LEADERS IN CARE

STORIES OF THE MOST AMAZING CARE ANYWHERE
FALL 2021

Leading by Example

National Patient Ambassadors Seth and Sydney share their stories to give hope to others
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 or insurance status.

WHAT ARE OUR PEDIATRIC SPECIALTIES?
+ Treatment for orthopedic conditions
+ Burn care
+ Spinal cord injury rehabilitation and management
+ Cleft lip and palate care

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

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

THE SHRINERS FRATERNITY
Shriners International, a fraternity based on fun, fellowship and the Masonic principles of brotherly love, relief and truth, founded Shriners 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,

At this time each year, we introduce two new National Patient Ambassadors who have gratefully accepted the responsibility of representing Shriners Hospitals for Children, sharing their stories about their achievements in the midst of adversity and the difference our health care system has made in their lives. Seth and Sydney, our 2021–2022 National Patient Ambassadors, received innovative care and treatment for scoliosis at our Philadelphia location, including vertebral body tethering, a new surgical technique developed by the medical team there. The care Seth and Sydney received helped them to be able to participate in the activities they love. Developing new treatment options is just one example of the ways Shriners Hospitals for Children strives to give patients every possible advantage and opportunity to achieve their goals.

Last year, the pandemic largely prevented National Patient Ambassadors Mia and Connor from sharing their stories of hope and healing. We are pleased that they will be continuing their journey with us this year. We invite you to read more about these four amazing teens on page 15.

This issue also includes additional stories focused on the ways our medical teams use technology to help patients achieve better outcomes.

Since 1922, Shriners Hospitals for Children has been committed to providing excellent specialty medical care for children, conducting innovative research to improve lives and add to the worldwide body of medical knowledge, and offering quality educational programs for medical professionals—all with a single goal of transforming lives. As we plan for our second century of service, we look forward to continuing to pursue that one goal.

Sincerely,

Mel Bower
Chief Marketing and Communications Officer
Shriners Hospitals for Children

PATIENT PERSPECTIVES

WE RECEIVED A NOTE FROM JOAN, whose mother, Mary, received care at Shriners Hospitals for Children almost 100 years ago—and credited her care with helping her live a fulfilling life.

Mary was born to a family of farmers in 1925. When her parents noticed that one of her legs was much shorter than the other, they mistakenly believed Mary’s older brother had tugged on it. They didn’t have the money to have it treated, and they thought she could manage. For years, Mary pushed through the discomfort and challenges that often accompany her condition—what we now know as hip dysplasia.

When she was 10, Mary’s mother, then widowed, learned that Shriners Hospitals for Children—Greenville could give her daughter extraordinary care, regardless of the family’s ability to pay. They left their small town in a horse and buggy and made the 20-mile trip to the hospital, where nurses and doctors helped Mary feel like a kid—even giving her the only doll she’d ever have.

Mary eventually married, had two children of her own, and was widowed at 41. “She never gave up on anything,” Joan explained. “Because of Shriners Hospitals, she was able to go back to work for 20 years and care for my brother and me by herself.”

At 94, Mary passed away, leaving a rich legacy behind. “My mom always talked about how the care she received gave her a chance to do what she wanted in life,” said Joan. “She was a great example to me.”

AS WE MOVE toward a full implementation of our new brand, Shriners Children’s, readers may see both the new phrase and the traditional Shriners Hospitals for Children nomenclature in use.
A Staff of Leaders

We congratulate these staff members for their leadership and accomplishments

Congratulations to Diana L. Farmer, M.D., FACS, FRCS, chief of pediatric surgery at Shriners Hospitals for Children — Northern California, the new president-elect of the American Surgical Association, the nation’s oldest and most prestigious surgical organization, for the 2021-22 year. She is the third woman to be named to this position in the association’s 141-year history.

Dr. Farmer is an internationally renowned pediatric surgeon – the world’s first female fetal surgeon – known for her expertise in complex intestinal, rectal, chest and neck disorders. She is a pioneer in the field of finding ways to repair damage to the fetal spinal cord prior to birth.

In 2018, Dr. Farmer was awarded a nearly $6 million grant from the California Institute for Regenerative Medicine and Shriners Hospitals for Children to study surgical and stem cell treatments for spina bifida. The grant allowed her team to justify a combination of fetal surgery and stem cell therapy as a treatment for babies diagnosed with spina bifida. The Food and Drug Administration has given approval for clinical trials to begin this year.

We also congratulate Ingrid Parry, a physical therapist at our Northern California location, who has been named president-elect of the American Burn Association (ABA). She will be the first non-surgeon to lead the organization. Parry has published many scientific articles on burn-rehabilitation-related topics.

Parry has been an active member of the ABA, serving on many committees, including the Verification, Program and Rehabilitation committees, and has received previous awards from the ABA for her work. Parry is also a member of the International Society of Burn Injuries.

Corrina Franklin, M.D., orthopedic surgeon at Shriners Hospitals for Children — Philadelphia, was appointed to the board of directors of the Pediatric Orthopaedic Society of North America (POSNA) during the organization’s annual meeting in Dallas, Texas, in May. She will serve as Communications Council Chair.

Dr. Franklin has several areas of special interest, including lower extremity disorders, sports injuries, cerebral palsy, spina bifida and hip problems.

Henry Iwinski, M.D., chief of staff of Shriners Hospitals for Children Medical Center — Lexington, also serves on the POSNA board of directors.

POSNA has the important goal of providing education and fostering research in pediatric orthopedics. Shriners Hospitals for Children is proud to be a platinum-level supporter of POSNA, helping to accomplish this goal.

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The entire staff of Shriners Hospitals for Children – from researchers to nurses, physicians, clinicians and therapists – is committed to improving the lives of our patients. Here are some ways that our innovative care is fulfilling that mission.

**Putting power in kids' hands**
Shriners Hospitals for Children leads the way in advanced technology in pediatric orthotics and prosthetics (POPS). For example, the POPS teams at the Salt Lake City and Chicago locations provide M-Fingers, an innovative device that helps children who are missing fingers attain the fine motor skills needed to accomplish daily tasks and have a better quality of life.
The POPS teams build artificial hand devices incorporating the M-Fingers, which are created by Partial Hand Solutions. The artificial hands are lightweight and durable and are controlled by a child’s own movement. This makes the fingers more responsive and precise. For example, the fingers can conform around objects to provide a secure grip.

Through wrist movements, this technology helps children navigate classroom activities and also promises to take playtime to new heights. Tasks like holding a pencil, picking up a piece of paper, playing with Legos, holding on while on a swing and other activities requiring fine motor skills become possible with M-Fingers.

Before M-Fingers, children who were missing fingers often chose not to get an artificial hand. The devices were heavy and uncomfortable to wear, while lighter-weight options provided limited functionality. These children would learn to adapt to everyday tasks without the use of their hand.

“It’s rewarding to be able to see kids reach their goals,” said Kelly Brooks, certified prosthetist and orthotist at Shriners Hospitals for Children — Salt Lake City, regarding the potential impact of M-Fingers on patients’ abilities.

**Customizing care**

Understanding each patient’s pain and disability allows Shriners Hospitals’ surgeons to practice innovative and tailor-made medicine.

At Shriners Hospitals for Children — Canada, Thierry Pauyo, M.D., an orthopedic surgeon and sports medicine specialist, and Mitchell Bernstein, M.D., an orthopedic surgeon specializing in limb differences, have combined their expertise to customize patient care. The impact on patients has been immense.

“We are now looking at pain and disability objectively,” said Dr. Bernstein. “We are proving with patient-recorded outcomes that it’s
not just that patients aren’t participating in sports, but they could also be unhappy or have a poor quality of life. What’s innovative is that we are targeting the pathology.”

At the hospital’s motion analysis center, patients are evaluated by a multidisciplinary team, which can include kinesiologists, physiotherapists, biomedical engineers and researchers. They use EOS imaging and 3D modeling to determine the specifics of each patient’s condition.

An example of this approach is the treatment of miserable malalignment syndrome, which causes an abnormal rotation of bones in the leg. Patients with this condition typically experience knee pain and can also have hip, ankle and back pain, as well as a different gait pattern. The multidisciplinary team uses motion analysis data to study what’s happening with the knee joint and determine the most appropriate treatment for each patient, said Louis-Nicolas Veilleux, Ph.D., principal investigator at the Canada hospital’s motion analysis center.

“If the femur is twisted, it can induce abnormally high pressure on a specific area of the knee,” he said. “If we find that the large rotations do not induce abnormal pressure points in the knee, we may look for an alternative to surgery to fix the problem.”

Cameron, 18, became a patient of Drs. Bernstein and Pauyo two years ago. “When I was in seventh grade, my knee kept dislocating while playing hockey and baseball,” Cameron said. He was referred to Shriners Hospitals, where they discovered that his femur was rotating outward. After EOS imaging, an MRI and other tests, he had surgery to turn his femur by 30 degrees and align his tibia. “Since then, life has been fantastic,” he said. “It is great to get back to normal and play basketball without any worry, problems or pain. I am looking forward to playing hockey again.”

Using breakthrough technologies
Advancing technology is another way Shriners Hospitals pursues innovative care. For example, virtual surgical planning tools developed in part at Shriners Hospitals for Children — Chicago, along with 3D printing, allow craniofacial surgeons to provide better outcomes for functions like breathing and eating, in addition to improving patients’ appearance.

One of the challenges of jaw surgery occurs when patients’ jaws don’t open and close correctly. Surgeons must envision a plan to achieve the best result. When plastic surgeons at our Chicago location needed more complex tools to plan jaw surgeries and complicated reconstructive surgeries, they developed their own platform – “virtual reality” surgery, or virtual surgical planning (VSP). This allows surgeons to virtually manipulate and even operate on a 3D version of the patient’s unique anatomy.

“We use VSP in planning myriad craniofacial cases in which we cut the facial bones and reposition them to improve facial proportion and facial symmetry, and

“Since [my leg surgery], life has been fantastic! It is great to get back to normal and play basketball without any worry, problems or pain. I am looking forward to playing hockey again.”
- CAMERON
“We use VSP in planning myriad craniofacial cases in which we cut the facial bones and reposition them to improve facial proportion and facial symmetry, and to achieve a stable dental occlusion.”

- DR. MORRIS

to achieve a stable dental occlusion [how the teeth come together],” said David Morris, M.D., chief of plastic surgery. Cutting guides and splints (devices that hold a jaw in the corrected position during healing) are 3D-printed after virtual planning to use in the actual operation. The Chicago Shriners Hospital’s craniofacial team also 3D-prints teeth and skull models to help surgeons evaluate if the patient is ready for jaw surgery, or whether more orthodontic treatment or facial growth is needed.

**Measures of success**

Research has shown that patients with scoliosis who wear a brace for the prescribed amount of time – up to 23 hours a day – often see a significant difference in controlling their spinal curve. However, it’s not easy to do, and it’s difficult to track.

Shriners Hospitals for Children Medical Center — Lexington has implemented a brace compliance program to help objectively measure brace wear time, providing care teams with information about how patients with idiopathic scoliosis wear their braces, helping to improve outcomes.

Working within the recommendations of the Scoliosis Research Society (SRS) and the Shriners Hospitals for Children Spine Study Group, the medical team at the Lexington location began using temperature monitors in 2018 to collect and measure patients’ brace wear time.

This technology provides several benefits, which include:

- The patient and family do not have to record or remember how long and when the brace was worn. (Appointments are often six months apart, so it can be challenging to recall.)
- The temperature monitors provide specific and reliable information that can indicate progress, so care providers can make the best clinical decisions possible and provide support and encouragement.
- The reports help improve communication among the care provider, patient and family, which also helps improve outcomes.

At Shriners Hospitals for Children, innovation and research inform the treatment of each patient. Our multidisciplinary teams are dedicated to working together to continually improve outcomes for every child who comes to us for care.
Facing Challenges with Confidence

Shriners Hospitals for Children empowers kids with craniofacial conditions

Medical care can be scary. Just ask Megan. After having traumatizing experiences at other hospitals, Megan was extremely anxious at the thought of surgery. But when her family found its way to Shriners Hospitals for Children — Portland, that all changed.

Megan was born with a severe case of cleft lip and palate, as well as hemifacial dysplasia, a condition affecting the growth rate of the bones in her face. Her journey with the Portland Shriners Hospital began when she was 5. The child life team there recognized Megan’s fears and worked closely to help her. The techniques they used empowered Megan, and the fear of hospitals she once had were replaced with confidence.

“Shriners is a totally different hospital – in a good way,” said Megan, now 30.

Understanding craniofacial conditions

Orofacial clefts are one of the most common birth differences in the United States. Many babies born with cleft lip also have an opening in the roof of their mouth called a cleft palate. This occurs when the tissues that form the roof of the mouth don’t join together before birth and can cause functional changes in breathing, hearing, speaking and eating. Children may require multiple surgeries to correct the mouth, jaw and nose.

Craniofacial differences can be caused by a combination of genetic and/or environmental factors and are sometimes diagnosed before birth. Our physicians often meet with expectant parents to discuss our approach to cleft lip and/or palate repair and to help them know what to expect after delivery and in their baby’s first few months.

Cleft repair at Shriners Hospitals for Children is done by experienced pediatric surgeons. Other members of a child’s care team may include speech therapists, audiologists, dentists and dental radiologists, child life specialists and anesthesiologists.

Finding reassurance

Parents Carly and Max knew their son, Saint, would need cleft treatment even before he was born. They were referred to Eric Liao, M.D., co-director of the Cleft and Craniofacial Center, a collaboration between Shriners Hospitals for Children — Boston and Massachusetts General Hospital for Children. “We visited Dr. Liao before Saint’s arrival,” Carly said. “We left the appointment not only with an understanding of the anticipated course of action for repairing Saint’s cleft, but also with a sense of reassurance that we were going to get through this.”
“I remember Dr. Liao assuring us that once the repair was made, it would look like it never happened. I didn’t think it was possible at the time, but he was right.”

– MARCY, ABIE’S MOM

Abraham, called “Abie” by his family, was also treated by Dr. Liao at the Boston Shriners Hospital. “As soon as we met the cleft team, we knew we had found the right people to take care of Abie,” his mother, Marcy, said.

Marcy recalled underestimating how dramatic the outcome of Abie’s surgery would be. “I remember Dr. Liao assuring us that once the repair was made, it would look like it never happened,” she said. “I didn’t think it was possible at the time, but he was right.”

A team effort
Terilyn, 8, is treated by a multidisciplinary team, including craniofacial plastic surgeon David Morris, M.D., at Shriners Hospitals for Children — Chicago. Their approach helped put the little girl and her mother, April, at ease. “When your child is an infant, the surgeries are hard on you as a parent,” April said. “But now she’s older and she understands what’s happening.”

Repetition at a pre-op appointment helped Terilyn grasp what was coming. “One nice thing about Shriners Hospitals’ approach is that everyone on the team had the same consistent story for Terilyn at that visit,” said April. “Dr. Morris told her everything to expect and asked her if she had questions. Then the psychologist said some of the same information. Then the nurse practitioner talked to Terilyn about her surgery. As a mom, I can see that she’s getting this in her head from that visit because they all shared the same story with her.”

Six weeks later, after surgery, Terilyn was thrilled to get cleared to enjoy her favorite snack. “I’ll go home and probably just have chips and more chips,” she said.

An adult perspective
As for Megan, she remained a patient of the Portland Shriners Hospital for 16 years, and the care she received had a life-changing effect on her. She graduated from the health care system in 2012, having had 28 surgeries.

Megan has authored and illustrated three children’s books, donating proceeds to Shriners Hospitals for Children — Portland. Copies of these books hold a special place in the family resource library at the hospital, which is available for all patients and families to enjoy.

Growing up spending a lot of time in hospitals sparked Megan’s career interest. “I had some really wonderful nurses at Shriners Hospitals, and that’s what made me want to get into nursing,” she said. Last year, Megan graduated from nursing school at Whatcom Community College in Washington. She began working as a nurse at a long-term care facility, with hopes of someday working at Shriners Hospitals.

“It’s a loving hospital,” Megan said. “It’s like a second home.”
EASING THE PAIN

Shriners Hospitals for Children is committed to reducing the use of opioids and providing new techniques for pain management.

Due to the dangers of opioid use, Shriners Hospitals is implementing new protocols and introducing alternatives to reduce the use of this class of medications. Here are some of the efforts we’re making to ensure safe and effective pain management for our patients. >>
Non-narcotic interventions
At Shriners Hospitals for Children — Spokane, as well as other hospitals systemwide, all inpatients scheduled for surgery are seen by a staff pediatric anesthesiologist prior to the day of surgery to discuss expectations and plans for pain management. Standard non-narcotic analgesics, such as Tylenol or non-steroidal anti-inflammatory drugs, are provided for patients before surgery.

During surgery, additional non-narcotic interventions occur. These can include specific drugs or regional anesthesia, which uses local anesthetics (numbing medicine) to provide pain relief to a specific area of the body. It can be administered through an epidural or as a peripheral nerve block, which can last for three days. Pediatric anesthesiologist at the Spokane Shriners Hospital, Lloyd Halpern, M.D., has detailed the use of regional anesthesia to decrease opioid use and reduce pain during a specific knee procedure in a manuscript submitted to the Journal of Pediatric Anesthesia.

After surgery, non-drug treatments like ice, massage, exercise, physical therapy and relaxation training can be especially useful in treating pain.

A patient-focused mission
At the Spokane Shriners Hospital, our pediatric anesthesiologists treat children with expertise and compassion to help them feel comfortable and recover as quickly as possible. To further this mission, we have created detailed protocols for pain management. This reduces variability, improves patient safety and supports evidence-based care. In addition, we are leading a multisite survey of pain management and opioid use after hospital discharge.

“When opioids are required, patients and families are given the necessary information on the usage, safe storage and disposal of opioids,” said Dr. Halpern.

Innovative solutions
Shriners Hospitals for Children — Springfield is using cryoablation, a technique involving temporarily freezing nerves to ease pain after Nuss bar surgery to correct pectus excavatum, a chest wall deformity in which the breastbone sinks into the chest.

“Recovery from Nuss bar surgery is lengthy and often very painful for patients due to a sudden, dramatic change in their chest,” explained pediatric surgeon David Tashjian, M.D. “Cryoablation minimizes the need for pain-relieving narcotics after surgery.”

Brothers Hayden, 19, and Hudson, 16, both had Nuss bar surgery at Shriners Hospitals for Children — Springfield, two years apart. Even though they had the same procedure, they had very different experiences. Hayden spent a week in the hospital recovering, while Hudson went home the next day. The difference was cryoaablation.
Limiting the use of narcotics was important to the boys’ mother, Amy. “We lost a relative to opioid addiction a few years ago, so this was really personal to us,” she said. “We were over the moon to hear that Shriners Hospitals offered a way to reduce the use.”

After his surgery, Hayden felt nauseated and had no appetite due to the pain medication he needed. He spent the next few months mostly on the couch. Hudson, on the other hand, was walking around shortly after his surgery. “Within a few days, he was making his own breakfast,” April recalled. “Both Hayden and Hudson received amazing care at Shriners Hospitals. But the addition of cryoablation was life-changing.”

The future of pain management
One of the goals of a new field of medicine created by investigators with the Research Center at Shriners Hospitals for Children — St. Louis is to prevent post-surgery pain by triggering a patient’s own cells to prevent it.

This new field is called mechanogenetics, and its first target is to stop the damage caused by osteoarthritis, a painful joint condition. The work by researchers with the St. Louis Shriners Hospital and its partner, the Washington University School of Medicine, was published online Jan. 27 in the journal Science Advances.

“Drugs such as ibuprofen and naproxen that ease joint pain and lower systemic inflammation are the main treatments for osteoarthritis pain, but there are no therapies that actually prevent damage in the joints of patients with this debilitating form of arthritis,” said senior investigator Farshid Guilak, Ph.D., director of the St. Louis Shriners Hospital’s Research Center. “Through mechanogenetics, we can engineer cartilage cells to respond to the mechanical loading of the joint. Every time cells are under that stress, they produce a biologic drug to reduce inflammation and limit arthritis-related damage.”

Guilak and his team’s research revealed key pathways in cells that respond to stress, said Robert J. Nims, Ph.D., a postdoctoral researcher in Guilak’s laboratory and the study’s co-first author.

Lara Pferdehirt, the other co-first author, a biomedical engineer and graduate research assistant in Guilak’s lab, said it’s like flipping a switch to turn on a light. “In this case,” she said, “the switch is the mechanical loading of a joint, and the bulb is the anti-inflammatory drug.”

Although this technology is still years away from being available, it could make a huge difference one day to people everywhere, including our patients and former patients, many of whom may be at risk for osteoarthritis. 🏡

“Through mechanogenetics, we can engineer cartilage cells to respond to the mechanical loading of the joint.”

– DR. GUILAK
Navigating Life as Pandemic Restrictions Fluctuate
Shriners Hospitals offers tips for families adjusting to changing routines

Having a meal together helps children handle the stresses of daily life and can strengthen relationships within the family. It is an excellent time to turn off screens, talk about the day and genuinely connect with each other. Greenman suggests asking open-ended questions to initiate communication during meals. “Instead of asking ‘How was your day?’ try asking, ‘What were the best and worst parts of your day?’”

**FUN:** Greenman said it is important to find ways to have fun, while still being safe. Although schools may be opening for in-person learning, many extracurricular activities that students enjoy may not be back to normal. Families can get creative and find ways to adapt activities for enjoyment and socialization outside of school. “Following an injury or surgical procedure, a child may not be able to participate in the traditional sports that they previously enjoyed,” said Greenman, “so we try to get them involved with adapted sports.” The same efforts can be applied to those affected by the pandemic – finding new ways for kids to participate in activities they love.

**ACCEPTANCE:** Finally, Greenman advised easing back into socialization and acknowledging that we may not get a complete return to normal. Many changes that are occurring due to the COVID-19 pandemic could remain in place for a long time, if not forever.

“It’s OK to feel a little awkward in social situations,” she added. “Social anxiety may be heightened after becoming accustomed to being separated from peers.” But using these elements to plan transitions back to normal activities can help alleviate that awkwardness and bring kids back to the comfort of familiar routines.

“Social anxiety may be heightened after becoming accustomed to being separated from peers.”
— JENNIFER GREENMAN, LCSW

Returning to school and community activities after sustaining an injury or enduring a prolonged hospital stay can be overwhelming and stressful for children and their families. Specialists at Shriners Hospitals for Children are skilled in helping families create plans to ease these transitions. Many of the tactics they use can also be helpful for all children and families as restrictions related to the pandemic fluctuate.

Jennifer Greenman, LCSW, is a social worker at Shriners Hospitals for Children — Erie. She collaborates with patients and families to develop a custom “safety plan.” Each patient’s unique plan helps them identify ways to feel safer in an uncomfortable environment. Following are some elements included in the plan.

**SCHEDULES:** Schedules help kids know what to expect and maintain a sense of control over their environment, which boosts their confidence and feelings of security. “We create routines and structures for the kids to follow and the parents to model,” Greenman said. “We develop a daily schedule, which includes getting up, getting dressed, eating breakfast, etc.”

**RELATIONSHIPS:** Another important part of making a child feel safe and comfortable during a transition is their relationship with their parents or caregivers. These relationships can be fostered in many ways.

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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 Shriners Hospitals for Children has made a dramatic difference in their lives.

This year, new National Patient Ambassadors Seth and Sydney will be joined by Connor and Mia, who are continuing their National Patient Ambassador journey after a year interrupted by the coronavirus pandemic. We are honored and grateful to have these four impressive young people advocating for our health care system.

> National Patient Ambassadors share their stories to give hope to others

Sydney and Seth both received an innovative treatment for scoliosis at Shriners Hospitals.
Meet Seth

Seth was 11 when his doctor noticed a curvature in his spine. They began with a “wait and see” approach and, later, treatment from a chiropractor. Still, the curvature quickly progressed to a severe degree. He and his family learned about Shriners Hospitals for Children from a social media group focused on the vertebral body tethering (VBT) treatment for scoliosis – an innovative procedure developed at Shriners Hospitals for Children.

Seth, from Fort Wayne, Indiana, underwent VBT surgery at Shriners Hospitals for Children — Philadelphia when he was 13. The surgery, performed by Joshua Pahys, M.D., helped the young athlete quickly return to the playing field. “My pain has been reduced dramatically, my curvature is half what it used to be, and my flexibility is on par with my peers,” Seth said.

Seth, now 17, enjoys playing many sports, including football, baseball and basketball, and is now focusing on competitive golf. “VBT has given me the opportunity to perform my best in athletics without the limitations of scoliosis,” Seth said. “The extra inch I gained on the operating table didn’t hurt on the basketball court, either.”

Seth is pleased and proud to have the opportunity to be a National Patient Ambassador for Shriners Hospitals for Children. “I was impressed by the amazing treatment that I received at Shriners Hospitals, and I would be honored to guide someone to their care,” Seth said. “It will mean a lot to me to give back to the Shriners Hospitals community because of the gift that they gave me.”

Connor and Mia

Due to the pandemic, Connor and Mia missed out on the typical opportunities they would have had as National Patient Ambassadors last year. We’re pleased that they’re staying on, joining Seth and Sydney in spreading the word about Shriners Hospitals for Children.

Connor, 15, was born with a bilateral incomplete cleft lip and complete cleft palate involving the hard and soft palate. 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. Through numerous surgeries and interventions, Connor is an example of the healing powers of Shriners Hospitals, as
Meet Sydney

Sydney, who is from Oklahoma City, Oklahoma, learned she had scoliosis when she was 10. Her treatment began with bracing, but despite a strict exercise regimen and wearing her brace 23 hours a day for 1½ years, her curvature progressed. Searching for an alternative to spinal fusion surgery, Sydney and her family learned about the VBT treatment option.

When she was 12, Sydney had the VBT procedure at Shriners Hospitals for Children — Philadelphia, performed by Steven W. Hwang, M.D. “VBT has allowed Sydney to retain her flexibility and to get back to all the things she loves faster and stronger than ever,” said her mom, Melissa.

Now 16, Sydney loves playing the oboe in the school band and enjoys painting and swimming. Her great-grandfather was a Shriner, and she looks forward to continuing that family legacy by telling her story as a National Patient Ambassador.

“To make my scoliosis journey a more positive experience, I had to reach out and help others,” Sydney said. “I said ‘yes’ to being a National Patient Ambassador because Shriners Hospitals has done so much for me, and I feel I could never repay that. That surgery has changed my life. It has shaped me to be the person I am today.”

Innovation at Shriners Hospitals

Seth, Sydney and their families trusted Shriners Hospitals enough to seek out our innovative care and expertise. Medical staff at the Philadelphia Shriners Hospital, led by Amer Samdani, M.D., chief of surgery, developed the methods and techniques underlying vertebral body tethering and worked with the FDA and industry partners to bring the technology to approval. Today, the procedure is offered at not only the Philadelphia Shriners Hospital, but also at other Shriners Hospitals locations, including Portland, Oregon, and Sacramento, California.

Shriners Hospitals for Children is proud that our research and innovation help improve patients’ lives. We are grateful to National Patient Ambassadors Seth, Sydney, Connor and Mia for sharing their positive experience with others.

TO WATCH
Seth and Sydney’s video, Reaching New Heights, visit YouTube.com/ ShrinersHospitals.

well as the perseverance of our patients. Throughout years of treatments, he has used his passion for golf to inspire kids and raise money for Shriners Hospitals.

Mia, 17, 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. Her journey has inspired her gift for singing and performing, which she has graciously shared with the Shriners community.
Transforming Lives

First Lady’s program raises awareness of scoliosis prevalence and treatments

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

Our unique health care system was founded in 1922 by the Shriners fraternity and is still supported by its members today. The leader of Shriners International and his wife serve one-year terms and are known as the Imperial Potentate and First Lady. This year, First Lady Debby Bailey, of Ogden Dunes, Indiana, is pleased to support the efforts of Shriners Hospitals for Children in providing information and treatment for scoliosis through her fundraising program, Transforming Lives.

Scoliosis is a common condition that, if left untreated, can have debilitating impacts on a child’s life. The physicians and staff of Shriners Hospitals for Children have pioneered medical breakthroughs and new treatment options that allow children who have scoliosis to enjoy rich, full lives.

“Detection and treatment of scoliosis are so important,” said First Lady Debby. “We are so proud that our medical teams have the opportunity to change and improve children’s lives.”

Customized treatments

Scoliosis is a disorder that results in a curved spine, causing it to take on an appearance that is sometimes similar to an “S” or “C” shape. No two cases are the same. Some children develop the condition during infancy, while others don’t exhibit symptoms until they’re approaching adolescence. Shriners Hospitals for Children’s medical teams create custom treatment plans for each child based on the severity of their condition.

Serial casting is often an effective option to slow the progression of a spinal curve. Children typically wear a cast for two to three months, then transition to a new one. Bracing is one of the least invasive treatment options for scoliosis. At Shriners Hospitals for Children, every scoliosis brace is customized to best address the severity and location of the patient’s spinal curve.

When surgery is the best option, our renowned orthopedic specialists have a wealth of experience. In fact, the medical team at our Philadelphia hospital developed an innovative treatment known as vertebral body tethering (VBT), a surgical procedure that both corrects the scoliosis curve and maintains flexibility of the spine. Shriners Hospitals for Children offers a variety of surgical options to meet the needs of individual patients.

 Detect Scoliosis with the SpineScreen App

The COVID-19 pandemic has caused a dramatic reduction in routine preventive health care. With fewer doctor visits, more conditions are going undiagnosed and untreated.

According to a recent American Academy of Pediatrics survey, the pandemic caused a dramatic reduction in pediatrician visits. Rolando Roberto, M.D., of Shriners Hospitals for Children — Northern California, is especially concerned about how the pandemic has affected preteens in the early stages of developing adolescent-onset scoliosis. Scoliosis is diagnosed most often during routine pediatric visits, and the first signs of adolescent scoliosis are often easy to miss.

The first signs of adolescent idiopathic scoliosis in fast-growing preteens and teenagers include:

- Uneven shoulders
- One shoulder blade protruding more than the other
- Ribs that are more prominent on one side
- Uneven waistline and/or difference in hip height

Parents can increase their awareness and regularly check for these indicators. If parents spot signs of scoliosis, Dr. Roberto encourages them to perform a simple spine check on their children at home using the Shriners Hospital’s SpineScreen app. If there are irregularities, schedule an appointment with your pediatrician right away.

Women & Philanthropy

Now in its third year, Women & Philanthropy is another effort that benefits the First Lady’s program. Membership is open to all women with a passion for helping 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 inspiring group.
“I wanted to be a coach. But, while in the hospital following my injury, I thought about what my new path might look like. That’s when I saw the child life therapists at work and thought, ‘Hey, I could do that!’”

For over four decades, Child Life Therapist Elaine Hardin has entertained and provided essential emotional support to patients at Shriners Hospitals for Children — Greenville. With her kind voice and playful temperament, Hardin has seemed more like a favorite aunt than a hospital employee to the thousands of children she has cared for since the 1980s.

A former Lander University basketball star, Hardin has a level of determination that is common among many high-achieving athletes, and it’s a spirit she passes along to recovering patients. This winning attitude makes her memorable. However, another aspect of her life makes her unforgettable, particularly to our patients: She uses a wheelchair.

Paralyzed from the waist down due to a car accident when she was in her early 20s, Hardin can relate to patients in a way she never planned.

As someone who drives from her home near North Carolina to the hospital in South Carolina and enjoys an active, full life, Hardin shows patients, without even trying, that physical disabilities don’t define life’s possibilities.
The Ultramarathon Man

As Zach approached the starting line for his first 50-kilometer (about 31 miles) ultramarathon this past spring, his thoughts drifted back to his time at Shriners Hospitals for Children — St. Louis.

He was born in 1984 without part of his right leg and was cared for at the St. Louis Shriners Hospital his entire childhood. When Zach was 22, he discovered a love for running, eventually becoming a sponsored long-distance athlete outfitted with a futuristic prosthetic blade.

He often thinks back to the days when he had to regularly visit the hospital to replace prosthetic legs he seemed to break again and again. “They would always say they liked to see the broken and dirty legs because it meant you were living life,” he said.

Zach is definitely living life – all while helping others find purpose in their own lives. With every race he competes in, more people learn about the charity he started in his California hometown, the Mendocino Movement Project, which seeks to unite people who want to start moving, whatever their condition. Every time he posts a training video, he hears from young people, most with leg injuries or conditions, who look to him for inspiration.

“I get to be that person I didn’t have as a kid,” Zach said.

Zach fell six miles short of finishing his first ultramarathon on an unseasonably scorching-hot April day at Zion National Park in Utah.

“I was disappointed for maybe 30 seconds,” he said. “But then I thought, ‘This is kind of like life. Sometimes you expect things to happen that don’t, and all that’s left to do is to get back up and try again.’”

And so that’s what Zach will do. He’s training for September’s Lake Sonoma 50. This time, “50” isn’t in kilometers – it’s in miles.

TO READ Zach’s full story and watch a video interview, visit myleadersincare.com.