

LEADERS IN *Care*

STORIES OF THE MOST AMAZING CARE ANYWHERE

FALL 2020

Coming *Home*

Adopted teen boys with
complicated conditions
get a new family and
life-changing care



Shriners Hospitals
for Children®



OUR MISSION

At Shriners Hospitals for Children®, our three-part mission has one goal: to change and improve lives. We do this by caring for our patients, conducting research to gain knowledge and develop new treatments, and providing educational opportunities for physicians and other health care professionals.



WHO DO WE TREAT?

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



WHAT ARE OUR PEDIATRIC SPECIALTIES?

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



GROUNDBREAKING RESEARCH

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



CONTINUING EDUCATION

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



THE SHRINERS FRATERNITY

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

COMMUNITY CONVERSATIONS

Dear Readers,

As our team works through the summer to prepare this fall edition of *Leaders in Care* for you, we are acutely aware that much of the world – and certainly the U.S. – remains under the threat of the COVID-19 pandemic. At the same time, across the globe,



we see countless people continuing their lives and work as best they can, which is nothing short of inspiring and impressive.

For the people of Shriners Hospitals

for Children, more than anything else, that means remaining focused on our mission of improving lives by providing excellent care, conducting innovative research and offering educational opportunities for medical professionals. It also means that our patients and families are, and will always be, our first priority.

What does being patient-focused mean? For us, it means taking the time to

listen to the patients and their families, and including their hopes and goals in care plans. It is also the reason for our signature wrap-around care – care that emphasizes the overall well-being of each patient, offering programs and opportunities that strengthen confidence and self-esteem, encourage positive outlooks and introduce a world of possibilities.

Being patient-focused also means seeking answers through research – answers that will one day add to the world's collective medical knowledge, as well as offer new treatment options.

We offer the stories of our amazing patients, dedicated and talented medical and clinical staff, and some of our current research efforts on the following pages in a spirit of hope and confidence – in both today and the future.

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

PATIENT PERSPECTIVES

SHRINERS HOSPITALS FOR

CHILDREN – CHICAGO received this via Facebook Messenger: “I want to thank Shriners Hospitals and Dr. Peter Smith for all he has done for me. On 31 August, I retired as a Sergeant First Class from the Army after 20 years, 1 month and 16 days. I no longer have his email, but I would like to share a picture of me at my retirement ceremony receiving an Infantry Medal for supporting the infantry throughout my 20 years in the Army.”

We congratulate Retired Sergeant First Class Peggy on her 20-year Army career. She credits the care at our Chicago hospital with allowing her to live a healthy, full life as a mother and soldier.

As a very young child, doctors in her area diagnosed Peggy with spastic diplegia, a type of cerebral palsy. “My mother and grandparents were told I would never walk or talk. I proved those doctors wrong when I finally started walking and talking toward



Retired Sergeant First Class Peggy had a successful Army career after being treated for cerebral palsy as a child.

3 years of age,” she said. Eventually, her family came to the Chicago Shriners Hospital. Peggy’s legs were turned, so she walked with her feet turned in. Peter Smith, M.D., a pediatric orthopaedic surgeon, performed a surgical procedure to turn her femurs out and correct the issue.

FALL 2020

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

ON THE COVER: The Askvig family, photo by My Soul’s Anchor Photography



New Location, Same Excellent Care at Twin Cities Facility

Our Twin Cities location has moved! The brand-new, state-of-the-art outpatient facility is located on Radio Drive in Woodbury, Minnesota. Here, patients and families will receive the same excellent care that is the hallmark of the Shriners health care system. The clinic features:

- Radiology suite with a brand-new digital X-ray system and EOS imaging system
- Rehabilitation suite to provide physical, occupational and recreational therapy
- Orthotics and prosthetics lab
- Interactive audio/video play area

In addition to serving children from Minnesota, our Twin Cities location also provides care to children from North Dakota, South Dakota, Nebraska, Iowa, Wisconsin, Michigan and the Canadian provinces of Manitoba, Ontario and Saskatchewan. 📍

Research Funding for OI

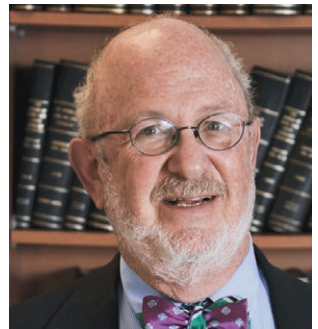
Shriners Hospitals for Children — Chicago recently received funding from the National Institutes of Health (NIH) to extend the Brittle Bones Research Consortium, a study of adults and children with osteogenesis imperfecta (OI), a rare disorder that causes bones to break easily. These individuals have been tracked annually for medical procedures, treatment and testing — many since 2010.

Four of the 12 centers participating in this multimillion-dollar research project are our locations in Chicago, Illinois; Tampa, Florida; Montreal, Quebec, Canada; and Portland, Oregon, along with medical institutions such as Baylor University, the Kennedy Krieger Institute and the Hospital for Special Surgery.

"We are enthusiastic about the opportunity to learn more about this rare disorder and share information through research and publications to improve care," said Peter Smith, M.D., principal investigator at the Chicago Shriners Hospital. 📍

Portland Physician Honored with Lifetime Achievement Award

Michael Sussman, M.D., pediatric orthopaedic surgeon at Shriners Hospitals for Children — Portland, received the Lifetime Achievement Award from the American Academy for Cerebral Palsy and Developmental Medicine (AACPDMD) at a virtual meeting in September. The recipient of this award is honored for making creative contributions of outstanding significance to the field of medicine and for the benefit of patients with cerebral palsy and other childhood-onset disabilities. Dr. Sussman joined the Portland Shriners Hospital team in 1992 and was instrumental in forming the clinical research department, dedicated to examining the efficacy of the treatments provided to patients. 📍



Michael Sussman, M.D.

Spokane Physician Receives Trainer Award

Ryan Baker, M.D., a pediatrician at Shriners Hospitals for Children — Spokane, was awarded the 2020 Washington State Athletic Trainers Association (WSATA) Physician Award. Dr. Baker, who also has a fellowship in sports medicine, is the only pediatrician with this specialization in the region.

The WSATA Physician Award recognizes a doctor in Washington who exemplifies the commitment of service to the profession of athletic training.

In addition to serving the Spokane Shriners Hospital, Dr. Baker is the team doctor for three local high schools. Dr. Baker is also one of the leaders on the Northeast Washington Sports Medicine Advisory Council, which helped to develop "concussion return to learn" and "return to play" protocols for the greater Spokane area. These guidelines are now used by area health care providers, schools and club sports teams.

We congratulate Dr. Baker on this well-deserved recognition. 📍



Ryan Baker, M.D.

pioneers IN PEDIATRICS

EVERYDAY EXCELLENCE IN SPECIALTY TREATMENTS AND RESEARCH

Libbie, 12, has been receiving care for arthrogryposis at Shriners Hospitals for Children — Houston since she was 3. The following is an excerpt from a letter from her mother, Shelly:

We adopted Libbie in 2011 from China. She was 3 years old. We were told she had a corrected clubfoot. When we arrived in China, we knew immediately she had more than a corrected clubfoot. She was not able to walk or stand unassisted. We were not sure what her medical condition was, but we were very concerned.

In the U.S., we saw several orthopaedic doctors. They were not familiar with her condition and mostly handled sports injuries. A client suggested that we reach out to Shriners Hospitals. >>

After seeing several doctors, Libbie and her parents found the Houston Shriners Hospital. Her treatment for arthrogryposis has given her family hope.

UNDERSTANDING ARTHROGRYPOSIS

How Shriners Hospitals helps children with this condition grow and thrive

When we first visited Shriners Hospitals for Children — Houston, we found ourselves in the most amazing place on Earth. The incredible staff knew almost immediately what our daughter's condition was, and for the first time since our adoption, we felt hope and love.

Libbie was diagnosed with arthrogryposis, and we were given a treatment plan. But more than that, we were given a support network. We were connected to other families in our situation, reassuring us that Libbie was going to thrive.

Libbie was asked if there were areas in her daily life that could be improved. She said she loves to play ping-pong but has difficulty holding the paddle for extended periods. So her orthotist designed a custom brace with a ping-pong paddle.

What is arthrogryposis?

Arthrogryposis multiplex congenita (AMC), or simply arthrogryposis, is a condition in which joint contractures – the tightening or shortening of muscles and joints that can lead to rigidity and immobility – are present at birth in two or more body areas. It affects one in 3,000 people. There are more than 400 specific conditions associated with arthrogryposis. What those conditions seem to have in common is a baby's lack of movement in the womb. When a fetus can properly move, the muscles and ligaments are stretched. When something goes wrong and movement in utero is limited, contractures may occur, leading to arthrogryposis.

Providing help

While the effects of arthrogryposis vary individually in terms of severity, children with this condition need a lot of medical attention, including intervention by an orthopaedic surgeon as soon as possible.



Libbie enjoys playing ping-pong using paddles made just for her.

Types of Arthrogryposis

The main types of arthrogryposis are:



Amyoplasia: This most common type is seen in approximately one in three children with

arthrogryposis. It involves an overall lack of muscular development, growth and strength, and contractures of most joints. The severity of the contractures and accompanying muscle weakness vary by patient.



Distal Arthrogryposis:

This type primarily affects the joints in the hands and feet. There are 19 specific types of distal arthrogryposis, all of which have an underlying genetic cause.



Syndromic Arthrogryposis:

This category includes approximately 300 different conditions, all of which also have lack of fetal movement during pregnancy as the underlying cause.

Libbie's doctor and the Houston Shriners Hospital Chief of Staff, Douglas Barnes, M.D., said they took a coordinated, multidisciplinary approach to her care. Libbie saw a physician, prosthetics and orthotics team and a rehab team. "For Libbie, asymmetry in motion about her knees led to an awkward-appearing walking pattern," Dr. Barnes said. They used bracing and heel wedging to maximize her range of motion and help her achieve a more fluid and efficient walking pattern.

While every patient at Shriners Hospitals for Children receives a personalized care plan tailored to meet their individual needs and goals, generally, treatment for arthrogryposis may include splints, casts, orthotics and/or surgery, as well as an intensive program of physical and occupational therapy dedicated to helping kids achieve maximum mobility and independence. Finding support from others with similar experiences can also be invaluable.

Harold van Bosse, M.D., orthopaedic surgeon at Shriners Hospitals for Children — Philadelphia, is on the board of directors and is medical advisor to Arthrogryposis Multiplex Congenita Support, a support group for families living with AMC. "The peer-to-peer support that families gain is phenomenal," he said. "Arthrogryposis may be an uncommon condition, but with this support group available throughout the U.S. and abroad, families are brought together by the commonality of arthrogryposis."

Research efforts to find answers

As a rare disease, arthrogryposis is not often represented in research. Shriners Hospitals for Children has begun a four-year multisite research effort to establish a registry that will serve as the foundation for providing innovative and evidence-based therapies.

"Arthrogryposis may be an uncommon condition, but with this support group available throughout the U.S. and abroad, families are brought together by the commonality of arthrogryposis."

– HAROLD VAN BOSSE, M.D.



Woman with AMC Joins Research Effort

Jennifer, who is studying bioinformatics and computational biomedicine at Oregon Health and Science University, was born with AMC. She has joined the research team at Shriners Hospitals for Children — Portland as a student researcher and will be studying this condition.

Jennifer moved to Portland to work with Ronen Schweitzer, Ph.D. Dr. Schweitzer, interim director of research at the Portland Shriners Hospital, is a leader in tendon development and tendon biology research. Since AMC is a condition defined by joint contractures, these studies are incredibly applicable to the study of arthrogryposis.

"I was really struck by Jennifer's positive energy and how fiercely independent she is," said Dr. Schweitzer. He said the Shriners Hospitals for Children system is the ideal place for Jennifer to conduct her research. "Very little is known about arthrogryposis," he said. "While it's a rare condition, we currently have close to 3,000 active

patients (in the Shriners health care system) who have arthrogryposis. While she's here, she'll be in an environment that will allow her to work in both clinical and fundamental research and have access to system-wide AMC initiatives at Shriners Hospitals."

As for Jennifer, she is thrilled to be part of the Shriners Hospitals family. "As someone who understands this condition on both a scientific level and a personal level, my hope in joining Shriners Hospitals is to be able to bridge the scientific community and the patient community as we work toward the goal of developing treatments," she said.

TO LEARN MORE about arthrogryposis, visit amcsupport.org. To learn about obtaining care at Shriners Hospitals for Children, visit shrinershospitalsforchildren.org/shc/refer-a-patient.

The information from the registry will help answer important questions about the different kinds of arthrogryposis, how these conditions affect children and what kinds of treatments may be effective. The data collected will advance our knowledge of early detection, effectiveness of treatments and genetic causes. With its multicenter, collaborative approach, the study will be able to recruit a large number of patients with this rare condition, making the data extremely meaningful. See more about the research centers involved in this effort on page 8. 📖

Putting Medical Advan

The Shriners Hospitals for Children system



Finding answers for children with ARTHROGRYPOSIS

RESEARCH CENTERS

- Canada (lead)
- Philadelphia
- Northern California
- Portland

Arthrogyposis multiplex congenita (AMC), or simply arthrogyposis, is clinically defined as joint contractures at birth of two or more body areas, and it affects one in 3,000 individuals. Rare diseases such as arthrogyposis are often underrepresented in research, although research activities are essential to ensure the delivery of exceptional health care. The objective of this multisite, four-year study is to establish a registry that will provide the foundation for providing therapies for arthrogyposis that are innovative and evidence-based.

The registry will include data around risk factors, medical history, functional abilities, pain level and quality of life among 300 children with arthrogyposis. In a subset, next-generation sequencing will be performed on blood or saliva samples in order to identify genetic causes. This systematic recording of data will generate multiple research possibilities, ultimately leading to enhanced care and new treatment methods for children with this complex condition. (See more about AMC on page 5.)



Shriners Hospitals for Children

is committed to conducting research that will one day impact and improve lives, as well as increase the worldwide body of medical and scientific knowledge. Many of our clinical research projects are multicenter efforts that bring together physicians and scientists with similar research interests and different but overlapping areas of expertise. Here are just a few examples of current multicenter efforts.



Marking growth patterns in real time to improve SCOLIOSIS treatment

RESEARCH CENTERS

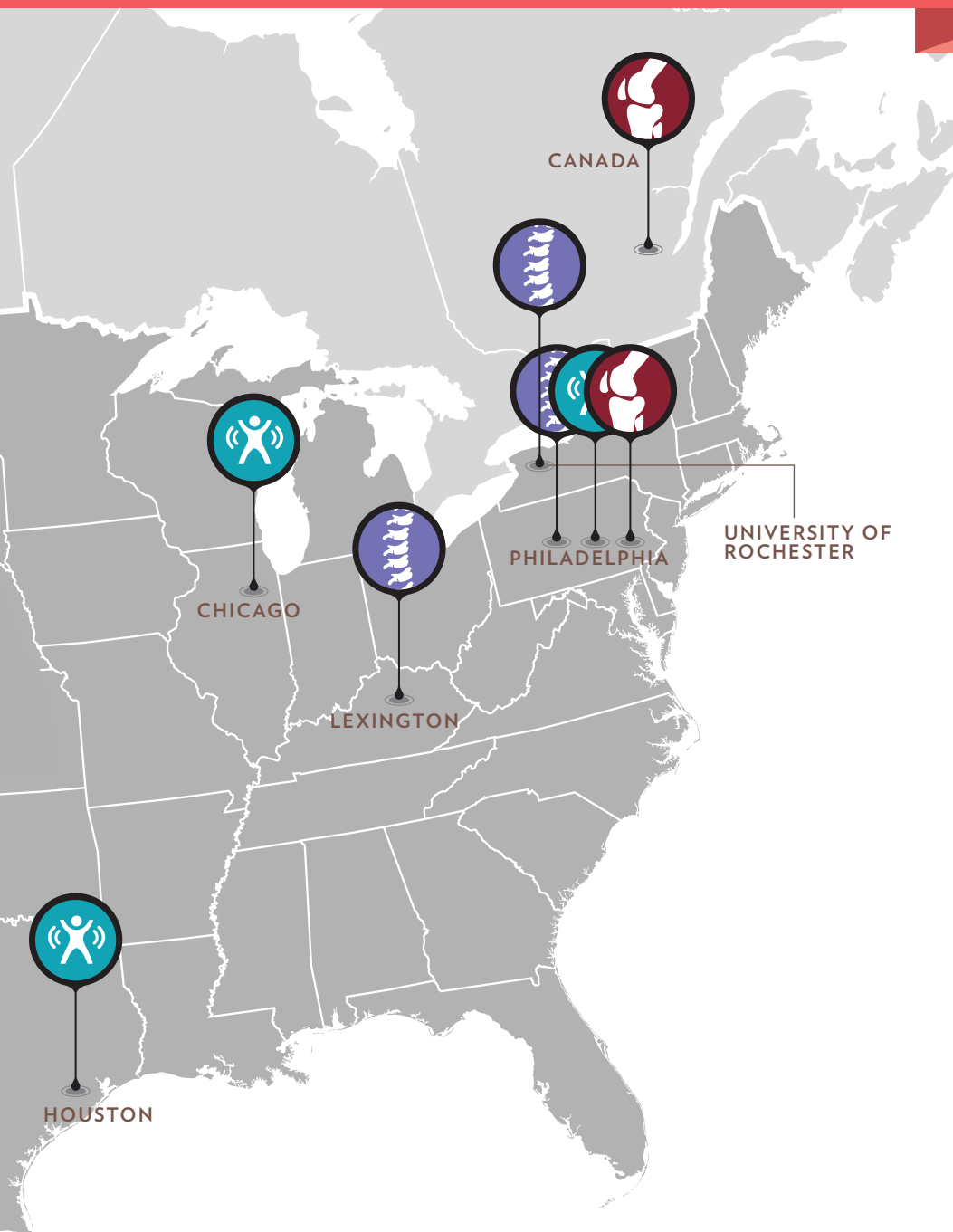
- Portland (lead)
- Philadelphia
- Lexington
- University of Rochester

The biomarker CXM has the potential to revolutionize scoliosis treatment for growing children. As a patient-specific, low-risk, radiation-free, real-time assessment of bone-growth velocity, it provides critical information about health status, and it can guide orthopaedic care, especially the treatment of scoliosis, which is

highly impacted by bone-growth velocity. There is a critical need to establish a clinically validated, patient-specific marker of real-time growth velocity so that the treatment of scoliosis can be individualized for the practice of precision medicine. Ultimately, we will use this knowledge in conjunction with CXM to develop a decision-making guide for the treatment of scoliosis, clarifying the timing of bracing versus growth-friendly surgery, versus growth-guided surgery, versus fusion surgery. Validation of CXM has the potential to fulfill the critical need to establish a real-time marker for bone-growth velocity to personalize the treatment of scoliosis.

Advancements on the Map

continues to commit to life-changing research



Using machine learning to improve MOTION ANALYSIS


RESEARCH CENTERS:

- Chicago (lead)
- Northern California
- Houston
- Philadelphia

Shriners Hospitals for Children is an internationally recognized leader in clinical motion analysis, and our research programs department has supported several new multicenter research projects in motion analysis as part of its strategic plan. In the simplest terms, motion analysis brings the animation techniques used in Hollywood to the clinical and research setting. In our analysis centers, high-speed cameras, reflective markers, force platforms and muscle sensors record, measure and evaluate how a child with a mobility impairment actually moves.

The data collected helps provide an understanding of the interactions between the child's muscles, joints and bones, which helps the patient's medical team create an effective care plan. The goal of this project is to explore the applications of machine learning algorithms to quantitative motion analysis data to more effectively and efficiently recommend evidence-based interventions for pediatric patients with movement disorders.

 **TO LEARN MORE** about our research efforts across the Shriners Hospitals for Children system, visit shrinershospitalsforchildren.org.

ALL OF THE RESEARCH EFFORTS at Shriners Hospitals for Children are meant to one day improve available treatments for children with orthopaedic conditions, burn injuries, spinal cord injuries, and cleft lip and palate, and help fulfill our mission of improving and transforming lives. 

Healing as They Grow

Shriners Hospitals offers a new and innovative option for scoliosis treatment

Finally, Leticia, 13, has little to no back pain. The difference is VBT – vertebral body tethering – an innovative surgical procedure that corrects a scoliosis curve while maintaining flexibility in the spine as the patient grows. About a year ago, spinal surgeon Rolando Roberto, M.D., medical director of pediatric spinal surgery at Shriners Hospitals for Children – Northern California, performed the surgery on Leticia to correct her scoliosis.

“Dr. Roberto was very thorough and provided a lot of resources and information about the VBT procedure,” said Destiny, Leticia’s mother. “He also answered all the questions that we had about the surgery.”

After the surgery, Leticia is doing much better. “I feel more confident and active,” she said.

A huge difference

The medical staff of Shriners Hospitals for Children – Philadelphia, led by Amer Samdani, M.D., chief of surgery, developed the methods and techniques underlying this



Leticia is virtually pain-free after her VBT surgery for scoliosis.

treatment. They worked closely with the FDA and the medical device industry to bring the new device, specifically designed for VBT surgery, to approval.

“Dr. Roberto was very thorough and provided a lot of resources and information about the VBT procedure.”

– DESTINY, LETICIA’S MOTHER

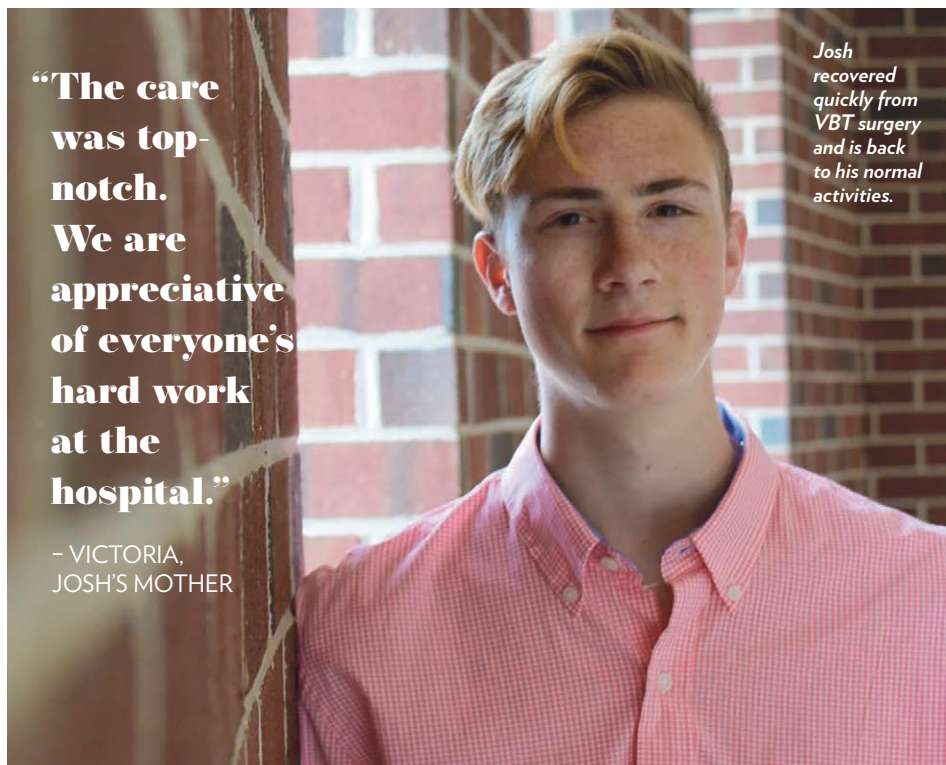
“The ability to utilize a child’s growth to correct the curve in their back is a leap in the way these children are treated. Properly selected patients can achieve curve correction while maintaining spinal mobility,” said Dr. Samdani.

The best option

Josh, 17, had scoliosis, and the curve progressed quickly. After seeing a few doctors, his mother brought him to Shriners Hospitals for Children – Greenville for another opinion. Orthopaedic surgeon Michael Mendelow, M.D., suggested that Josh have spinal fusion surgery. He also recommended that Josh see Joshua Pahys, M.D., at Shriners Hospitals for Children – Philadelphia, as he might be a candidate for VBT. The procedure would help control spine growth during periods of rapid growth spurts, with shorter recovery time than spinal fusion surgery. Ultimately, Josh’s mother, Victoria, decided VBT surgery with Dr. Pahys was the best option for her son.

“The care was top-notch,” said Victoria. “We are appreciative of everyone’s hard work at the hospital. The staff walked us through each step. That really put our minds at ease.”

Following the surgery, Josh recovered quickly and was able to go home after only four days in the hospital. Shortly after that, he returned to his normal activities. He graduated high school this past summer and is hoping to study carpentry in college. 🧑🔧



“The care was top-notch. We are appreciative of everyone’s hard work at the hospital.”

– VICTORIA, JOSH’S MOTHER

Josh recovered quickly from VBT surgery and is back to his normal activities.

TO LEARN MORE about VBT and other treatments for scoliosis, please visit shrinershospitalsforchildren.org.

champions IN HEALING

A FAMILY-CENTERED APPROACH TO COMPASSIONATE CARE

COMING HOME

Adopted teen boys get a family to call their own and life-changing care

Jonah and Miles have seen incredible improvements to their mobility and overall health since joining the Askvig family.



The Askvig family (left to right): Parents: Jackie and David Kids: Miles, Arlo, Robby, Joy, Jonah and Mae

What makes a couple with four young biological children decide to adopt two teenage boys with overwhelming disabilities from a Ukrainian orphanage? Jackie of Salt Lake City, Utah, would tell you she didn't decide. She and her husband, David, felt called to take these boys in. That calling, rooted in a strong Christian faith, was the catalyst for their decision to pursue the boys with all of their hearts. But they did so with reserved expectations. They'd bring the boys home, but would they thrive?

Meet the boys

Miles lived his entire 16 years of life in a crib at an orphanage in Ukraine without access to adequate medical care for cerebral palsy. The lack of socialization, physical touch and nutrition resulted in stunted growth and incredibly low body mass. At the time of adoption, he weighed only 15 pounds – less than an average 6-month-old baby. Neglect had left him nonverbal and non-ambulatory.

The Journey of Miles and Jonah

Though the two boys had no interaction with each other at the orphanage, they're now brothers for life.



At 16 years old, Miles weighed only 15 pounds.



Miles' therapy has made a dramatic difference.



Jonah had complications due to an ill-fitting wheelchair.

Jonah, who has spina bifida and lived at the same orphanage as Miles, dreamt of living with a family. The adoption went through just in time, when he was 16, as he was close to death. When he arrived at his new family home, he had life-threatening pressure sore complications caused by inadequate care. He had osteomyelitis (an infection in the bone) and was nearly septic.

Though the two boys had no interaction with each other at the orphanage, they're now brothers for life.

A turning point

When the family arrived home, mobility was the last thing on the adoptive parents' minds as they addressed Miles' nutrition and Jonah's emergent wound care. The boys' doctors advised the family to wait on mobility and seating. For six months, Miles was pushed around in a baby stroller and Jonah continued sitting in an ill-fitting chair.

But Jackie and David trusted their instincts and pressed for more – and they found it at Shriners Hospitals for Children — Salt Lake City. Everything changed with the help of the surgeons, seating specialists and physical therapists.

"Both of my boys are incredibly medically complex, but Shriners Hospitals doesn't even bat an eye," said Jackie. "Everyone at the hospital has been so accommodating, and no mobility challenge presented to them has been outside their scope. A safe, custom wheelchair for Jonah is what prevents pressure sores that could kill him. For Miles, encouraging his mobility is ultimately what opened up his world cognitively."

A whole new world for Miles

The staff of the hospital's wheelchair and seating and therapy services departments wanted to give Miles a way to be mobile as soon as possible because of the link between mobility and cognition. Once his therapist placed him upon a crawler – a small board with wheels (like a square skateboard) – he experienced self-propelling

for the first time. His face lit up with joy as he began scooting himself around, and Jackie began imagining all the possibilities for his quality of life.

They also swapped the baby stroller for a custom wheelchair. The mobility interventions made a marked difference in Miles' cognition. He started making different noises, babbling more and interacting with his environment.

His improved nutrition has been incredibly important, but Jackie said the therapy he's had has made the most dramatic difference.



Miles using a crawler.

"When a 16-year-old is the size of a baby, you assume nutrition is to blame, but it was also the lack of exposure," said Jackie. "Once we introduced mobility, he started changing before we even upped his calories."

Matt Lowell, MPT, said treating the boys has been amazing to watch. "We have really enjoyed working with the family and seeing the boys develop, not only their mobility, but their social and physical health as well," he said. "Miles had gained so much weight that from the time his chair was ordered to the time it was delivered, we actually had to send it back and go to the next size. The family is so caring, and they're such great advocates for the boys."

Innovative answers for Jonah

Jonah's unique needs were met head-on by the wheelchair and seating team's innovative approach. Jackie marveled as the seating specialists created his chair right before her eyes. "They traced his feet and cut the shape out of a foam cushion, melted and molded materials, sewed a cover for the footrest and customized his seat cushion to accommodate a limb difference," said Jackie.

Jonah's manual chair fits him perfectly and comes equipped with power assist, which he controls with a bracelet, essentially making his manual chair a power chair when he needs it. Jonah

"Everyone at the hospital has been so accommodating, and no mobility challenge presented to them has been outside their scope."

– JACKIE, MOM OF MILES AND JONAH

can propel around the house, and for longer family walks or going uphill, he can activate the motor so he doesn't get worn out. It's also helpful for joint preservation, as wheelchair users are prone to having shoulder issues from overuse.

Living a full life

It's been a year and a half since the boys were adopted, and they're thriving. Miles has grown more than 12 inches and tripled in weight. He's even begun talking, saying "gaga" and "baba." Jonah's had critical wound care and is sitting up taller, thanks to spinal fusion and endless mobility interventions. The parents and their specialists at the Salt Lake City Shriners Hospital are dreaming big for the boys. Jonah is on the hospital's wait list for an adaptive bike, and they're looking into self-propel wheelchair options for Miles.

The boys have put down strong roots in their new, loving home. But now their definition of home is expansive in a way it's never been. They're at home in their special needs schools. Miles is at home rolling around on the floor with his siblings and playing in the backyard. Jonah is at home on his Special Olympics basketball team, where he deftly maneuvers his chair on the court. And they're at home at Shriners Hospitals for Children.

More than a hospital, it's a place where the staff and Shriners International fraternity members commonly refer to patients as "our kids." Parentless for 16 years, Jonah and Miles now have countless individuals in their lives eager to love them as their own, dedicated to helping them reclaim all of those lost years. 🙌



Jonah now plays basketball on a Special Olympics team.



Before (left) and after shots of Jackie and David with the boys.

Innovation During a Pandemic

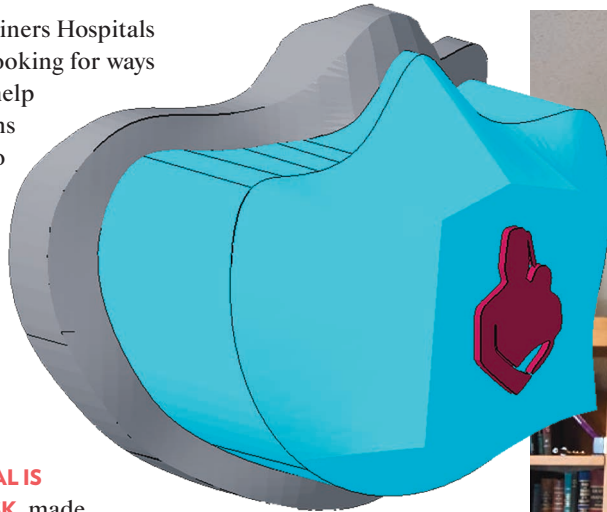
Shriners Hospitals for Children finds creative solutions during the COVID-19 crisis

The staff members of Shriners Hospitals for Children are always looking for ways to innovate, so they can help improve treatment options for kids and contribute to the global body of medical knowledge. This doesn't stop during a pandemic.

Here are two examples of our innovative research efforts during this difficult time.

OUR PORTLAND HOSPITAL IS DEVELOPING A NEW MASK,

made especially for medical use. Lee Taylor, M.D., anesthesiologist at Shriners Hospitals for Children — Portland, has designed a 3D-printed, hard-shell N95 mask using face-scanning technology. The mask has two parts: a hard outer shell and an inner medical-grade silicone liner, which provides the fit and comfort. The pediatric orthotics



Above: Dr. Taylor is currently working on the mask's CAD version, in which the silicone part (shown in gray) is smaller. This version is also made from a scan of the user's face, so each one has a custom fit.



Dr. Bernstein models the medical mask made with face-scanning technology.

FOR MORE INFORMATION on Shriners Hospitals' efforts during this pandemic, visit myleadersincare.com.

Please select all symptoms you are currently experiencing.
(Select none if none apply)

Fever or feeling feverish	<input type="checkbox"/>
Sore throat	<input type="checkbox"/>
New cough (not related to a chronic condition)	<input type="checkbox"/>
New nasal congestion or new runny nose (not related to seasonal allergies)	<input type="checkbox"/>
Muscle aches	<input type="checkbox"/>
Loss of smell or taste	<input type="checkbox"/>
Shortness of breath	<input type="checkbox"/>
Respiratory infection	<input type="checkbox"/>
None	<input type="checkbox"/>

The screening tool helps track symptoms of COVID-19 within the hospitals.

and prosthetics (POPS) staff at the hospital have worked on construction of the mask prototype with a personalized fit, an important feature when wearing a mask during long medical procedures. Dr. Taylor and Robert Bernstein, M.D., chief of staff of the Portland Shriners Hospital, are collaborating with a consortium that includes staff of the Georgia Institute of Technology to identify filter materials to increase the protective efficiency of the mask.

AN ELECTRONIC COVID-19 SYMPTOM SCREENING SURVEY TOOL was developed by Coleman Hilton, research data manager in the corporate research department at Shriners International Headquarters in Tampa, Florida, and Jeanine Ann-Marie Scholl, corporate director of nursing excellence, also at headquarters. The survey is accessible on mobile devices or desktop computers. It provides employees a daily pass or notifies leadership of reported symptoms using advanced tools for tracking data related

The pediatric orthotics and prosthetics staff at the hospital have worked on construction of the mask prototype with a personalized fit, an important feature when wearing a mask during long medical procedures.

to potential COVID-19 exposures in the workplace. The screening survey is active at headquarters and throughout our health care locations system-wide. 🏥

partners IN SERVICE

EVENTS, NEWS AND INSPIRATION FROM THE SHRINERS COMMUNITY

THROUGH DARKNESS, I SHINE

Meet Connor and Mia, our 2020-2021
National Patient Ambassadors



Connor has received treatments for cleft lip and palate since he was a baby. Now, he is a mentor for other kids.

Every year, Shriners Hospitals for Children selects two National Patient Ambassadors to represent its patients. The ambassadors share their inspiring stories and the ways the health care system has made a dramatic difference in their lives.

Connor

Connor, 14, was born with a bilateral incomplete cleft lip and complete cleft

palate involving the hard and soft palate. As a newborn, his condition was so severe that he was unable to create the suction needed to feed. By the time he was 3 weeks old, he was failing to gain weight and was about to be admitted to a hospital. That's when Connor's family learned about Shriners Hospitals for Children — Chicago.

There, his nurse care coordinator gave Connor's mother, Kelly, a special syringe, making it possible for her to finally feed her baby. From that moment, Connor began an extensive treatment plan of surgeries and interventions that will continue until he is 21, so that some repairs can be made after he has stopped growing.

Connor's condition affects not only his teeth and his ability to eat, but also his speech, hearing, and social and emotional well-being. In addition, Connor has a connective tissue disorder that eventually made it difficult for the active teen to participate in contact sports.

Still, Connor's can-do spirit and supportive family have helped him find many ways to pursue his passions. Connor umpires for youth baseball, acts as a physical education mentor for other kids with disabilities at his school, and is an advocate and community volunteer. Above all else, Connor is a golfer. He maintains a busy training schedule and hopes to one day become a pro. Along with his family, Connor is part of a large local annual fundraiser, a golf tournament that has raised more than \$200,000 over the years for Shriners Hospitals for Children.

"I want kids to know that no matter what they look like, or how they walk, or what makes them different, they shouldn't let anyone else make them feel bad," Connor said. "I want to help other kids feel good about themselves and their differences."

"I want kids to know that no matter what they look like, or how they walk, or what makes them different, they shouldn't let anyone else make them feel bad." - CONNOR

Mia

Mia, 16, was born with a severe case of infantile idiopathic scoliosis. Her journey with Shriners Hospitals for Children began at age 2, when she was first seen at the St. Louis location. Mia's treatments have included halo traction to gradually straighten and stretch her spine, as well as nearly 20 surgeries.

During her extensive time in the hospital, Mia and her care team developed a tight bond, and Mia considers the people she knows at Shriners Hospitals – her doctors, nurses, therapists and even the security guard – family. She has served as a patient ambassador for Shriners Hospitals for Children — St. Louis since she was 4 and has appeared in promotional videos and media interviews. Mia's passion is theater and singing, and she was featured singing *I'll Be Home for Christmas* in our holiday commercials. Mia is also part of the Shriners children's choir that performed in the recording of Foreigner's new version of their hit song *I Want to Know What Love Is*.

"I am so honored to be in this position," Mia said. "For as long as I can remember, I have always loved Shriners Hospitals. Not just because of the life it has given me, but the real love that comes from it. This community consists of the best people, and it truly makes my heart soar to know I'm a large part of it." 🎧

"For as long as I can remember, I have always loved Shriners Hospitals. Not just because of the life it has given me, but the real love that comes from it." – MIA



Mia has been treated at Shriners Hospitals since age 2. She has formed a tight bond with the staff and her care team.



TO WATCH Connor and Mia's video, *Through Darkness I Shine*, visit bit.ly/ThroughDarknessIShine.

Helping Kids Become ‘Rising Stars’

First Lady’s program helps patients discover their potential and believe in their dreams

First Lady
Alice Smith



“We all want our children to be happy. I want to help our patients move from the Shriners system to successful, independent adult lives.”

– FIRST LADY
ALICE SMITH

Shriners Hospitals for Children is committed to providing what we call wrap-around care: maintaining a family-centered approach and emphasizing our patients’ overall health and well-being.

This can mean different things for different patients. It can include finding ways to help them play with their friends, enhance their education, enjoy a hobby and live more independently.

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. First Lady Alice Smith believes that giving our patients every possible advantage and opportunity to achieve helps them to become *Rising Stars*. Through her program of the same name, she is dedicated to helping kids have full, satisfying and productive lives.

Treating unique needs

To help each child who comes to Shriners Hospitals for Children become as independent as possible, we often introduce and provide assistive devices, especially through our various therapy programs. We provide our patients with physical, occupational, speech and recreational therapy.

Assistive devices can range from items that help patients learn or regain the ability to walk, to computer-driven augmentations for those with speech difficulties, to items that help children learn to feed or dress themselves. Assistive devices also include mobility aids, such as crutches, walkers and wheelchairs.

We can also customize the devices to fit the specific needs of individual patients. The *Rising Stars* fundraising program will support these efforts.

Integrating technology

We also use assistive technology in our therapy programs, through the availability of various systems such as body-weight-supported gait training and functional electrical stimulation bikes. We are also concerned with our patients’ quality of life and work to provide, or make them aware of, adaptive recreation opportunities and items that provide additional kid-friendly mobility, such as adaptive toy cars or bikes.

“We all want our children to be happy,” said First Lady Alice. “I want to help our patients move from the Shriners system to successful, independent adult lives.”



Women & Philanthropy

Now in its second year, *Women & Philanthropy* is another effort that benefits the First Lady’s program. Membership is open to all women. The only criteria are having a passion for helping others and a desire to improve the lives of children. Members recognize that by joining together, their 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 please visit lovetotherescue.org/first-lady-program and lovetotherescue.org/womenandphilanthropy.

BENTLEY'S BIG STEPS

NAME: BENTLEY

CONDITION:
QUADRIPLLEGIC
CEREBRAL PALSY

LOCATION: SHRINERS
HEALTHCARE FOR
CHILDREN – FLORIDA



***When naysayers said,
“He’ll never walk,”
Bentley said, “Prove
them wrong!”***

Bentley was born prematurely at 29½ weeks with quadriplegic cerebral palsy, a condition that affects movement in all four limbs of the body.

“Our doctors at that time basically gave us no hope,” his mother, Linda, said. “They thought Bentley would never be independent – he wouldn’t be able to talk ‘normally,’ walk or even feed himself.”

Bentley’s parents researched other health care options for their son, and Bentley became a patient of Shriners Healthcare for Children – Florida in 2013, where he has since had two surgeries. In addition, Shriners Healthcare provides Bentley with the equipment he needs to stay on the move: both a manual and a power wheelchair, as well as a pair of ankle-foot orthoses each year to help support him while he grows. Bentley uses his newest devices, hip-knee-ankle-foot orthoses, to help stabilize his legs during physical therapy as he learns to walk.

Bentley took big steps – his first outside of his physical therapy appointments – at the University of South Florida’s Dance Marathon event in Tampa, Florida, earlier this year. After participating in the event the year before from his wheelchair in two full-leg casts, Bentley told his family he was determined to walk across the stage this year. In a packed ballroom of nearly 1,000 people, Bentley did just that. Onlookers cheered, wept and shouted for him as he took the stage alongside his mom for this monumental moment.

TO WATCH Bentley’s big steps, please visit bit.ly/BentleysSteps.

MARKETING

Mel Bower
Chief Marketing and Communications Officer

Victoria Beck
Senior Editor and Writer

William S. "Bill" Bailey
Marketing and Communications Committee Chairman

Contact Shriners Hospitals for Children

Phone: 813-281-0300

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SHC-009

Recognized for Excellence

Our hospitals have received the following awards



U.S. News and World Report

We are so proud! Six of our locations have been recognized as providing top-ranking pediatric orthopaedic care and services by U.S. News and World Report in its Best Hospitals rankings for 2020. The listing highlights the top 50 U.S. pediatric facilities in 10 specialties. Rankings are based on a combination of clinical data and the reputations of pediatric specialists. Our recognized locations are:

#6 Shriners Hospitals for Children — St. Louis (along with St. Louis Children's Hospital — Washington University)

#18 Shriners Hospitals for Children — Erie (together with UPMC Children's Hospital of Pittsburgh)

#24 Shriners Hospitals for Children — Salt Lake City (combined with Intermountain Primary Children's Hospital, University of Utah)

#33 Shriners Hospitals for Children — Northern California (shared with UC Davis Children's Hospital)

#40 Shriners Hospitals for Children Medical Center — Lexington (along with Kentucky Children's Hospital)

#44 Shriners Hospitals for Children — Portland (together with Oregon Health & Science University)

Press Ganey Awards

Shriners Hospitals for Children has also been honored with several Press Ganey awards. The following locations have received a Press Ganey Guardian of Excellence Award, given annually to health care facilities that reach the 95th percentile for patient experience, employee or physician engagement or clinical quality performance:

- Shriners Hospitals for Children — Canada
- Shriners Hospitals for Children — Greenville
- Shriners Hospitals for Children — Mexico
- Shriners Hospitals for Children — Shreveport
- Shriners Hospitals for Children — St. Louis



Shriners Hospitals for Children — Canada also received a Press Ganey Pinnacle of Excellence Award, which recognizes those who have maintained consistently high levels of excellence over three years.

LOCATIONS



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