriners Hospitals for Children — Canada have provided more than 500 reusable masks and 450 reusable gowns to the hospital. The women are members of the sewing units of Ladies’ Oriental Shrine of North America,

Daughters of the Nile, Wawa Ladies Auxiliary, Ladies of the Saber, and Karnak Ladies Auxiliary. They even made it a priority to choose fabric with fun and colorful patterns to brighten up the days of staff members and patients.

There are countless examples of stories like these across our health care system. We thank the many generous volunteers who have done so much. 🧡

*Signs and smiles show support and lift spirits at Shriners Hospitals for Children — Canada.*

***“I started sewing with the intention of making [masks] for my family and friends, but then I got connected to an organization that was coordinating seamstresses to make masks and donate them to local hospitals.”***

– JANET WELSH





# Let's Play!

*From toys to bikes, there's a world of fun just waiting for kids with disabilities*

*Starlit takes her adaptive bike for a spin.*

All children benefit from play – it can help develop motor and cognitive skills, increase self-esteem, enhance social awareness, promote physical strength and activity, and be an overall source of fun and joy.

Shriners Hospitals for Children is committed to helping children be as healthy and independent as possible. Our efforts include providing opportunities for children of all abilities to play and socialize with their friends and families.

## On the go with adaptive bikes and ride-on toys

Some Shriners Hospitals for Children locations offer adaptive bicycles and ride-on toys that give kids more than just mobility – they provide hours of fun.

For example, Shriners Hospitals for Children — Chicago offers the

**“This bike is so amazing for her and could gain her so much strength on her right half, which is weaker, and independence in playing with her sisters and simply enjoying life!”**

– STEPHANIE, STARLIT'S MOM

Go Baby Go program, which provides adapted ride-on toy cars that use a switch instead of a pedal. They are custom fit to allow the child to “drive” the vehicle.

Also, through a collaboration with the nonprofit organization Special Bikes for Special Kids, patients of the Chicago Shriners Hospital can apply for the specialized bikes, which are provided to the hospital by Project Mobility and are given to selected recipients at no charge. Since 2011, the Chicago Shriners Hospital has provided 71 adaptive bikes to patients.

Starlit, a patient of the Chicago Shriners Hospital, received her bike just in time for her seventh birthday. Starlit has cerebral palsy with weakness on her right side, which means she can't ride a typical off-the-shelf bicycle. Back in February, Starlit was staying in the hospital for intensive rehabilitation involving physical, occu-

pational and recreational therapy. She attended a Project Mobility bike night at the hospital, where patients were able to try out bikes and be fitted for a bike in their size range and ability level. Starlit's mom, Stephanie, wrote a thank-you email to the hospital, sharing these thoughts:

“This bike is so amazing for her and could gain her so much strength on her right half, which is weaker, and independence in playing with her sisters and simply enjoying life! This is a piece of equipment that I feel could far outweigh the independence she gets from her wheelchair or walker! Literally, there couldn't be a better birthday present.”

As for Starlit, she simply kept saying, “I love this bike!”

At Shriners Hospitals for Children — Salt Lake City, staff work with local Proud Supporters to fund adaptive bikes for patients, with at least one bike giveaway a week. Adaptations range from hand pedals and secure seat belts, to larger seats with a back and lower center of gravity. Cycling benefits include a sense of independence, lower extremity strengthening, cardiovascular exercise, weight management, balancing skills and fun – making this a wonderful extension of an individualized therapy program.





Kreck



Kaleb

The adaptive bikes offered at Shriners Hospitals for Children — Honolulu allow children to pedal using the strength of their arms. The hand-powered bicycles allow patients who may have limited mobility or reduced function of their lower body to still experience the thrill of riding a bike. For some patients, this is the first (and maybe only) opportunity to ride a bike. The bikes are used as part of a patient's rehabilitation plan to promote healing, both physically and emotionally. The recreational therapy department also incorporates the bikes into weekly "walks" to nearby neighborhood parks, holiday parades and other activities, making it possible to include children with mobility issues in hospital and community events.

### Modifications make the difference

Darlene Kelly, a certified therapeutic recreation specialist at our Chicago location, said modifying typical toys is another way to help patients at Shriners Hospitals experience playtime. "A lot of what we use are regular toys and activities that we modify to make the child as independent as possible," she said. "For example, we can increase the size of a handle with a foam grip, add a mouth-piece for painting, use a different size ball that is lighter weight or pushed with a wheelchair, use adapted controllers with

oversized buttons, and use table-top easels or tables that have adjustable heights."

### Playing with a purpose

Adaptive toys are important elements of therapy for patients.

"Toys are either purchased already adapted, or some toys can be modified using battery interrupters and other adapters. They are used with a variety of switches based on the child's unique skills and therapy goals," explained Kathryn Hess, MS-CCCSLP, lead speech-language pathologist at the Chicago Shriners Hospital.

"In the rehabilitation department, we use adapted toys with patients to help >>

*Toys like adaptive bikes are an important part of therapy for many patients. For information on how you can help provide these bikes, please visit [bit.ly/WheelsForLove](https://bit.ly/WheelsForLove).*

***"In the rehabilitation department, we use adapted toys with patients to help them work toward goals such as active participation in play, paying attention, learning cause/effect, practicing taking turns and improving motor skills."***

— KATHRYN HESS, MS-CCCSLP





**“For children with disabilities, depending on their challenges, ‘switch toys’ allow the child to gain control over their environment, help motivate them to participate, foster confidence and aid in their success to accomplish a task.”**

– DARLENE KELLY, CTRS



them work toward goals such as active participation in play, paying attention, learning cause/effect, practicing taking turns and improving motor skills,” said Hess. “When children are able to activate and participate with the adapted toys, it helps to build their independence, confidence and cognition, and it is a lot of fun.”

For Kelly, the advantages are too many to count. “Children benefit from play, and there are so many learning tools that play provides, from developing gross motor and problem-solving skills and increasing self-esteem to learning how to make friends,” she said. “For children with disabilities, depending on their challenges, ‘switch toys’ allow the child to gain control over their environment, help motivate them to

participate, foster confidence and aid in their success in accomplishing a task. They help the child to gain independence as well as an ‘I can’ attitude. Switch toys help the child to participate in play activities and engage with other kids their age and form friendships.”

As the world becomes more and more accessible and open to people with disabilities, there is an ever-increasing number of resources devoted to the special needs of these children, including toy guides, specialized toy stores and other tools to help enhance playtime. 🧡

**TO LEARN MORE** about adaptive recreational programs, please visit [shrinershospitalsforchildren.org](https://shrinershospitalsforchildren.org).



## partners IN SERVICE

EVENTS, NEWS AND INSPIRATION FROM THE SHRINERS COMMUNITY

# GOODNESS, GRACIOUS

*Patients and families find ways to show their appreciation of Shriners Hospitals through generous acts*



*Roger and Kyle rode their bikes across the country to raise money for Shriners Hospitals.*

**W**hether they're riding bikes cross-country to raise awareness or putting on a huge ball to raise money, our patients and their families have the energy and determination to do big things – and for a big cause. Many of them are inspired by the care given at Shriners Hospitals for Children to give back. Here are a few of their stories:

### Coast to coast

A grandfather and grandson teamed up to raise money to benefit Shriners Hospitals for Children — Portland after seeing the amazing care provided to their loved one, Rachel.

Rachel had been experiencing back pain, and when she noticed a lump in her back, her parents, Jenny and Paul, decided to seek a medical opinion. In the summer of 2017, they took Rachel to the Portland Shriners Hospital, where she was diagnosed with severe scoliosis, requiring surgical intervention.

Rachel underwent a spinal fusion to correct two spinal curves and a rotation of her spine. “She immediately was different,” Jenny said. “She grew two inches after her surgery, sat up straighter, and her shoulders were level. She can literally do anything she wants now.” >>



This inspired Rachel's grandfather, Roger, and her brother, Kyle, to embark on a cross-country adventure to raise funds and awareness for the hospital. Equipped with their bikes and camping supplies, Roger and Kyle set off from Washington on a coast-to-coast journey.

"I was already looking forward to this ride, but making this a fundraiser gave the trip an entirely new level of meaning: a small token of thanks for Shriners Hospitals' amazing care," Kyle said.

Kyle brought Rachel's X-rays into every restaurant where they dined to illustrate the reason behind their journey. "We would bring up why we were doing it and what Rachel had overcome. We would show them pictures. There was a lot of shock about the severity of her curvature," said Kyle.

Kyle and Roger shared details of Rachel's remarkable recovery and passed out business cards directing people to the donation website they created for the hospital. "It was interesting to see how impactful the story was to people," said Roger. "A lot of times when we stopped to chat with people, we'd see later that day that they donated to our fundraiser."

After 92 days of bike-riding and over \$3,000 raised, Kyle and Roger completed their 4,049-mile journey by touching their

tires to the Atlantic Ocean. They celebrated their hard work with a lobster dinner in Bar Harbor, Maine.

What has the journey meant to Roger? "It trumps just about anything else I've ever done," he said. "I wish there was more that I could do. We are extremely grateful for Shriners Hospitals and can't thank them enough!"

## From Iowa to Boston with love

Not many people say they look forward to going to the hospital, never mind going in for surgery. However, 12-year-old Paige looks forward to traveling to Shriners Hospitals for Children — Boston every three months, even though it means going into the operating room.

Paige, who was born with a port-wine stain birthmark on her face, began seeing plastic surgeon Matthias B. Donelan, M.D., for treatment when she was 2. As a patient ambassador, Paige finds joy in helping others, from supporting other patients to helping raise funds to benefit the Boston Shriners Hospital.

"Shriners Hospitals means a lot to me," Paige said. "One of my favorite times of year is when I get to go to Boston and hang out with the friends that I've made over the years, including nurses, patients and Dr. Donelan."

**As a patient ambassador, Paige finds joy in helping others, from supporting other patients to helping raise funds to benefit the Boston Shriners Hospital.**

*Whenever Paige is in the hospital, she and Dr. Donelan wear matching caps, which are embroidered with "Paige's Dr." and "I love Dr. Donelan." For Dr. Donelan, the cap is a cherished gift from his patient's family.*



Shelly, Paige's mom, said, "Our local Shrine center here in Iowa, Za-Ga-Zig, supports us."

In honor of Paige, the Iowa Shriners organization created a fundraiser specifically for the Boston hospital. The Firefighter's Ball took place in October 2019, and local firefighters were invited to attend.

"The event was very educational, because many people didn't know where their donations were going," Shelly said.

"Paige was asked to speak about her experience at the Boston Shriners Hospital. When people look at Paige, she looks fine," Shelly said. "People do not understand why she would need to go to a burns hospital. So, we were able to educate attendees on her port-wine stain birthmark and the amazing laser treatments at Shriners Hospitals that help kids like Paige. She made people cry with her story and her positive outlook on life! The event was a huge success, and we hope to double, or even triple, the earnings raised next year."

Paige's willingness to share her story had a tremendous impact on those in attendance and on the donations received.





*The Kōkua Club encourages patients to better the world around them with various community service projects.*

## A helping hand from Kōkua Club

The Hawaiian word “kōkua” means “to extend help to others with no intent of personal gain.” Our patients receive this help daily from their nurses, doctors and therapists, so recreation therapy staff members at Shriners Hospitals for Children — Honolulu wanted to help kids pay it forward with selfless giving.

“We wanted our patients to experience the opportunity to give back to others,” said Recreation Therapy Manager Helene Freni-Rogers.

The Kōkua Club was born.

“Kōkua Club is good because I learned how to help other people, like how the doctors and nurses help me,” said a 15-year-old patient.

Organized in 2019 by Recreation Therapy Intern Kathleen Tuckness, the program helps young patients to show appreciation, gratitude and kindness to others. Projects extend to three important areas of the patients’ lives:

- Their neighborhood: Showing “aloha” (love) to their families and their Honolulu Shriners Hospital.
- Their community: Extending “mālama” (care) to nearby care homes, schools and others in the surrounding neighborhood.
- The world around them: Being “pono” (righteous, virtuous) in reducing their impact on natural resources and leading a more sustainable lifestyle.

“The Kōkua Club empowers patients to do projects within their abilities in and out of the Honolulu Shriners Hospital that are helpful and meaningful to the hospital, the community or the world,” said Tuckness.

***“The Kōkua Club empowers patients to do projects within their abilities in and out of the Honolulu Shriners Hospital that are helpful and meaningful to the hospital, the community or the world.”***

– KATHLEEN TUCKNESS

Opportunities take place throughout the year and have included activities both small and large – from sharing handmade flower pens with patient care departments for World Kindness Day, to baking trail mix for community firefighters, to cleaning up beaches and neighborhood parks.

“I really enjoyed when we sewed heart pillows for the nurses for Nurses’ Week. They were so happy, which made me happy,” said a 13-year-old patient. 🍷

# A Gift of Gratitude Across Generations

A son gives back decades after his father's care

In the mid 1920s, a boy named Del was diagnosed with polio at the age of 3. He received care at Shriners Hospitals for Children — Salt Lake City, the eighth location to be opened by the Shriners fraternity, which established the fledgling health care system in 1922 largely in response to a polio epidemic. As Del was one of 11 siblings and his father had recently passed away, Del's mom had to leave him at the hospital and was often unable to visit for months at a time. Eventually, the child went home with a prosthetic leg. Later in life, he used a wheelchair, but he never let anything slow him down.

Over the years, Del often spoke of his love and gratitude for the fraternity, doctors, nurses, staff and volunteers who changed the trajectory of his life.

In November 2019, Del's son, Kurt, reached out to the donor relations department at Shriners Hospitals for Children headquarters in Tampa, Florida, to inquire about potential donor-related naming opportunities in the health care system that would honor his father. Although Kurt and his wife, Karen, live in Kearney, Missouri, and closest to Shriners Hospitals for Children — St. Louis, they felt strongly about making a

memorial gift to Shriners Hospitals for Children — Salt Lake City, where Kurt's dad had received care so many years ago.

Wanting to provide the family with excellent options, Nathan Clark, director of development, and Hospital Administrator Kevin Martin, brainstormed on potential naming opportunities for their gift. Hospital staff also searched for information regarding Del's time at the hospital. Imagine how excited the family was when hospital staff were able to locate Kurt's dad's records.

When Kurt and his wife visited family in Salt Lake City, Utah, they visited the Shriners Hospital. Clark and Martin gave the family a tour and shared the story of the evolution of the hospital since its establishment in 1925. The couple learned about Kurt's father's time as a patient and were moved to discover what a profound impact the hospital had in helping him live a happy and productive life.

Ultimately, Kurt committed to name the hospital's Wheelchair Therapy Services Office Suite with his gift.

It was the combined work of multiple people across departments that secured this generous first-time gift, which will be such a benefit to Shriners Hospitals for Children. We are so grateful for all the donors who support our health care system and glad to assist them in determining how they can best support us. 🍀



## More Ways to Give

*Consider these ways to donate*

- 1 Make a monthly gift online.**  
Gifts can be designated for a specific health care location.
- 2 Join the Annual Giving Program.** By making an annual gift to Shriners Hospitals for Children, you help ensure that we can continue to provide quality medical care to children, conduct innovative research and offer educational programs to future generations of medical professionals.
- 3 Make a Legacy of Love gift.**  
Give in honor or memory of a loved one.

To learn more about the many other ways to give to Shriners Hospitals for Children, including planned gifts, gifts of appreciated securities, real estate and corporate giving opportunities, call donor development at **866-958-6277** or visit [lovetotherescue.org](http://lovetotherescue.org). 🍀



# Our Donors Truly Care

*Using creative and innovative ways to support our patients and our mission*

We are so grateful for all those who work with us to support the mission of Shriners Hospitals for Children and help us to ensure we can continue to improve and change the lives of children.

Here are just a few examples of their very special efforts:

## The gift of a smile

In June, Shriners Hospitals for Children and Kodak Smile teamed up to bring inspiration, smiles and fun to social media. Kodak Smile provided a handful of our patients with Kodak Smile instant print digital cameras to record and share their journeys and experiences during a special week of fun.

## Women coming together to support our health care system

It is customary for our First Lady, wife of the Imperial Potentate (or CEO) of Shriners International, the fraternity that founded and continues to support Shriners Hospitals for Children, to initiate a fundraising program. This year, that effort includes the *Women & Philanthropy program – Shriners Hospitals for Children*, which also supports the health care system, especially through annual membership dues. All women are welcome and

invited to join. The only criteria are having a passion and concern for others, and a heartfelt, strong

desire to make the world a better place and improve the lives of children. Our First Lady, Alice Smith, believes that women have an increasing ability to effect change through their leadership and philanthropic efforts.

## Your cars help our kids

One of the many ways to support Shriners Hospitals for Children is to donate a vehicle. Almost any type of vehicle, in any condition, may be donated – cars, trucks, RVs, boats and even airplanes. Since our program is designed to get top dollar for all donations, it is also an amazing way to donate your unique vehicle, classic car or beloved car collection.

*Patients throughout the health care system take photos for Kodak Smile.*



“My granddaughter was born with arthrogryposis and club feet, which prevented her from using her arms and legs,” said Tim, a donor. “Shriners Hospitals for Children — Spokane did a wonderful job taking care of her. When an opportunity came for us to make a donation, we couldn’t think of a better nonprofit to give to.”

Interested in donating a vehicle? The process is easy and free. Just fill out the donation form online at

**[shrinerscardonations.org](http://shrinerscardonations.org)** or call **833-SHC-KIDS (833-742-5437)**.

We take care of the rest, including sending you a sincere thank-you letter, which will also serve as your tax receipt.

We appreciate every donation – of every kind – and thank all our amazing donors for helping us improve lives. 🙏

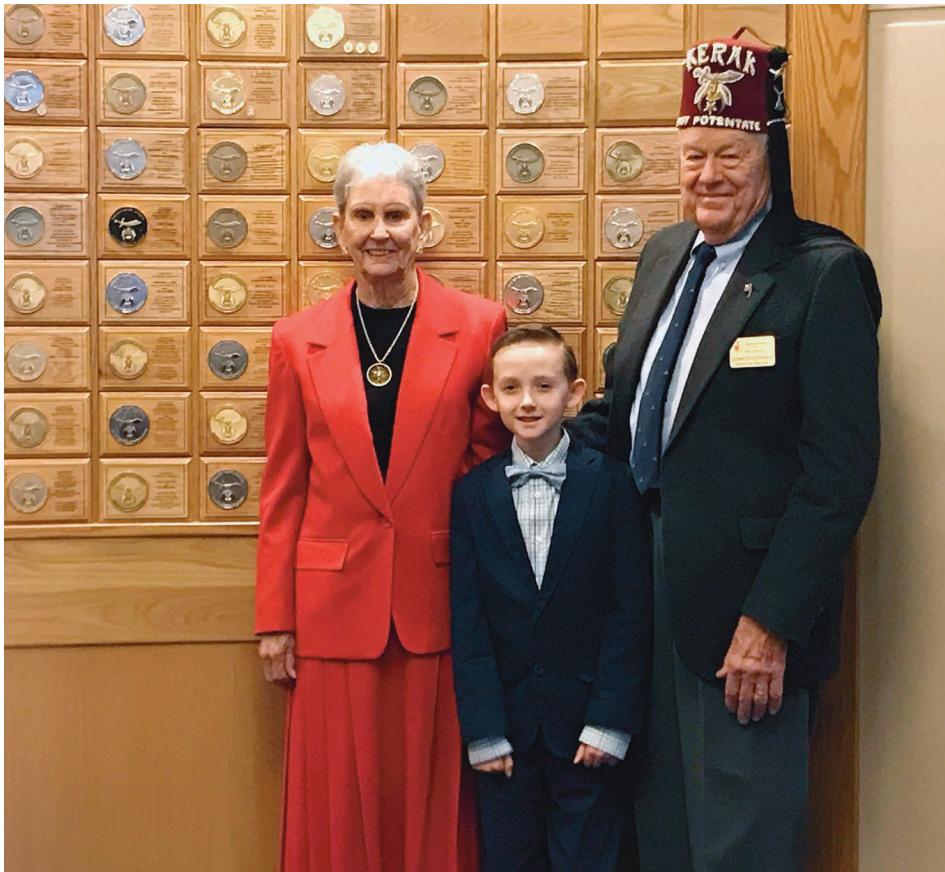


**[ShrinersCarDonations.org](http://ShrinersCarDonations.org)**

**BENEFITING**  **Shriners Hospitals for Children**

# Planned Giving Helps Support Shriners Hospitals

*Shriner gives to the health care system in more ways than one*



*Elwin Studebaker Jr. and his wife, Terry, with Phoenix, a patient ambassador for Shriners Hospitals.*

Elwin Studebaker Jr. is a man of numbers, often adding them up before others can even get them down on paper. Now retired, he served as controller at International Game Technology, among other positions in finance.

When it comes to Shriners Hospitals for Children, however, Studebaker, 84, adds heart to his giving equation, multiplying his impact immeasurably.

Studebaker and his wife, Terry, a retired accountant, are not only champions of the Shriners Hospitals mission, but also of charitable gift annuities (CGAs), or gifts that pay them back with fixed income for life. Altogether, the couple has established nine CGAs to benefit Shriners Hospitals.

***“Shriners Hospitals does what no other hospital can do for children. They’re particularly advanced in burn care, and they treat patients regardless of their families’ ability to pay.”***

– ELWIN STUDEBAKER JR.

for your entire life, and the payout percentage is higher the older you are when you establish them.”

In fact, the income they receive from their CGAs totals enough to pay a substantial portion of their retirement community home’s monthly fee. For the couple, it’s a smart match.

## **A history of connection and support**

Studebaker has decades of history with Shriners Hospitals, becoming a Shriner in 1983 and later Potentate (leader) of Kerak Shriners in Reno, Nevada, where he was part of the groundbreaking and dedication of Shriners Hospitals for Children — Northern California. Studebaker recalled a time he noticed his friends’ child limping, so he recommended that they send the boy to Shriners Hospitals.

“Turned out, he had a shortened tendon, and Shriners Hospitals was able to fix it,” Studebaker said. “After that, he didn’t walk with a limp. He even went on to become captain of his high school football team!”

Most important, Studebaker said, Shriners Hospitals does what no other hospital can do for children. “They’re particularly advanced in burn care, and they treat patients regardless of their families’ ability to pay,” Studebaker explained. “The children and their recovery always come first.”

## **Multiplying the impact**

“With CGAs, you get a tax benefit now (when you establish them) and a return on your money until you pass away,” said Studebaker. “We’re all living longer, and CGAs benefit us because income continues



**TO LEARN MORE** about how CGAs can be a smart choice for you and a life-changing one for Shriners Hospitals for Children, contact the planned and major giving office at **866-954-1576** or **plannedgiving@shrinenet.org**.



## ATHLETE AND ASPIRING SURGEON EARNS SCHOLARSHIP

NAME: JOE

CONDITION: PES PLANUS

LOCATION: SHRINERS  
HOSPITALS FOR  
CHILDREN — ERIE

***“[Shriners Hospitals] put me on the path of doing everything I wanted to be able to do,” Joe said.***

As a younger brother watching his siblings compete from the sidelines, Joe was inspired to run, regardless of the fact that he struggled to walk. Born with muscles and ligaments that were too tight, Joe walked on the insides of his ankles. His doctors said as he grew and his muscles and ligaments continued to tighten, walking would become harder, and he eventually might not be able to do so without assistance.

Joe remembers one inspiring moment: “I was in first grade,” said Joe. “We were at a varsity race, and it was very muddy. It looked like so much fun!” Joe made up his mind that one day he was going to do that. After the race, the coach said to Joe, “I’ll be here when you’re ready.”

Joe began receiving care at Shriners Hospitals for Children — Erie when he was 5. He wore casts for the first eight weeks of treatment and then moved on to leg braces, which he wore for many years, followed by inserts. He also had physical therapy, which helped him remain mobile and flexible and built up muscle in his legs.

By the time Joe was in seventh grade, he was running cross country. “My first goal in cross country was just to finish the race,” said Joe. “I came in 20 minutes behind everyone else.” By his senior year of high school, he was team captain for his cross country team. “My cross country coach always told me to believe in myself,” said Joe. “All the support I had got me to where I am today.”

Joe is attending Gannon University in Erie to study health sciences. He was nominated by the athletic director and received a district 10 athletic scholarship. Joe hopes to become an orthopaedic surgeon one day because of his experience with the Erie Shriners Hospital.

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SHC-010

# Achieving the Extraordinary

*Shriners Hospitals for Children is recognized for excellence*



Image: iStock.com/linna\_Shtelnikova

Nine Shriners Hospitals for Children locations have been honored with awards from Press Ganey, a leader in health care performance improvement and measurement. The following Shriners Hospitals received Guardian of Excellence Awards for Patient Experience:

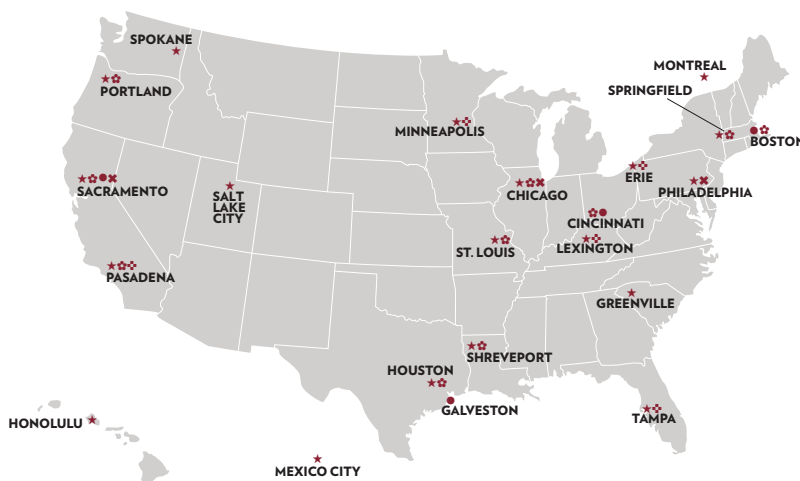
- Canada
- Chicago
- Greenville
- Honolulu
- Mexico
- Northern California
- Portland
- Salt Lake City
- St. Louis

The Guardian of Excellence Award recognizes top-performing health care organizations that have achieved ranking in the 95th percentile or above for performance in a variety of categories, including Patient Experience.

Our locations in Canada, Northern California and Salt Lake City also received Pinnacle of Excellence Awards for Patient Experience, which recognizes those that have achieved this excellence for at least three years.



## LOCATIONS



- ★ Orthopaedics
- Burns
- ✕ Spinal cord injury
- ✱ Cleft lip and palate
- ✱ Outpatient care only; necessary inpatient care provided at an affiliated facility