This Is My Moment

National Patient Ambassadors
Madelyn and Cristian
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.
Dear Readers,

Welcome to Leaders in Care, the premier publication of Shriners Hospitals for Children. We have revamped the magazine to more effectively showcase the successes our patients experience and emphasize the work, mission and focus of our unique health care system.

For nearly 100 years, the staff and volunteers of Shriners Hospitals for Children have focused on the needs of patients and families first and worked tirelessly to make a real difference in their lives. We are known for spending the time and energy to determine what is best for each patient – for listening and for offering hope, compassion and healing. Every day, our staff works to fulfill our three-part mission: improving the lives of children by providing excellent specialty care, conducting innovative research and offering outstanding educational opportunities for medical professionals.

While much has changed since we opened our first hospital in Shreveport, Louisiana, in 1922, we have remained true to that mission. And we continue to keep the promise made by our founders: to provide the best care we can to all who come to us regardless of their ability to pay.

Within these pages, you’ll meet some incredible people: patients who are taking their place in the world with confidence, grace and strength; parents and families who are supporting them; and physicians and researchers dedicated to finding new ways to improve the lives of children all over the world. It’s the most amazing care anywhere – Shriners Hospitals for Children.

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

THE PATIENT AMBASSADOR PROGRAM has not only given me the confidence that I have today, but it has allowed me to connect and help many wonderful patients and their families, who have become forever friends. I have proudly assisted other patients, helping them learn how to give speeches and share their stories. One time that resonates with me is while helping at a Kansas Shrine Bowl event I was paired with two younger ambassadors. I remember they were shy and afraid to talk at first; however, after asking them questions and showing them how to do different activities with the football players, by the end of the day they were leading our presentations!

Social media has also played a big role through my years as an ambassador. I have had the ability to connect with many parents who have children who are upper limb different just like me. I have encouraged the parents to seek assistance with their local Shriners Hospitals for Children, answered countless questions they might have, and shared my practices of being proactive as opposed to reactive in situations they may encounter. I am forever grateful to be able to represent Shriners Hospitals for Children on a national level and be able to connect with more patients and their families!

Sincerely,
Madelyn
(see Madelyn’s story on page 15)
# Shriners Hospitals for Children Locations

<table>
<thead>
<tr>
<th>Location</th>
<th>Services</th>
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<td><strong>Boston, MA</strong></td>
<td>Burn Care</td>
<td>51 Blossom St., Boston, MA 02114</td>
<td>617-722-3000</td>
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<td>Cleft Lip and Palate</td>
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<td><strong>Chicago, IL</strong></td>
<td>Spinal Cord Injury</td>
<td>2211 N. Oak Park Ave., Chicago, IL 60707</td>
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<td><strong>Erie, PA</strong></td>
<td>Orthopaedics</td>
<td>1645 West 8th St., Erie, PA 16505</td>
<td>814-875-8700</td>
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<td>Burn Care</td>
<td>815 Market St., Galveston, TX 77550</td>
<td>409-770-6600</td>
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<td><strong>Greenville, SC</strong></td>
<td>Orthopaedics</td>
<td>950 West Faris Rd., Greenville, SC 29605</td>
<td>864-271-3444</td>
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<td><strong>Honolulu, HI</strong></td>
<td>Orthopaedics</td>
<td>1310 Punahou St., Honolulu, HI 96826</td>
<td>808-941-4466</td>
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<td>Orthopaedics</td>
<td>6977 Main St., Houston, TX 77030</td>
<td>713-797-1616</td>
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<td><strong>Lexington, KY</strong></td>
<td>Orthopaedics</td>
<td>110 Conn Ter., Lexington, KY 40508</td>
<td>859-266-2101</td>
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<tr>
<td><strong>Mexico City, Mexico</strong></td>
<td>Orthopaedics</td>
<td>Av. del Iman No.257, Col. Pedregal de Santa Ursula Deleg. Coyocánc Ciudad de México México City, 04600</td>
<td>55-5424-7850</td>
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<tr>
<td><strong>Philadelphia, PA</strong></td>
<td>Orthopaedics</td>
<td>3551 N. Broad St., Philadelphia, PA 19140</td>
<td>215-450-4000</td>
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<td><strong>Portland, OR</strong></td>
<td>Orthopaedics</td>
<td>3101 SW Sam Jackson Park Rd., Portland, OR 97239</td>
<td>503-241-5090</td>
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<td><strong>Sacramento, CA</strong></td>
<td>Burn Care</td>
<td>2425 Stockton Blvd., Sacramento, CA 95817</td>
<td>916-453-2191</td>
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<td></td>
<td>Orthopaedics</td>
<td>2025 East River Pkwy., Minneapolis, MN 55414</td>
<td>612-596-6100</td>
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<tr>
<td><strong>Salt Lake City, UT</strong></td>
<td>Orthopaedics</td>
<td>1275 E. Fairfax Rd., Salt Lake City, UT 84103</td>
<td>801-536-3500</td>
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</tbody>
</table>

**SHREVEPORT, LA**
- Orthopaedics
- Cleft Lip and Palate
- 3100 Samford Ave., Shreveport, LA 71103
  - 318-222-5704

**Spokane, WA**
- Orthopaedics
- 911 W. 5th Ave., Spokane, WA 99204
  - 509-455-7844

**Springfield, MA**
- Cleft Lip and Palate
- Orthopaedics
- Rheumatology
- Urology
- 516 Carew St., Springfield, MA 01104
  - 413-787-2000

**St. Louis, MO**
- Orthopaedics
- Cleft Lip and Palate
- Pediatric Surgery
- Spinal Cord Injury
- 4400 Clayton Ave., St. Louis, MO 63110
  - 314-432-3600

**Tampa, FL**
- Orthopaedics
- 12502 USF Pine Dr., Tampa, FL 33612
  - 813-972-2250

*This location is an outpatient, ambulatory care center.*
In addition to providing top-notch medical care, our staff is committed to helping our young patients develop confidence and discover and pursue their goals. For many patients, learning they can participate in sports, despite their medical issues, opens a new world of hope and opportunity.

**Daisy pulls no punches**

With cool intensity, the 13-year-old girl attacks the small punching bag suspended just higher than her head. Left, right, left, right, left, right — a fast, unbreaking rhythm. She’s working on developing her timing and coordination, with hopes of competing in mixed martial arts (MMA) one day.

She’s Daisy, a middle schooler, all-around athlete and a patient of Shriners Hospitals for Children — Spokane, where she receives treatment and support that helps her work toward her dreams.

Daisy loves to stay active. “I do softball, Little League baseball, volleyball, basketball, anything outside really,” she said.

Daisy’s parents adopted her from China when she was 6. Daisy was born missing part of her left leg, and her left hand was underdeveloped. Before they brought her home, her parents knew that Shriners Hospitals could help their daughter. >
“My hand was not actually spread apart, it was webbed together,” Daisy explained. “I had three surgeries on my hand to separate the thumb and the middle finger and the pinky. After my last hand surgery, I had a big leg surgery done.”

To help Daisy pursue her goals with MMA, her prosthetist suggested a running foot.

“I couldn’t name another amputee that I’ve worked with who wanted to do mixed martial arts,” said Peter Springs, L/PO, pediatric orthotic and prosthetic services manager at the hospital. “You try to adapt to what their desires are and what they want to accomplish.”

Daisy said the new foot “has more spring.”

“I remember the first time she walked in the hall and ended up going on a little jog with it,” Springs said. When she tried to describe the experience, he could tell “it was a different category of better for her.”

Now Daisy is a regular at a local gym, where she works on her own training and coaches younger kids. In the process, she’s knocking down preconceived notions about what she can accomplish.

“We thought it would be a little challenging with her limitations, but it hasn’t been at all. We don’t even notice,” her father said. “It’s just a part of her.”

Working with Daisy has been a revelation for her coach, Sarah Howell, owner of Wolfpack Fitness in Pasco, Washington. “She wants to be pushed, she wants to be challenged, and she’s perfectly fine and capable of doing anything that you throw at her,” said Howell. “So eventually my attitude changed as a coach.”

With hopes of competing in MMA in the future, Daisy and her family are working through the rules concerning the use of her prosthetic. In the meantime, she is dedicated to increasing her skills and helping other kids improve as well.

“A lot of people underestimate my ability to push myself harder,” Daisy said, “but I feel like I can do anything that I can put my mind to.”

**Sol sticks the landing**

Facing the judges, the freshman gymnast projects confidence. An inner discipline prevents her from showing any weakness.

“I take a deep breath, and I know I’m going to be solid,” she said.

She smiles and steps up to the balance beam. For Sol, competition for the state title has begun.

Like many gymnasts, Sol began participating in the sport at a young age. But unlike others, by the time her mom enrolled her in gymnastics at 3½ years old, Sol had already had foot surgery twice. She learned to walk wearing a cast.

Sol was born with her left foot turned inward. The congenital condition, known as clubfoot, is caused when the tendons connecting leg muscles to the foot are shortened and tight. This affects the positioning of one or both feet and, if left untreated, may affect the ability to walk.

“Whenever a parent knows their child has a disability, they should listen to their gut and pursue the best care for their child,” Sol’s mother, Elda, said. “You don’t know how much the disability is limiting them – or not limiting them.”

Sol’s parents sought treatment at Shriners Hospitals for Children — Chicago, which is where the family met pediatric orthopaedic surgeon Haluk Altiok, M.D.

With a reliance on research and a focus on best outcomes for patients, Shriners Hospitals for Children was exactly where Elda wanted Sol to be. Treatments are customized to the patient and include both surgical and non-surgical interventions. The Chicago Shriners Hospital has an in-house motion analysis center that doctors used to identify the best treatment for Sol’s clubfoot, based on how her leg and foot actually moved. In addition, the hospital has provided Sol with follow-up care over the years for other injuries related to her sport.

Treatment allowed Sol to take to the mat and pursue her passion. “Gymnastics is an escape for me,” she said. “I get to release my energy and express the hidden talent that I have.”

Competing in USA Gymnastics events for years, Sol had a demanding schedule: 20 hours a week in the gym, plus accelerated classes at school. But, having broad interests and limited time, Sol opted to make a change, joining her high school’s gymnastics team.

The switch opened up time for school, social activity and a new sport – track and field – where coaches saw her athleticism and encouraged her to try pole vaulting.

“I feel like I’ve had a lot of success and nothing can stop me, not even the surgeries.”

**Matthew swings big**

Like most golfers, Matthew, 16, is in pursuit of that day when it all comes together: the drives, the putts and the intensity that brings focus rather than stress.

He plays for his high school team, practicing every other day and sometimes joining his dad as a player or volunteer at area charity golf tournaments. And now, with the treatment he’s received in the past year from Shriners Hospitals for Children — Portland, he’s ready to reach for the next level.
In 2018, Matthew was diagnosed with scoliosis. His treatment plan, provided by Michelle Welborn, M.D., included wearing a brace for 20 hours a day for seven months. This past March, his mother said, X-rays showed his growth plates had closed and the teen received the green light for surgery in early April.

Matthew said his support network, along with his faith, helped him power through. “For me, it was about wearing the brace and how it would feel, how it would look, and how I would look,” he said. “My family, teachers and friends were so encouraging and supportive.”

Add to that: trust in his medical team, particularly Dr. Welborn, whose focus is on pediatric spinal deformity. “Dr. Welborn was absolutely awesome,” Matthew said. “I couldn’t not trust her!”

Matthew confirmed that having his scoliosis corrected has had a positive impact on his life. “The surgery has helped to level out my shoulders, which has greatly improved my golf swing,” he said. “Also, I don’t feel as insecure when swimming.”

As a student athlete, Matthew’s plate is full this school year. He said his favorite classes are science-related. “I’m looking forward to Honors Chemistry. I love to ask ‘Why?’ and science encourages you to do that!”

In addition, Matthew started his high school’s cornhole club, and he plans to play ultimate Frisbee. “I like team sports,” he said. “That’s another reason I like golf: I’m playing against myself, but I can earn points for the team. A win-win for sure.”

Matthew’s mom, Jennifer, has focused on encouraging her son. “Let him try new things,” she said. “Let him fail, too. Kids are so much more resilient than we sometimes think.”

Worries about her child’s future health come with the territory. But Jennifer said her family focuses on the long game. “We’re just like any other parents. We want Matthew to pursue what he loves and be a blessing to others,” she said.

“After one of our recent checkups at Shriners Hospital, we walked around the building and found ourselves on the rooftop playground. Up there, we also saw several empty plaques that were naming opportunities for a future donor. After I explained what that meant, Matthew said he wanted to come back someday and donate enough money to sponsor one of the play spaces. I have no doubt he will make good on that.”

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**Rallying the Fans**

Paws is the lovable canine mascot for the Valley Blue Sox, a New England Collegiate Baseball League team based in Holyoke, Massachusetts. Always a fan favorite, he never shies away from a photo opportunity or chance to dance. But fans may not realize that the person bringing Paws to life at many home games is Irvin, a 14-year-old with cerebral palsy.

When Irvin was diagnosed at age 3, his family brought him from Puerto Rico to the United States in search of the best care for his condition. He came to Shriners Hospitals for Children — Springfield, located in Massachusetts.

“When he began treatment as a patient in the neuromuscular clinic, Irvin had limited movement on the right side of his body,” said Irvin’s mom, Isabel. “Bracing, physical therapy and participation in the hospital’s BFit power-based exercise and cycling programs improved his mobility and gave him the confidence and endurance he needed to pursue mascot acting, which is very physically demanding.”

Irvin admits that the job of mascot isn’t easy. “It can be hard to wear the costume for long periods of time while dancing and performing,” he said. “But the best part is having the opportunity to interact with people of all ages and entertain them, and making the audience a part of my mascot world.”

Chris Weyant, general manager of Valley Blue Sox, explained that Irvin is a valuable part of the team. “Irvin is the definition of a team player, always willing to help at the ballpark at every turn,” he said. “The job of being a professional mascot is not an easy one, but he is always able to leave Blue Sox fans with a memorable experience when they meet Paws.”

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**Shriners Hospitals for Children Open**

Matthew will represent the Portland hospital as a patient ambassador at the Shriners Hospitals for Children Open, held in Las Vegas Sept. 30 – Oct. 6. The FedExCup tournament features some of the world’s top golfers. Patient ambassadors get to meet and interact with the athletes and make memories to last a lifetime.

**Watch the final rounds on The Golf Channel, Oct. 3 – 6.**
Children and families find hope, compassion and excellent care for complex medical conditions at Shriners Hospitals for Children. Every day at our locations throughout North America, we are improving lives and helping dreams become realities.

Since opening our first location in Shreveport, Louisiana, in 1922, our hospitals and staff have provided excellent care to the children and families who come to us, regardless of their ability to pay for services.

Today, Shriners Hospitals for Children is one of the largest pediatric sub-specialty health care systems in the world, with a dedicated, full-time staff of experienced pediatric surgeons, therapists and clinicians.

Here are just a few examples of our innovation and dedication.

**Advanced laser medicine to treat burn injuries**

At Shriners Hospitals for Children — Boston, patients like Leufry, a teenager from the Dominican Republic who sustained burns over 30% of his body at the age of 6, when a live high-tension wire fell on him, are experiencing incredible outcomes with fewer trips to the operating room thanks to advances in laser medicine. Many of these laser techniques have been pioneered by plastic surgeons at the Boston Shriners Hospital.

It’s common practice in burn care to cover a burn wound with skin grafts taken from an unburned part of the body. It’s a highly effective treatment, but the recovery can be painful and the area where the graft is taken, known as the donor site, is left scarred. Both the grafted area and the donor site can develop thick hypertrophic scars that impair mobility and function, and may create less-than-optimal cosmetic results.

Today, clinical practice is changing. Doctors may recommend allowing some less-severe burns to heal on their own. After healing has occurred, plastic surgeons use laser techniques to minimize hypertrophic scarring and restore the skin to its pre-injury state. In cases where grafting has been necessary and this type of scar develops, lasers are very effective at reducing them and improving the patient’s overall appearance without further surgery.

“Laser medicine decreases hospitalization and does not cause deformity in other parts of the patient’s body,” said Matthias Donegan, M.D., chief of staff, Shriners Hospitals for Children — Boston. “These advances are not only keeping kids out of the operating room, but they are ultimately contributing to better outcomes and a better long-term quality of life for our patients.”

**Confidence in cleft lip and palate care**

According to the American Cleft Palate – Craniofacial Association (ACPA), only 2% to 5% of families who have a child born with cleft lip and palate have another child born with the condition. When a family from Indiana was given this diagnosis for their second child, Evan,
before he was born, Shriners Hospitals for Children — Chicago was the first place they called. The family was already familiar with the hospital and its approach to cleft lip and palate care. It’s where their first child, Terilyn, is receiving care.

While the children typically have their appointments on separate days, the two recently visited the hospital together.

Both children had a day filled with appointments with their team of specialists, including plastic surgeons, speech pathologists, psychologists, audiologists, dental and orthodontic professionals, ENT physicians, nurse practitioners and social work care managers. The Chicago Shriners Hospital is recognized as an ACPA-approved team.

Eighteen-month-old Evan was having his first team visit since healing from his four surgeries in 2018, which included repairs to his palate, lips and nose, along with tubes for his ears. Evan’s mother, April, said the family was pleased with the results of the surgeries.

“We thought Terilyn’s surgery was amazing and she looks beautiful, but Evan’s work was like perfection,” she said. “Even the two little marks on his lip. They are his ‘trademark.’ We tell him that’s the special little stamp you’re going to have for life.”

The team visit included a focus on Evan’s challenges with eating solid foods. Speech language pathologists are working with his parents on this issue. Evan is also receiving weekly therapy at home for his sensory feeding issues. “He is doing well and continues to progress, but it is a very slow process in introducing him to different textures and also understanding the concept of needing to chew his food,” said April.

During this visit, the family and clinicians also discussed the future care expected for Terilyn, now 6. “Her next surgery will be a bone graft, but the beginning of that process probably won’t start for a year or so,” said April.

The Chicago Shriners Hospital’s cleft lip and palate team is happy to have played a major role in giving Terilyn and Evan new smiles. David Morris, M.D., a board-certified plastic surgeon, said the parents have played instrumental roles in the process. “It has been a pleasure working with their entire family in so many ways, the most obvious being having met both children as infants, watching them grow, hearing their speech develop, and seeing them interact as siblings,” he said. “As parents, April and Michael have been remarkable in finding ways to support and augment our efforts. Both parents have enthusiastically shared their experiences with other families. This is so important, as the information is coming from the direct experience and the unique perspective of another parent, rather than from the caregiver.”

Interestingly, despite the low percentage of families with more than one child with this condition, our Pasadena, California, location has also provided cleft lip and palate care to a family with multiple children coping with this condition.

### New Collaboration Means Better Care in Canada

**Shriners Hospitals for Children — Canada is part of a historic initiative to help treat musculoskeletal disorders**

In June, Montreal’s four leading pediatric institutions announced the creation of MUSCO, the first and largest collaborative initiative of its kind in Canada to help children with musculoskeletal disorders. The CHU Sainte-Justine and its Marie-Enfant Rehabilitation Centre, the Montreal Children’s Hospital and Shriners Hospitals for Children — Canada are coming together thanks to a $10 million donation from the Mirella & Lino Saputo Foundation.

The donation will provide the opportunity to revolutionize patient care and services in Quebec for children with musculoskeletal diseases requiring complex care (hence the name MUSCO). It will allow facilities to:

- Re-evaluate procedures and tools to facilitate a patient’s treatment and improve the patient experience
- Recruit key people to accompany patients and their families, ensuring they receive the right care at the right time and at the right place
- Build infrastructure and buy state-of-the-art medical equipment and technology, giving patients in our system access to the best and latest care and diagnostic techniques
- Create spaces encouraging innovation and discussion to share best practices and develop new protocols
- Organize events and help centers to offer patients and families the best information possible
- Train medical professionals to offer a better bedside manner
- Include patients and families as partners

“MUSCO will allow for incredible breakthroughs in pediatrics, benefiting thousands of children and their families from all over Quebec, Canada, and around the world,” said Reggie C. Hamdy, M.D., chief of staff at Shriners Hospitals for Children — Canada. “On behalf of everyone here at Shriners Hospitals for Children — Canada, thank you, Mr. and Mrs. Saputo, for having the vision to see what we can create together.”

Evan received cleft lip and palate care at Shriners Hospitals for Children in Chicago.

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**TO LEARN MORE about the care and services provided by Shriners Hospitals for Children, please visit shrinershospitalsforchildren.org.**

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SHRINERSHOSPITALSFORCHILDREN.ORG
Orthopaedic Surgeon Earns Prestigious Award

Beloved Dr. Schoenecker honored for devoting his life to caring for kids

Perry Schoenecker, M.D., orthopaedic surgeon and former chief of staff at Shriners Hospitals for Children — St. Louis, received the Distinguished Achievement Award at the 2019 Pediatric Orthopaedic Society of North America (POSNA) conference in Charlotte, North Carolina. Throughout his distinguished career, Dr. Schoenecker’s focus has been pediatric orthopaedics, particularly specializing in congenital developmental deformities of the lower extremities (hip, knee, foot and ankle).

Dr. Schoenecker began working at Shriners Hospitals for Children in 1975 and served as chief of staff from 1977 to 2017. In addition to practicing at Shriners Hospitals for Children, Dr. Schoenecker is a professor of orthopaedic surgery at Washington University School of Medicine and sees patients at St. Louis Children’s Hospital. He travels throughout the world lecturing and teaching at various symposiums and workshops. Each year, he evaluates and treats hundreds of patients in Belize during medical mission trips.

Dr. Schoenecker is beloved by his patients and families. One mom said, “We can’t thank Shriners Hospitals for Children — St. Louis and Dr. Schoenecker enough for everything they have done for our son!” A grateful former patient said, “If it weren’t for Shriners and Dr. Schoenecker, I would’ve never known what walking was like and the enjoyment of my kids and the things we’ve done together.”

We extend our congratulations to Dr. Schoenecker on this much-deserved honor.

A Rare Connection

Families and medical professionals united by arthrogryposis meet at annual conference

When Abigail was born in 2005 with amyoplasia, her mother, Ani, wanted to learn all she could about the condition, which is among a group of rare muscle disorders known as arthrogryposis multiplex congenita (AMC), or arthrogryposis. So Ani started a website, which eventually developed into Arthrogryposis Multiplex Congenita Support, Inc. (AMCSI), a support group and resource for affected families. Now, the group hosts an annual conference to allow families and medical professionals to share experiences and research.

What is AMC?

AMC is characterized by the presence of contractures at birth, affecting more than one body part, and abnormal muscle development. Shriners Hospitals for Children is known for its expertise and knowledge in treating this condition. Patients from as far away as Europe and even Asia have come to us for treatment.

“When the unborn baby is moving during pregnancy, the muscles and ligaments are being stretched. You know the wrinkles on your knuckles? They should be present at birth. They indicate movement. When something goes wrong and the baby stops moving – and up to 400 different abnormalities can cause this – it can result in arthrogryposis,” said Harold van Bosse, M.D., orthopaedic surgeon at Shriners Hospitals for Children — Philadelphia. Approximately 75% to 80% of Dr. van Bosse’s work at the Philadelphia Shriners Hospital is dedicated to helping children who have arthrogryposis.

A special event

This year’s 14th annual AMCSI conference drew about 600 participants and gave patients and families a powerful opportunity to connect and share stories. One young boy said this is the best week of his year and he is sad when he leaves. A mom of a 19-year-old patient hugged and encouraged a mother of a 7-month-old with the condition.

The conference is also attended by medical and research professionals, and several staff members from Shriners Hospitals for Children were on hand to share their expertise and insights into the rare disorder. These included Dr. van Bosse; Dan Zlotolow, M.D.; and Sarah Nossov, M.D., of the Philadelphia Shriners Hospital; Lauren Hyer, M.D., of the Greenville Shriners Hospital; and a team from Shriners Hospitals for Children — Canada. Topics discussed ranged from “AMC 101” to the ever-growing body of research on AMC.

“This conference is always one of the year’s highlights for me. I was fortunate to hear about AMCSI right after their first meeting, and have been able to participate in every meeting since then. It is such a joy watching all the children run or zoom around, just being full-bore, spontaneous kids with no concern for who’s got AMC or not,” said Dr. van Bosse, who is also a member of the AMCSI board of directors. “And the emotional moments, such as when a person with AMC or a parent meets another person with AMC for the first time ever. Sure, the talks are important, but it’s those moments that make the meeting memorable.”

To learn more about the condition and the conference, visit amcsupport.org.
Tommy is open to talking about his leg, helping to educate other kids about how we all have differences.

Stop looking at him! Don’t stare!” It’s something Mary Kay sometimes hears when she is out with her son, Tommy, especially at the pool. But her usual reaction surprises some.

“Oh, do you want to see?” she’ll invite. “Come look. He has a special leg.”

Tommy, 8, is missing part of his left leg. The young Shriners Hospitals for Children — Chicago patient typically uses a prosthetic leg provided by pediatric orthotic and prosthetic services at the Chicago Shriners Hospital. But at the pool he is more likely to be found hopping on his strong right foot.

Rather than hiding Tommy’s disability, Mary Kay has found that it helps build her son’s confidence when they work together to educate others. Gathering interested kids and parents around, she will explain about Tommy’s limb difference. “I tell them, ‘We have two bones in our leg. But he was born with one. He has a special leg. Come on over!’

“We like to be proactive instead of just pretending,” she said.
Planning for success
Mary Kay’s advice lines up with what Shriners Hospitals for Children psychologists recommend for promoting acceptance: Have plans in place ahead of time and find ways to help everyone become more comfortable.

Heather Russell, Ph.D., is a licensed clinical psychologist at Shriners Hospitals for Children — Philadelphia. She has many strategies to help families of children with disabilities foster acceptance and build confidence. Anticipating potential trouble spots is key.

At school, that means communicating with the teachers, the principal and the school nurse, early and often, Dr. Russell said. Set up meetings with these key people before school starts to answer their questions and let them know what sort of help your child may need — or not need. Before ending the meeting, schedule a follow-up to discuss how things are going and whether adjustments are needed.

Other things to help ease the way:
• Do a dry run with your child, practicing moving around the school from class to class.
• Know who to talk to — such as teachers, the principal or the school counselor — in case there are issues with other students, their parents or with staff.
• Schedule play dates or outings with school friends leading up to the first day of school in order to help all the kids feel more comfortable.

Another of Dr. Russell’s recommendations is to suggest a discussion about differences to occur early in the school year. Having a physical disability is only one of the ways people can be different. This can lead to a discussion, on a classroom level or at a whole school assembly, about diversity and respect.

When Tommy started preschool, Mary Kay reached out to his teacher. She said his class did a lesson similar to show-and-tell about everyone’s differences, not just Tommy’s. “Anyone who had a difference could raise their hand and share,” Mary Kay said. “‘I have glasses,’ ‘I have this or that.’ When it was Tommy’s turn, he said, ‘I have a prosthetic leg.’”

Dr. Russell said it’s good for children to know how to talk about their disability when asked. Kids should find a short, honest answer that feels comfortable to them. They can practice this answer by role-playing various situations with a trusted adult or friend.

Mary Kay said Tommy is learning to gauge his own comfort level with how much he wants to share. She said sometimes children ask him to remove his prosthetic leg. “Sometimes he is willing to pop it off and show them,” she said, while other times he chooses not to.

Education and celebration
Sometimes all the preparation in the world can’t prevent a tough situation from occurring, Mary Kay admitted. If Tommy runs into kids who don’t know him and pepper him with questions or make unkind comments, she’ll let Tommy handle it, up to a point. “He’s only 8, so sometimes I’ll step in and help.”

Even in these situations, she sticks to her message of education and celebration. “I point out that everyone is different, and wouldn’t it be boring if we were all the same,” she said.

The messages of confidence and acceptance can have lasting effects. Far from being defined by his limb difference, Tommy has many interests and special qualities, his mother said. “He is very independent in not caring what other people think he should be into,” Mary Kay said. The youngest of four siblings, he is a sensitive, creative little boy who loves eating sweets and making people laugh.

In fact, she said, his developing sense of humor keeps his family on their toes. Mary Kay said Tommy recently pulled a prank on one of his older sister’s new friends, taking off his leg and pretending to fall in front of her.

Through it all, Mary Kay said, “Celebrate your child.” “As moms, as parents, we already have an idea of what our child’s life will be like,” she said. “Then, it isn’t what you imagined. But you have to just embrace what God gave you and make the best of everything. Difference is what makes the world go around.”

Shriners Hospitals for Children has specialized orthotic and prosthetic professionals onsite at many of our locations to help provide devices and support for children who need them.

More tips for smooth school days

Dr. Russell at the Philadelphia Shriners Hospital recommends including the following in your child’s Individualized Education Plan (IEP):

- Request two sets of books, one for home and one for school
- Get permission for your child to leave classes a few minutes early in order to avoid crowded hallways
- Arrange for a friend to help carry supplies or take notes
- Schedule regular times in the nurse’s office
- Request special seating arrangements
Bringing Care Where the Kids Are

Telehealth and outreach clinics connect patients and medical teams across the miles

“I wish I had another hour in the day!” It’s a common refrain for most parents. Families with children who have a disability or medical condition may feel it more acutely at times, as they devote valuable minutes or hours a day to care routines. And when the child’s health care provider is far away and getting the proper care requires travel, there’s even less time to spend on the things that really count – school, work, visiting friends, playing sports – just being a family, and being a kid.

But now, thanks to advances in technology and our ever-growing partnerships across the globe, we’re able to reach more kids in more places, giving them the time to spend on the things that matter most.

**Telehealth connects patients**

There are still only 24 hours in a day. But, by reducing the need for lengthy travel, telehealth gives time back to families.

Telehealth care is provided in a nearby clinic where children can be seen for a scheduled appointment with their Shriners Hospitals medical team, without traveling to the Shriners Hospital.

At the telehealth clinic, which may be at a Shriners Hospitals location or an associated affiliate site, a medical professional takes the patient’s clinical measurements including weight and height, just like any other clinic visit. Then, the child and family move to a private telehealth exam room, where they are able to communicate directly with their Shriners Hospitals medical team, via a computer system that uses a camera and a large screen to create live, two-way video and audio.

After the exam, families have time to talk with the local medical team, ask follow-up questions, complete paperwork and plan the next visit.

**In 2018, 246 outreach clinics were held in the U.S., helping to reach and care for children closer to their homes.**

Outreach clinics bring care closer to home

Our primary locations also hold outreach clinics within their local areas. In 2018, 246 outreach clinics were held in the U.S., helping to reach and care for children closer to their homes.

International outreach clinics were held in several countries in 2018, including Cyprus and Panama. In addition, we initiated clinics in new locations, including Guatemala, El Salvador, Bolivia, the Dominican Republic and the Philippines. Our physicians also worked with other relief organizations and cared for patients in additional international locations.

The outreach clinic in Panama coordinated by Shriners Hospitals for Children — Shreveport is a prime example of the initiative’s impact. Earlier this year, the program served 550 patients, and 120 were scheduled to come to the U.S. for further treatment.

Overall our health care system held more than 300 outreach clinics in 2018.

We are proud of our continuing efforts to fulfill our promise to care for children wherever they may live, and bring medical excellence, hope and healing to communities around the globe.

Reaching more kids in more places

Although Shriners Hospitals for Children has health care facilities in just three countries, our health care system has, over time, provided care for children from more than 170 countries. And we are determined to provide our unique, compassionate wrap-around care to as many children as possible, wherever they may live.

Using technology, community partnerships and affiliations, as well as creating additional ways to access our health care system, we can reach many more kids in need of our services, in many more places. We continue to increase our efforts to serve as many children as possible who, otherwise, would likely never experience the special brand of hope and healing that is the hallmark of our health care system.
Standing Tall for Kindergarten

Rilynn gets new legs for the new school year

“I’m really excited to go into kindergarten with some tall legs,” said Rilynn. “I think they can take me all over the world.”

Rilynn, a patient at Shriners Hospitals for Children — Portland, was born with tibial hemimelia in both legs, a condition in which the tibia bone (lower leg) is shortened or absent. When Rilynn was old enough to walk, she received her first pair of “stubbies,” hard sockets that level her legs and allow her to walk, but didn’t have a knee or foot. Her stubbies had a design reflecting her favorite Disney character — the Little Mermaid!

Now Rilynn is a 5-year-old kindergartener. Before starting school, she decided that she wanted to have “tall legs” in order to be the same height as her peers. Rilynn and her family worked with orthotist/prosthetist Sabrina Jakobson Huston, CPO, at the Portland Shriners Hospital to get Rilynn conventional prosthetic legs that have knees that bend and distinct feet that allow her to wear shoes and have her toenails painted. Once again, Rilynn chose the Little Mermaid as the design on her prosthetic legs.

When asked what activity she’s looking forward to trying with her new prosthetic legs, she jumped at the answer. “I’m going shoe shopping!”

“This is really important for her, especially going into kindergarten at a public school,” said Rilynn’s mom, Janell. “She’s going to have a knee that bends, shoes to wear and toes to paint.”

Models for Acceptance

My Pals program helps children learn to see the ability

For more than 25 years, Shriners Hospitals for Children — Springfield has run an exceptional program to help foster acceptance for kids with differences. My Pals is led by a hospital team that brings lessons in respect and courtesy to area classrooms.

The presentations, designed for children in kindergarten through second grade, use dolls to portray different conditions treated at the hospital. My Pals gives students the opportunity to learn about the abilities of kids who use wheelchairs, braces or orthotic and prosthetic devices.

Ian, a young Shriners Hospitals for Children patient, happened to be in a class during a recent My Pals event. Afterward, his mother, Jen, sent a note to the hospital:

“Your visit made such a powerful impact on Ian and his peers. On the day you visited, it was Ian’s one-year anniversary of his first day in an American school. Prior to that, he had been living in an orphanage in China, where he was regularly ostracized for his limb difference, but on this day it was embraced and celebrated. We are so grateful for you sharing how all children have abilities and that physical differences are opportunities to explore new ways to do things. Thank you for this important work!”

backpack safety tips

It’s a ritual of the new school year: shopping for fresh supplies, sharpening new pencils and picking out the perfect backpack to carry it all.

Once you have the perfect pack, it’s important to use it correctly. Most backpacks are designed to distribute the weight of the load among some of the body’s strongest muscles. Backpacks that are too heavy or carried incorrectly can injure muscles or joints and contribute to muscle fatigue, poor posture, pain in the shoulders and neck, as well as injuries from tripping and falling.

Here are some backpack tips to keep in mind this school year:

The proper backpack is:
- No wider than the child’s chest
- Worn no higher than the base of the neck
- Worn no lower than 2 to 4 inches below the waist
- Supported by a waist or a chest strap

To help prevent pain and injury kids should:
- Lift with the legs: Bend at the knees, hold the backpack with both hands, then straighten the knees to lift the pack to waist height.
- Use both shoulder straps.
- Adjust shoulder straps to fit snugly between the neck and the curve of the lower back.
- Avoid carrying an overloaded backpack. For heavy loads, consider hand-carrying larger books or using a backpack with wheels.

A backpack is too heavy if:
- It forces the child to lean forward.
- It weighs more than 15% of the carrier’s weight. (To determine the proper maximum weight, multiply the child’s body weight by 0.15.)

FOR MORE INFORMATION and to download or order an informational brochure, please visit tinyurl.com/carry-the-load-safely.
National Patient Ambassadors Madelyn and Cristian say they look forward to inspiring other families along their journey with Shriners Hospitals for Children.

Cristian and Madelyn share the impact of the life-changing care they received at Shriners Hospitals for Children

THIS IS MY MOMENT
Every year, Shriners Hospitals for Children selects two National Patient Ambassadors to represent the health care system’s patients. The ambassadors spend the year sharing their stories of perseverance in the face of adversity and the ways in which Shriners Hospitals for Children has made a dramatic difference in their lives. Introducing our two new ambassadors:

**Cristian, age 18**
Cristian was born with spina bifida and hydrocephalus. In his first two weeks of life, Cristian had two surgeries. He went on to have nearly a dozen more. Cristian faced several of the same challenges that many other patients with spina bifida do, including gastro-intestinal system and balance issues, as well as complications from various surgeries. For several years, his family had difficulty finding doctors who understood how to best help Cristian.

That all changed one day in 2012, when Cristian met a Shriner who referred him to Shriners Hospitals for Children. Cristian was 13 when he had the surgery that he says changed his life and gave him hope, at Shriners Hospitals for Children — Los Angeles (now Shriners for Children Medical Center in Pasadena, California).

Devoted to his schoolwork, seminary studies, a part-time job and playing the cello, Cristian has also been active in supporting Shriners Hospitals for Children. He even dedicated his Eagle Scout project to the cause, raising funds to present more than 200 Build-A-Bear toys to our Pasadena medical center. He finds inspiration in the other patients he encounters. “I have been very inspired by many other kids I have met. Most of the people I look up to and admire are the kids I have met through Shriners,” he said.

Cristian is enjoying his responsibilities as a National Patient Ambassador. “I know that I am who I am because of the Shriners,” he said. “I have been able to see that I can do whatever I want, and I can overcome any obstacle that I face. I want to give back to them because of that — because of the life that they’ve given me. Through Shriners Hospitals for Children and the national ambassadorship that I’ve been given, I hope to share a message of positivity and hope to all those who need it.”

**Madelyn, age 19**
Madelyn was born 10 weeks early. Doctors told her parents that she was beautiful, healthy, tiny — and was born without her left arm.

“When I see other Shriners patients working hard to achieve their own goals, I realize more and more that the sky is the limit.”

—CRISTIAN
“Nothing is impossible in my mind. It’s just the ability to adapt and work around it.”

–MADELYN

Madelyn’s journey with Shriners Hospitals for Children began with her first visit to our St. Louis location when she was just 3 months old. Throughout her childhood, Madelyn used prosthetics, mainly for balance, and to help with various activities. Occupational therapists at the hospital helped Madelyn learn to function and interact in the world. As she grew older, Madelyn began using her prosthetics less often, and by middle school, she opted to stop using them.

In school, Madelyn’s busy schedule included not only her classwork but also competitive swimming, first on a team for children with disabilities, then on her high school team. She also participated in competitive, coed water polo. “Nothing is impossible in my mind,” she said. “It’s just the ability to adapt and work around it.”

Madelyn has always devoted herself to advocating and educating. She loves to make YouTube videos showing how to accomplish things using only one arm. During Ability Awareness Week, an annual program at St. Louis-area elementary schools, Madelyn has shared her story about the ways Shriners Hospitals for Children changed her life. Drawing from her own experiences of being bullied for having only one arm, Madelyn likes to incorporate anti-bullying themes into her presentations.

Madelyn is currently a student at Maryville University in St. Louis, where she is very active in student activities and made the Dean’s List her first two semesters.

“I am incredibly excited to see where this year takes me,” Madelyn said. “I hope to inspire other kids and be able to show them that they can do anything they put their mind to – they might just do it a little bit differently.”

We congratulate Cristian and Madelyn, and thank them for their willingness to represent Shriners Hospitals for Children and share their stories.

**Building a Partnership One Bear Hug at a Time**

Our collaboration with Build-A-Bear Workshop provides new ways to bring smiles to children.

It was the rainbow shoes that did it.

Jing, 9, was at the Build-A-Bear Workshop store near Cincinnati, happily dressing up her new bear friend. She had a Girl Scout theme in mind, with Brownie accessories like the ones she wears to her troop meetings.

And then she saw the shoes. Just like her own rainbow shoes. For Jing, it was a joyful cap to an exciting day. Her mom, Laura, said that as soon as they got home, Jing quickly changed clothes so she and her bear could pose for a picture in their matching outfits.

Jing was among 55 Shriners Hospitals for Children patients nationwide who participated in a Build-A-Bear event designed to bring joy to kids. The patients enjoyed the full Build-A-Bear experience, which involves creating a custom stuffed toy and filling it with all the magic and love a child can imagine. The month-long event also included a fundraising campaign in which Build-A-Bear Workshop customers were able to donate in support of Shriners Hospitals for Children.

![Madelyn shared a YouTube video on how to drive with one arm.](image1)

![Jing proudly shows off her new bear, with shoes just like her own.](image2)

**TO WATCH** their video, *This Is My Moment*, please visit [youtube.com/shrinershospitals](https://youtube.com/shrinershospitals).
It’s all part of a new corporate partnership between the Shriners Hospitals health care system and Build-A-Bear Workshop. It’s a natural fit for the two organizations, which both have missions that aim to help kids. As Build-A-Bear Workshop indicates on its website, “When a child is sick, scared or lonely and reaches for their teddy bear, Build-A-Bear is there ... the simple joy of a teddy bear hug can make a difference.”

During the 30-day campaign, 83 Build-A-Bear stores raised more than $29,000 in donations to help support Shriners Hospitals for Children. A check presentation ceremony was held at Shriners Hospitals for Children — St. Louis, in July. Patients who attended were able to meet the Build-A-Bear mascot.

Build-A-Bear and Shriners Hospitals for Children are looking forward to creating new ways to move their partnership forward in the future.

Shriners Hospitals for Children patients enjoy building their new bears.

First Lady Cheryl Sowder

Make a Difference in the Lives of Children

One of the many ways to support the work of Shriners Hospitals for Children is through the unique effort known as the First Lady’s program.

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 to benefit our health care system.

Heroes among us

This year, First Lady Cheryl Sowder’s initiative, Heroes Among Us, is supporting the Patient Ambassador programs of Shriners Hospitals. A Patient Ambassador is a current or former patient who is an advocate for Shriners Hospitals for Children. Patient ambassadors donate their time to promote the health care system and their local facility, as well as the Shriners International fraternity. They volunteer at events, provide tours of their hospital or outpatient center – and host fundraisers.

“Our patients are the true heroes of Shriners Hospitals for Children,” said Cheryl. “They give hope and inspiration to others and reinforce the message that Shriners Hospitals for Children provides life-changing care.”

Cheryl believes we need to acknowledge the incredible spirit and abilities of our patients and support their efforts to share their stories as Patient Ambassadors for the health care system.

“These children can tell the story of Shriners Hospitals better than anyone,” said Cheryl. “We are pleased to provide a program to support and enhance their efforts.”

Cheryl’s program will help the Patient Ambassadors of Shriners Hospitals for Children gain skills that will serve them throughout their lives, such as the public speaking experience they get while sharing stories of their life-changing care at Shriners Hospitals for Children. To learn how you can support this effort, please visit lovethetherescue.org/first-lady-program.

Women & Philanthropy program

This year, Cheryl is also beginning a second program, Women & Philanthropy – Shriners Hospitals for Children, also for the benefit of the hospitals through the annual First Lady’s program. Membership is open to all women. 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. Cheryl believes that women have an increasing ability to effect change through their leadership and philanthropic efforts. Members recognize that by combining gifts and donations, these gifts go further and can have a greater influence. All women who support the life-changing work of Shriners Hospitals for Children are invited to be part of this effort.

TO LEARN MORE about this unique initiative, please visit lovethetherescue.org/womenandphilanthropy.

Shriners Hospitals for Children patients enjoy building their new bears.
DR. SMITH WALKS FOR AWARENESS

“To know that children I have treated when they are very young, and I’ve seen them progress – to think that’s part of the result of our influence is very rewarding.”

Peter Smith, M.D., is an attending orthopaedic surgeon and director of the osteogenesis imperfecta (OI) clinic at Shriners Hospitals for Children — Chicago. He is also co-medical director of the hospital’s motion analysis center.

At the “Medics on the March” event earlier this year, Dr. Smith and other physicians from around the country logged 50 miles walking in Maryland and Virginia to raise awareness of OI.

The OI Foundation, for which Dr. Smith serves as a member of the medical advisory board, was started by families who received care at the Chicago Shriners Hospital.

Photo courtesy: OI Foundation

□ TO LEARN more about the OI Foundation, visit oif.org.
Shriners Hospitals for Children®

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LEADERS IN care

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Shriners Hospitals for Children*

THE MOST AMAZING CARE ANYWHERE

Shriners Hospitals for Children improves the lives of children by providing pediatric specialty care, conducting innovative research, and offering outstanding educational programs for medical professionals. Children with orthopaedic conditions, burns, spinal cord injuries, and cleft lip and palate are eligible for care, regardless of their family's ability to pay, and receive all care and services in a compassionate, family-centered environment. Many techniques and treatments common in most hospitals today were pioneered by Shriners Hospitals for Children. We send Love to the rescue® to thousands of children worldwide because of you and your support.

57,663 new patients in 2018

148,811 children cared for in 2018

1.4+ million children treated since 1922

$38 million invested in research in 2019

Over time, patients from 50 states and more than 170 countries served

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