LEADERS IN

STORIES OF THE MOST AMAZING CARE ANYWHERE
SUMMER 2021

Back in the Jame

Young athletes overcome sports injuries with help from the winning teams at Shriners Hospitals



Shriners Hospitals for Children®

ABOUT 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 worldrenowned 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**.

COMMUNITY CONVERSATIONS



Dear Readers,

We have exciting news to share with you! In the near future, we will be launching a completely new website for Shriners Hospitals for Children. We have

been working on this for a very long time – putting months and months into planning a site that will be:

- · Easy to navigate
- Intuitive and responsive to our viewers
- A showcase for our mission: improving the lives of children through providing amazing patient care, conducting innovative research and offering outstanding educational opportunities for medical professionals
- Vibrant, bright and beautiful just like the children we serve

We are also launching a new brand. You will begin to see and hear the phrase "Shriners Children's." With this concise phrase, we honor the vision of the Shriners fraternity members who founded our unique and compassionate health care system nearly 100 years ago, and we name the single focus of our work: children.

The Shriners organizations are committed to the ideals and the power of hope and healing. In this issue, we share those values through awardwinning photographs from several of our locations. We hope they bring you joy and inspiration.

In that same spirit, we hope for continued progress in the fight against the pandemic and a return to normalcy as soon as possible – for everyone, everywhere.

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

PATIENT PERSPECTIVES

JENSON STAYED IN ROOM 7 at Shriners Hospitals for Children — Portland. Below is a note and illustration the family shared after their stay.



To: The nurses, doctors, cleaning staff and therapists at Shriners Hospitals

Thank you so much for your great care of Jenson and all of us. You made our stay here as pleasant as it could be under the circumstances. We thank God for you! This pic was inspired by the beautiful view in our room.

Thanks again, Justin, LaDonna, and Jenson



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

ON THE COVER: Jaylen is back to playing the game he loves after having ACL reconstructive surgery at Shriners Hospitals for Children — Northern California.

ANNOUNCEMENTS

Stronger Together

Photo exhibit showcases how children's hospitals nationwide have persevered through the pandemic

Stronger Together - Children's Hospitals During COVID-19 is an online photo exhibit dedicated to capturing the effect of the pandemic on children's hospitals - and their incredible ability to adapt and overcome. Assembled and displayed by the Children's Hospital Association (CHA), the exhibit shares nearly 70 photographs and stories that highlight the ways in which children's hospitals have been able to innovate and transform health care delivery for their most vulnerable patients during this especially difficult and challenging time.

Shriners Hospitals for Children is proud to have photographs from several of our locations included in the collection.

As COVID-19 spread throughout their communities, Shriners Hospitals for Children's patients still needed specialty medical care. Our teams found ways to continue to safely treat our patients, to keep therapies going and to maintain a compassionate, family-centered environment through it all. Photos in the exhibit highlight the many special activities and efforts at Shriners Hospitals: From Boston, Massachusetts, to Houston, Texas, and Portland, Oregon, to Greenville, South Carolina, our staff and our patients found ways to bring light and hope to the most trying days.

"What these special images represent is resilience - the resilience of patients and families and their health care providers during the most stressful and difficult of times," said Amy Knight, president of CHA. "In the face of crisis and adversity, children's hospitals worked together, leveraging their expertise and strength of collective experience to care for our patients and to support our broader communities' responses."

VIEW the photo series and stories behind the photos at childrenshospitals.org/Newsroom/ Photo-Exhibit.



Patients. families and staff throughout the Shriners Hospitals for Children system found creative and compassionate wavs to overcome the challenges presented by COVID-19.

PHOTO BY JENNY MYERS, GREENVILLE









PHOTO BY HARLAN PINE, PORTLAND







PHOTO BY KENT SPIRY SPRINGEIELD

DIONCE'S IN PEDIATRICS

EVERYDAY EXCELLENCE IN SPECIALTY TREATMENTS AND RESEARCH

BACK GAME

Young athletes overcome sports injuries with help from the winning teams at Shriners Hospitals

en Wilson, M.D., knows what it's like to be sidelined by a sports injury. As a high schooland college-level athlete, he sustained shoulder and wrist injuries that eventually required surgery. Physical Therapist Adrianne Marx grew up swimming, running track and golfing. Spending all her time around other athletes, she witnessed firsthand the toll that sports injuries can take. That's why Dr. Wilson and Marx work hard at Shriners Hospitals for Children Medical Center — Lexington to help patients with sports injuries get back to the games they love.

"I think being an athlete myself helps me relate," Dr. Wilson said.

The medical teams at Shriners Hospitals are especially attuned to an athlete's concerns, as well as the differences between an adult athlete's body and that of a young, still-growing athlete. They work as a team to get them back in competing shape.

Conservative treatments

Sometimes athletes are wary of seeking treatment for pain or injuries because they are afraid they won't be allowed to play. However, many conservative methods that don't require surgery or long recovery times, such as rehabilitation programs, arch supports, bracing and taping, are often successful in treating injuries. >> Kiley was treated for her knee injuries without surgery.

8 Understanding Sports and Recreation Injuries | 9 Women Surgeons Make a Difference at Shriners Hospitals

CONT



Kiley completes exercises with her physical therapist.

"Rehabilitation, specifically physical therapy, can assist in conservative management of many sports injuries in order to return an athlete to full participation in their chosen sport as quickly and as safely as possible," said Physical Therapist Mary K.V. Eighmy, PT, DPT, of Shriners Hospitals for Children — Erie.

This conservative management worked for Kiley, a 15-year-old basketball player who was sidelined last summer when she was injured during a tournament. Kiley had fractured her knee and bruised her kneecap, which required 12 weeks of physical therapy at Shriners Hospitals for Children Medical Center — Lexington. For Kiley, it was valuable time to heal and also to maintain and build her strength to prevent more injuries.

"When I hurt myself, it felt like it was the end of the world," Kiley said, "but coming to Shriners Hospitals helped me know that I could go back to playing and not get hurt again, and that I could be better in time for the season to start again."

With the help of the team at the Lexington Shriners Medical Center, Kiley is back on the court and intends to play basketball in college.

Non-surgical treatment also helped a young dancer from Massachusetts, who dislocated her kneecap last fall while performing an acrobatic move she had executed perfectly many times before.

"I was in immediate pain. I couldn't put any weight on my knee," said Bridget, 12. "I think I was in denial that I was hurt because I had never had an injury like that before."

At Shriners Hospitals for Children — Springfield, Bridget met Ahmad Bayomy, M.D., medical director of the hospital's sports

health and medicine program. "Bridget was in such strong physical shape that I determined rehab was the best course of treatment," Dr. Bayomy said.

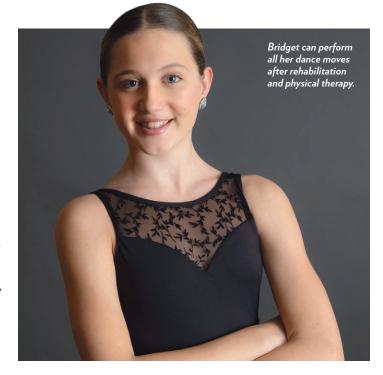
"It was important to us that she be recognized as an athlete as she entered therapy," said Bridget's mother, Erin.

Bridget was fitted for a knee brace and began eight weeks of physical therapy with Physical Therapist Erin Carpenter, PT, DPT, who is also a trained dancer. "It was so cool how Erin incorporated dance moves into my therapy," said Bridget. "We talked the same dance lingo!"

In December, Bridget returned to dance practice and executed a front aerial to perfection.

"I was so emotional," said Bridget. "It was such an amazing feeling." "It was important to us that she be recognized as an athlete as she entered therapy."

- ERIN, BRIDGET'S MOM



Preventing sports injuries

"One of the most important roles of pediatric orthopaedics is patient education and injury prevention," said Physician Assistant Christine Betancourt, PA-C, Shriners Hospitals for Children – Erie. Sports injuries often are sustained from overuse, such as working the same muscle groups without adequate rest periods, or from trauma, such as from collisions or falls. Jonathan Pellett, M.D., pediatric orthopaedic surgeon at Shriners Hospitals for Children — Honolulu, offers these tips to help kids play safe:

- Warm up before play, and cool down after.
- Be sure to stay hydrated.
- Cross-train to encourage the use of different muscle groups. For example, if you play soccer in the spring, sign up for swimming in the summer to let your leg

joints recover while allowing your arms and core to get stronger.

- Treat minor strains, sprains and bruises with RICE (rest, ice, compression, elevation). Children should not return to sports until the pain is resolved.
- Consider a mouthguard for any contact sport. "More than 1 million athletes per year suffer dental trauma, and that is a completely preventable injury," Dr. Pellett said.

When surgery is the only option

In summer 2019, Jaylen, a football player from Sacramento, California, attended a sports camp in Napa. The opportunity gave the promising young athlete the chance to live on a college campus, meet other players and learn from new coaches.

In a final scrimmage on the last day of camp, with parents in the audience, Jaylen, 12, was tackled on his blind side. The hit came just as Jaylen was pushing hard off his left leg. He heard a loud pop, felt tremendous pain in his left knee and fell to the ground.

"Jaylen normally jumps up quickly after he's tackled," said his mother, Yuri. "This time was different."

X-rays found no broken bones, but an MRI revealed that Jaylen had a torn ACL (anterior cruciate ligament), the primary stabilizing ligament of the knee joint. ACL tears are becoming more common in young athletes. According to the American Academy of Orthopaedic Surgeons, ACL injuries that occur before a child's bones have fully matured (in boys, typically by age 16) require special treatment and care to ensure proper healing and to prevent long-term complications.

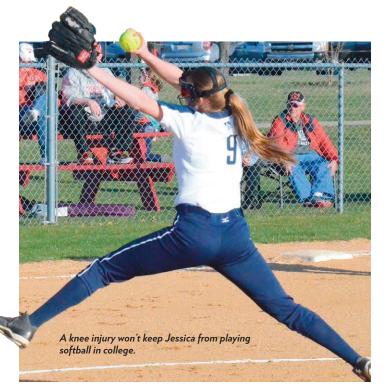
At Shriners Hospitals for Children — Northern California, Nicole Friel, M.D., orthopaedic surgeon and sports medicine specialist, reconstructed Jaylen's ACL. Jaylen had physical therapy to recover the full use of his knee and return to the game he loves.

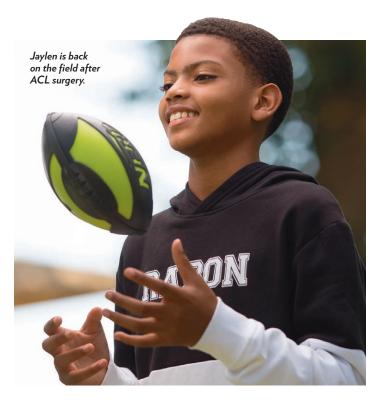
Using data to return to sports

How do the care teams know when a patient is ready to play again? One way is through data.

In March 2019, a knee injury took Jessica off the softball field for almost a year. "She was running to first base when the first baseman slipped, falling into Jess as she was running by," said Jessica's mom, Kimberly.

Jessica received care at Shriners Hospitals for Children — Chicago, where they use a team approach that includes pediatric





orthopaedic surgeons, on-site physical therapy and return-to-sports testing in the motion analysis center. She was treated by Pediatric Orthopaedic Surgeon Kelsey Elaine Davidson, M.D.

After arthroscopic surgery with a bone-patellar tendon-bone (BPTB graft), physical therapy and home exercises, Jessica underwent testing to provide data to her care team. High-tech motion and force testing – a multi-activity test of squats, jumping and balance done in the hospital's motion analysis center – provided information about her progress. Results were shared with the doctor and therapist, and her care team used the data to help evaluate when she was ready to safely get back on the field.

"Return-to-sports testing provides a lot more info than what we can obtain in a quick office visit," Dr. Davidson said.

Kimberly said Jessica's connection with Physical Therapist Nicole Viverito, PT, DPT, was another important part of her progress. "Nicole and Jessica had a strong connection from day one," said Kimberly. "She worked with Jessica's coaches to ensure that everyone understood where Jessica's recovery stood and what limitations she had."

Now, those limitations are few. Jessica, 17, recently signed a national letter of intent to play softball on an athletic scholarship for Ball State University in Indiana.



ACL injuries that occur before a child's bones have fully matured (in boys, typically by age 16) require special treatment and care to ensure proper healing and to prevent long-term complications.

Play It Safe: Understanding Sports and Recreation Injuries

More than 2.6 million children up to age 19 are treated in U.S. emergency departments each year for sports and recreation-related injuries.¹

Playground Injuries by the Numbers²

Data shows an annual average of 247,000 injuries associated with playground ______ equipment are treated in emergency rooms.

Of these injures, an estimated **61%** occur at schools or parks, and 14% happen at home.

Fractures account for an estimated **34%** of injuries, followed by contusions and abrasions (17%), lacerations (15%), and strains and sprains (13%).

The most common injury is equipmentrelated, followed by falls. Swings pose the biggest hazard.

Playground Safety Tips

Take your children to playgrounds with shockabsorbing surfaces.

Teach kids to go down the slide feet-first, one child at a time.

Remind children to swing sitting down. Encourage them to wait until the swing stops before getting off.



Sports Injuries by the Numbers³

An estimated **3.5 million** sports injuries occur each year in the U.S.

Almost 1/3 of all childhood injuries are sports-related, and the most common injuries are sprains and strains.

62% of injuries related to organized sports occur during practice.

In children **ages 5–14**, the most prevalent sports-related injuries occur in football, bicycling and basketball.

Sports Safety Tips¹

Use the correct protective gear for the sport, and make sure it's in good condition.

Make sure players are properly dressed and stay hydrated. Allow players to adjust to hot and humid conditions.

Be sure sports programs have a plan in place to teach young athletes how to play safely.

1 cdc.gov/safechild/sports_injuries/ index.html

2 bit.ly/CPSCPlaygroundInjuries

3 hopkinsmedicine.org/health/conditions-anddiseases/sports-injuries/sports-injury-statistics

Operating With an Important Perspective

Women orthopaedic surgeons make a difference at Shriners Hospitals

Growing up, Kristen Carroll, M.D., chief of staff at Shriners Hospitals for Children — Salt Lake City, had a female pediatrician. Her mother made the conscious decision to subtly provide a role model in medicine for her daughter. Today, Dr. Carroll is the one leading by example, giving her patients both expertise and empathy. She's developed a leadership style all her own that's equal parts skilled surgeon and nurturing friend. She once brought chicken soup to her patient after surgery. She humbly downplayed the comforting action, saying, "Well, it wasn't homemade – I just opened the can."

Bringing together different voices and perspectives is a source of strength for our health care system. Shriners Hospitals for Children is proud to have many female orthopaedic surgeons on staff. Of Shriners Hospitals' 301 orthopaedic surgeons (full and part-time), including hand and spine surgeons, about 25% are women. In contrast, according to a 2017 report by the Association of American Medical Colleges, of 10 surgical specialties, orthopaedic surgery has the least representation of women – at 5.3%.

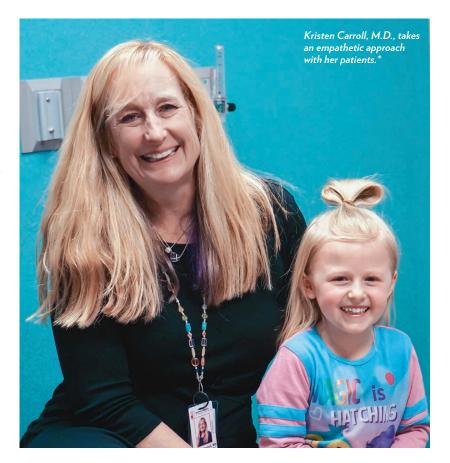
For Dr. Carroll, the most important strength women orthopaedic surgeons provide is empathetic care. "When you look at health care decisions, 80% of the time it's the mom, aunt, sister or grandmother making the decision," she said. "We are the caretakers. Being able to talk mom to mom, sister to sister is a very special bond. Women appreciate having a care provider they can relate to."

Opening the doors

Michelle James, M.D., holds dual leadership roles in Northern California. She is chief of orthopaedic surgery at the Shriners Hospitals location in Sacramento, and she also leads the pediatric orthopaedic service joint program of that hospital and University of California, Davis.

She is a noted pediatric hand surgeon and has served on the board of directors of the American Board of Orthopaedic Surgeons, the Perry Initiative and Orthopaedics Overseas. She is also the former president of the Ruth Jackson Orthopaedic Society, a support and networking group for women orthopaedic surgeons.

"Seeing a woman [perform orthopaedic surgery] is eloquent and speaks louder than trying to talk someone into the field."- DR. JAMES



Helping young women realize they can pursue their dream of becoming an orthopaedic surgeon is a cause close to her heart. Dr. James supports the Perry Initiative, an educational outreach program for young women interested in medical careers held annually at approximately 70 medical centers across the U.S. Every year, Shriners Hospitals for Children — Northern California hosts a daylong program for interested high school students. Participants learn to use surgical drills and perform other duties, such as suturing, and have opportunities to observe surgeries.

"Younger women need to see that it's possible," said Dr. James. "Seeing a woman [perform orthopaedic surgery] is eloquent and speaks louder than trying to talk someone into the field." She has had many former patients shadow her, and two have gone into medicine.

"A woman can be maternal and nurturing and also be a good surgeon," she said.

Supporting careers

For Dr. Carroll, there is no limit to women pursuing greater challenges in medical careers, although they might need extra >>

"We understand we are better served by having women in positions of leadership at all levels."

- DR. IWINSKI

encouragement and opportunities. She created a scholarship program. The recipients are typically medical assistants. She also provides guidance by working with interns. "It's important to have female mentorship," said Dr. Carroll.

Interns receive guidance in the field, clinic and operating room, making connections with other surgeons and getting exposure to research opportunities.

"It was all invaluable," said Alyssa Hales, a third-year medical student who served as an intern at the Salt Lake City Shriners Hospital and was mentored by Dr. Carroll. "When you don't have friends and family in the field, having someone to reach out to with ortho questions is so helpful. I don't know if I would have been able to continue pursuing this field, which is still so male-dominated, without her guidance." Hales noted, "In the last three years, only two females from the University of Utah matched for orthopaedics, versus 14 males."

The value of women in leadership

Having women serving as leaders throughout our facilities is important to our unique health care system.

"Everyone brings needed skills to the table; women often bring a particular empathy



sometimes making it easier for mothers to talk about their child's situation and needs," said Dr. James.

and ability to listen,

"We understand we are better served by having women in positions of leadership at all levels." said

Henry Iwinski, M.D., chief of staff, Shriners Hospitals for Children Medical Center — Lexington. "At Shriners Hospitals,



Left to right: Claire Manske, M.D.; Avreeta Singh, M.D.; and Michelle James, M.D., are part of the team of orthopaedic surgeons at Shriners Hospitals for Children.*

we are fortunate we can pick from the cream of the crop in orthopaedics. Somehow women are dissuaded from ortho, even though they are just as competitive and qualified as men." He added, "There's an intentionality toward our mission. Shriners Hospitals has really stuck to its mission of caring for kids

regardless of ability to pay. There may be a selection bias toward choosing Shriners. Women may be drawn to that mission."

Dr. Carroll agrees. "The reason I came to Shriners, instead of staying in



Robert Cho, M.D.

private practice, was that the mission really resonated with me," she said. "The only objective is improving the lives of children."

And men and women working together, sharing their insights and talents, strengthens everyone.

"We see the effects of women leaders in politics and business. Study after study has proven this," said Robert Cho, M.D., chief of staff of Shriners for Children Medical Center — Pasadena in California. "We are better thinking together." According to the American Women's Medical Association, gender inequality in health care is well documented.

Women make up **76%** of full-time, year-round health care workers in the U.S.¹

However, that majority position is not evident across all medical fields and disciplines. Although more than **30%** of all active physicians are women, they are not well represented in surgical fields, especially in orthopaedic surgery, where they only comprise **5.3%**.²

1 census.gov/library/stories/2019/08/your-health-care-inwomens-hands.html

2 aamc.org/news-insights/where-are-all-womensurgery#: -:text=According%20to%202017%20data%20 from,outnumber%20<u>men%2C%20at%2057%25</u>

*This photo was taken prior to the COVID-19 pandemic.

IN HEALING

A FAMILY-CENTERED APPROACH TO COMPASSIONATE CARE

Elijah and his family travel to destinations that can accommodate <u>his</u> needs.

VACATIONS WITHOUT LIMITS

Level up your planning to help kids with special needs experience the trip of their dreams

raveling with kids is never easy, and traveling with children with special needs requires even more careful planning and consideration. But seeing children experience a new place, try a new activity or get the ultimate treat – meeting Mickey Mouse – can be well worth the effort. Here are some tips to make your next trip an awesome adventure. >>

13 Tips for Airline Travel | 14 Robots and Goggles Bring the Fun to Health Care



"I almost took it for granted the first time that cruise ship cabins were automatically wheelchair accessible. When I was booking the trip, they told me l needed a handicap room to fit the wheelchair through the door." - LIZ. DREW'S

MOM

Consider the destination

Your destination may be the most important travel decision you make. It always pays to contact the destination ahead of time to find out what it can offer in terms of accessibility.

Leah, whose young son, Elijah, has been a patient of Shriners Hospitals for Children — Honolulu for most of his life, can attest that the destination makes all the difference. Leah also happens to be a flight attendant.

When the family traveled to Aulani, a Disney Resort & Spa on Oahu, they requested a room with a kitchen, which allowed Leah and her husband to prepare medications and special meals for Elijah. "If you're able to get creative with your travel plans or make little upgrades to elevate your peace and experience, it's worth it," Leah advised.

Leah said her family looks for calm environments and steers clear of areas that may be crowded or overstimulating. "Our special guy enjoys heated swimming pools, so we often look for resorts with a great pool experience."

Drew, a patient of Shriners Hospitals for Children — Chicago who has transverse myelitis, a spinal cord disorder, has traveled with his family of five, including going on hikes and a Disney cruise. Drew's mom, Liz, said it's important not to make assumptions. "I almost took it for granted the first time [we traveled] that cruise ship cabins were automatically wheelchair accessible," Liz said. "When I was booking the trip, they told me I needed a handicap room to fit the wheelchair through the door."





Shriners Hospitals has loaner programs for specialized wheelchairs.

Take advantage of adaptive devices

Families with children who use wheelchairs and want to go to the beach or take a hike through the woods can face challenges. Typical wheelchairs aren't made for such terrain, and power chairs, in particular, can be illsuited to sand and mud. Instead of avoiding these adventures, try exploring rental options.

At Shriners Hospitals for Children — Salt Lake City, a specialized wheelchair loaner program helps families go on vacation or simply explore the terrain in their hometown. Options include chairs designed especially for the beach that come in a range of sizes as well as the "free wheel," an adaptation that essentially turns a wheelchair into a jogging stroller, making hiking something the whole family can participate in and enjoy.

"We've seen families making memories together at the ocean, lake and even hiking in Moab [the gateway to the Red Rocks in Utah],"said Physical Therapist Matt Lowell, MPT, manager of the hospital's wheelchair, seating and mobility department.

A program at Shriners Hospitals for Children — Portland makes durable and recreational equipment available. It's complimentary to all patients and includes various all-terrain wheelchairs, adaptive joggers and bikes that allow patients to explore rugged trails or sandy beaches.

"This is a great way for patients to enjoy activities with their families that they may otherwise not be able to do," said Caroline Scott, CTRS, recreational therapist at the Portland hospital. "Everyone has a right to enjoy the outdoors and all of the benefits that it offers."

Prepare and practice

Advance preparation can help kids feel more comfortable with travel. Prepare your child for what to expect on your trip, and try to rehearse some of the steps you'll go through ahead of time. Juliet, 11, a patient of the Portland Shriners Hospital, was able to do just that through a mock pre-flight program offered in Portland by the Autism Society of Oregon and Alaska Airlines.

Before her trip to Disneyland, Juliet entered the program, which helps people with special needs become familiar with the airport and understand what to expect on the day of the flight. Juliet went through security and check-in, boarded a plane and experienced it taxiing down the runway and returning to the gate. "After Juliet returned to the gate, she actually believed she had flown to Disneyland," said her mother, Karen. All of the preparation paid off when Juliet was finally able to meet Mickey Mouse.

With the planning out of the way, the most important advice is to just have fun. "Prepare for the worst-case scenarios and be surprised by everything going to plan perfectly," Leah said. "Take lots of breaths, and remember to schedule in your respite, too. Make the most of this carved-out time and investment."



Taking Flight: Essential Tips for Airline Travel

Airline travel comes with unique challenges. Our patients' moms offer these tips:

Consider your carry-on. Include special requirements like diapering or toileting needs, as well as your child's medications, in the original packaging. Pack them in a separate bag, as these medications may not follow standard security protocols, and keep them with you if you have to check your carry-on at the gate. "Other than the necessary items that should be packed in your carry-on, do yourself a kindness and budget for checking your bags," Leah advised, so you don't have to worry about hauling your luggage through a busy airport.

Have necessities handy. Leah and Liz's top go-to items are:

- A fully charged iPad, recharging unit and USB cable. "I always download a few favorite shows in case there is no Wi-Fi. I also always download the airline's entertainment app at least the night before travel," Leah said.
- Snacks. Many airlines have not resumed food and beverage services due to the pandemic. Airports may have limited food vendors open. Eat before you leave for the airport and pack easy-to-eat meals and snacks. Bring empty water bottles to fill after you go through security.
- Doctors' notes. Liz brings information about her son's condition and what to do in an emergency. She also uses a helpful tool from the Christopher Reeve Foundation website: a travel card they can print and put in Drew's wheelchair anytime he is going somewhere independently.

Order special items in advance. If your child requires oxygen, you will need a written prescription in order to bring it onto the aircraft. Get this in advance, and inform the airline ahead of time.

Give yourself plenty of time. Arrive extra early to get your family through the screening checkpoints without rushing. "If there are any hiccups, as there often are with kiddos with special needs, you won't be in a tizzy," said Leah.

Ask for help. "I have found many people – porters, agents, security members, other travelers – are so happy to help, but they don't always know how," Leah said. Since Elijah is visually impaired, Leah often will ask flight attendants to communicate verbally. "I ask them to describe where the armrest is located, rather than point," she said.

Remember comfort items. For Drew, that means bringing ice, wash cloths and fan misters in case he needs to cool down. For Juliet, it's sound-canceling headphones. On her Disney trip, she wore them in the airport, on the plane and even on the rides.

Robots and Goggles Bring the Fun to Health Care

New technologies offer cool experiences and create welcome distractions

Shriners Children's Twin Cities has two unique staff members – Misty II robots, created by Misty Robotics.

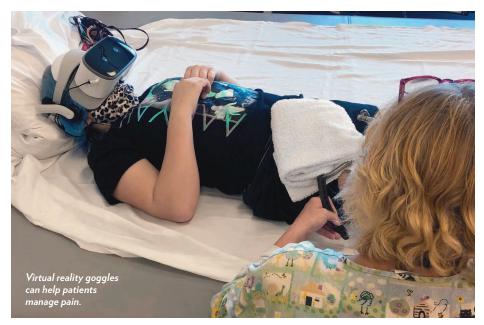
Misty robots assist the clinic and therapy teams in several ways, including distracting patients during procedures, motivating children to walk and run so their progress can be assessed, explaining complicated conditions and treatments, and making wait times more pleasant for kids.

Implementing this new robotic technology has been a great way to keep patients involved in their orthopaedic care, while having fun.

Misty robots are completely customizable, and their capabilities will continue to be utilized and developed to assist the hospital in creative ways.

A world away from pain

Distraction and pain relief are the two main reasons child life therapists at Shriners Hospitals for Children — St. Louis provide patients with virtual reality (VR) goggles.





The Misty robot engages a patient and brings a smile.

The goggles are used for a variety of procedures, the most common of which is blood draws. Instead of fearing a needle, kids are focused on something a world away – like swimming with dolphins, walking through a forest or throwing balls at bear cubs, all using only their gaze.

"When the draw is over, they say, 'It's done? You actually did it?'" said Laura Teague, senior recreational therapist at the hospital. "They don't even know we started."

While the apps might be all fun and games, the science behind the use of VR is anything but.

"We're into non-pharmacological ways to help kids reduce pain," Teague said. "These are specifically made for hospitals and the needs we're trying to meet."

+Online Exclusive For a video of the Misty robot in action, visit myleadersincare.com.

partners in service

EVENTS, NEWS AND INSPIRATION FROM THE SHRINERS COMMUNI

Nick's thrill-seeking activities include water skiing and zip lining.

How parents are changing our patients' lives

ike adopted his son, Nick, when Nick was 16. Nick has severe dystonia, a form of cerebral palsy marked by involuntary muscle contractions and movements that affect his entire body. He uses a wheelchair and is nonverbal. "But he can understand what you're saying," Mike said. Nick receives physical therapy, occupational therapy and orthotics (for hip dislocation), and bracing for scoliosis at Shriners Hospitals for Children — Springfield. >>

"There's nothing we've tried that he doesn't like. I think you're just limited by your own imagination." - MIKE, NICK'S DAD

Nick and his dad, Mike, are always in search of new, fun ways to spend time together.



The next great adventure

After his adoption, Nick joined BFit, the hospital's summer biking program for patients with neuromuscular conditions. "He was really tuned in with what he was doing," said Mike. From there, a thrill-seeker was born. "BFit is what started it all."

Mike looked for other adaptive activities that Nick could take part in to live life without limitations. So far, Mike and Nick's physical therapist have found ways for Nick to go horseback riding, ziplining, rock climbing and water skiing.

"There's nothing we've tried that he doesn't like. I think you're just limited by your own imagination," said Mike.

Mike said skydiving might be next on the list. "I'm always looking for our next great adventure."



Nothing to be afraid of

It's less than an hour before surgery, and Soumaila is taking deep whiffs from an oxygen mask that gives off the pleasing scent of cake batter. The mask isn't hooked up to anything. It's a replica used by the child life department at Shriners Hospitals for Children — St. Louis to help make kids more comfortable before surgery.

"Mama Amy! Mama Amy!" says the 10-year-old boy from the West African nation of Burkina Faso. The woman who has served as his host mom for two weeks puts the mask up to her face and smiles back at the boy who will soon undergo

"If you have a deformity in some parts of the world, you are completely shunned. You have to be hidden from your community. Your life is in danger."

- AMY, SOUMAILA'S HOST MOM

surgery. He slides over and folds himself into her arms.

Amy and her husband, Greg, have served as host parents to five children. She is one of four host mothers currently shepherding international patients through care at the St. Louis Shriners Hospital.

Kids who come to the hospital from developing countries are often in grave danger. Lorencia, who was the first child Amy and Greg hosted, arrived in 2017 from Haiti. She was living in an orphanage because it was a safe place for a girl whose legs were so malformed that she got around by scooting along in a handstand. "If you have a deformity in

> some parts of the world, you are completely shunned," Amy said. "You have to be hidden from your community. Your life is in danger."

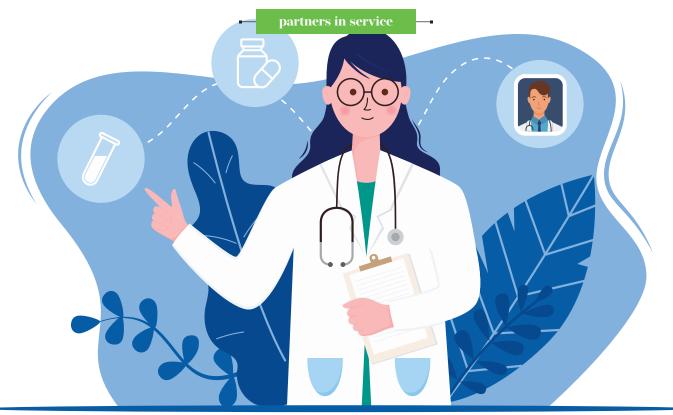
Lorencia came to Shriners Hospitals with the help of a nonprofit organization. As the care teams provide medical treatment, Amy, Greg and other host parents run the kids to and from medical and physical therapy appointments, feed them, clothe them and provide education. Most importantly, they give them love.

The family, including Amy's daughters Gabby, 21; Claire, 17; and Maura, 14, plays games and records funny videos. At bedtime, they provide comfort; Lorencia has slept alongside Claire during four stays with the family. Maura sleeps on the floor in Soumaila's room.

"This is all about rewriting their story," Amy said. "I just house them while the doctors actually rewrite their story. And then they go back to their home country, and they can continue rewriting that story by showing their peers and their peers' parents that they are nothing to be afraid of."

She smiles at Soumaila. "They're just kids."

At Shriners Hospitals for Children, we are made stronger by the parents who guide, nurture and advocate for the children who come to us for care. We are grateful to have these heroes as part of our team. $\widehat{\bullet}$



Role Reversal

A longtime patient is inspired to become a physician

Guadalupe, who is called "Kika," sustained a severe burn injury as a baby in Mexico. Frustrated by the quality of care and treatment options there, Kika's parents searched for alternatives outside their country. At hospital after hospital, they were told there was nothing more that could be done to help their daughter, until they found Shriners Hospitals for Children — Boston.

Life-changing care

Kika made her first trip to Boston, Massachusetts, when she was 6 and returned for care for several years. The course of her treat-



Kika was inspired by Dr. Matthias Donelan.

ment included more than 20 rounds of plastic surgery to her face and nose to undo the negative effects of earlier procedures, correct breathing problems and reduce scarring.

"The care I received at the Boston Shriners Hospital was nothing but the best that any human being can ask for," Kika said. "The detail, their care, their love, their hospitality, and the most important thing, is they managed my pain. Not once did I ever feel pain or discomfort," she added. "I am especially grateful to Dr. Matthias Donelan, who is and will always be my rock star."

Paying it forward

Now 28, Kika recently completed her final exam and is officially board certified as a medical doctor. Her dream is to become an emergency room doctor, and she attributes her experience at the Boston Shriners Hospital as one of the most significant factors behind her decision.

"My whole life I have been in and out of the hospital. Ever since I was little, I always wondered how the doctors managed to know so much and

help so many children. So I decided that my dream was to be like them," she said. "With every patient I meet I will always remember Shriners Hospitals."

"The care I received at the Boston Shriners Hospital was nothing but the best that any human being can ask for ... Not once did I ever feel pain or discomfort."

9-YEAR-OLD TAKES HER FIRST STEPS, WITH NO PLANS OF STOPPING

NAME: TAYLOR

CONDITION: ARTHROGRYPOSIS MULTIPLEX CONGENITA (AMC)



"For the first time in a very long time, we have hope. Taylor has been given a quality of life we never thought possible."

- RACHEL, TAYLOR'S MOM

From the time Taylor was diagnosed with arthrogryposis multiplex congenita (AMC) in utero until she was 8, her family never knew that treating the rare condition was an option. Doctors regularly told them that Taylor, now 9, would never live an independent life, as AMC causes a lack of muscle development along with stiffness and malformation in more than one joint of the body – and Taylor's case was severe. With almost no mobility in her arms and legs, Taylor had never set foot out of her power chair – until recently.

Taylor's mom, Rachel, learned of Lauren Hyer, M.D., at Shriners Hospitals for Children – Greenville through a Facebook support group. Rachel said the experience has been "absolutely life-changing."

After rounds of intensive therapy and bracing to help get her moving, Taylor's team of doctors and physical and occupational therapists gathered with the family to discuss what they believed to be the best path forward: amputating Taylor's most severely damaged leg.

During that meeting, Taylor made her decision. "Ultimately, Taylor was the one who decided to move forward with the amputation," said Rachel. "Today, she couldn't be more excited about the outcome: a custom-made prosthetic wrapped in unicorns."

Taylor recently took her very first steps – and she doesn't plan on stopping there. She intends to do the things she's always dreamed of, like riding a bike and heading outdoors all by herself, skateboard in hand.



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In Memory of Dr. Melanie Sanborn

Shriners Hospitals for Children — Spokane lost a member of its hospital family, Melanie Sanborn, M.D., in a tragic accident earlier this year.

"We mourn this loss of our dear friend and our colleague Melanie," said Chief of Staff Glen Baird, M.D. "Our thoughts and prayers go out to her sister (who is one of our nurses), her husband and daughter, and her extended family during this terribly sad time."

Dr. Sanborn began her medical career in 2006 after graduating from Creighton University School of Medicine. She completed a residency in pediatrics at the University of Florida College of Medicine – Jacksonville and joined the Spokane Shriners Hospital medical staff in 2015 as a pediatrician and hospitalist.

Dr. Sanborn was a tireless advocate for kids and beloved by her patients. She provided care for the hospital's children who undergo surgery and managed the Spokane Shriners Hospital specialty clinics for kids living with osteogenesis imperfecta (OI) and muscular dystrophy. A mom of one of her patients with OI said the care Dr. Sanborn provided was one in a million. "There is not one appointment that we ever had with her where she didn't make us feel special, educated and confident. My son loved her," she said. Being a part of the Spokane Shriners Hospital was so important to Dr. Sanborn that she recruited several family



members to join her Shriners Hospital family, including her sister, mom and father-in-law. She lived her life from the spirit of fun, evident not only in her patient care, but also in her participatation in hospital competitions. She would never pass up a door-decorating contest, corn-hole tournament or dress-up day.

Dr. Sanborn mentored and supported her co-workers, freely sharing her knowledge. "She was not just my co-worker, she was my friend," recalled Deborah Reich, manager, respiratory care services. "She was an awesome hospitalist. She led with a team approach and valued each member of the team with the care of our patients. She will be forever in our hearts, and we miss her daily."

As the hospital staff continue to process the loss, they are hoping to honor Dr. Sanborn in a memorial garden on the hospital's campus. "Our Shriners Hospital family is a small and close one," Dr. Baird said. "Her loss will be felt for some time to come."

