

# LEADERS IN Care

STORIES OF THE MOST  
AMAZING CARE ANYWHERE

FALL 2023

## Becoming the Best Version of Me

International Patient  
Ambassadors share  
their messages of  
resilience and  
life-changing care



Shriners  
Children's™





## ABOUT SHRINERS CHILDREN'S



### OUR MISSION

At Shriners Children's™, 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 healthcare 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 Children's as its official philanthropy in 1922. What began as one hospital is now a world-renowned healthcare system with locations in three countries. The fraternity, which has approximately 200 chapters in several countries and thousands of clubs around the world, continues to support this unique healthcare system. To learn more, please visit [shrinersinternational.org](https://shrinersinternational.org).

## COMMUNITY CONVERSATIONS

Dear Readers,

I am delighted to introduce you to two spectacular young people, Gianna and Juan Diego. They have graciously accepted the responsibility of representing Shriners Children's as our 2023-2024 International Patient Ambassadors.



In this role, they will spend the year sharing their stories about their achievements in the midst of adversity and the difference our healthcare system has made in their lives.

Gianna, 15, was born with a condition creating limb differences. She came to Shriners Children's Southern California as a baby, where she underwent an amputation and received her first prosthesis. Over the years she has received many such devices, but even more meaningful may be the care and emotional support she received as well.

Juan Diego, 19, was burned in an accident at his home in Honduras when he was a young teen. A few months later, he arrived at Shriners Children's Boston, where, as a first step, his acute injuries were treated. Then came the hard work of reconstruction and rehabilitation. Through it all, Juan Diego's positive outlook has never wavered.

We invite you to read their inspiring stories on page 15.

Also in this issue, you'll learn more about Shriners Children's research efforts. Research is so important to us that it is enshrined in our mission, right there with providing excellent pediatric medical care. We are devoted to helping our patients – and all children – by discovering brand-new knowledge that can lead to improved care for the conditions we treat.

Sincerely,  
Mel Bower  
Chief Marketing and Communications Officer  
Shriners Children's

## PATIENT PERSPECTIVES

Retired NFL superstar Rob "Gronk" Gronkowski made a surprise visit to Shriners Children's New England in Springfield, Massachusetts, on Dec. 20, 2022. The four-time Super Bowl champ came to spread holiday cheer to patients and their families. Dressed as "Robbie the Elf," Gronk participated in various activities and brought gifts, including footballs, jerseys and sneakers, all of which he was happy to autograph.

One of the families Gronk met with was 11-year-old patient Sam, his brother Ben, 9, and his mom, Michelle. Michelle had this to say:



*On behalf of Sam, Ben and myself, I just wanted to say thank you to the entire Shriners Children's team and organization for making two young boys' dreams come true! This is a day that we will never forget! The boys so enjoyed their experience and are beyond grateful! We are so blessed that because of Shriners Children's hard work, Sam is thriving and growing. He is a real testament to what excellent care means in the life of a child who needs it!*

## LEADERS IN CARE AWARDS 2020-23



FALL 2023

# Contents

## ANNOUNCEMENTS

- 4 Patient Makes Her Mark on Reality TV



## PIONEERS IN PEDIATRICS

- 5 It's All in the Genes  
9 Fulfilling Our Research Mission



## CHAMPIONS IN HEALING

- 11 The Long Road to a Smile



## PARTNERS IN SERVICE

- 15 Becoming the Best Version of Me  
18 It Takes Two

## OUR COMMUNITY

- 19 Something to Cheer For

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

**ON THE COVER:** This year's International Patient Ambassadors, Gianna and Juan Diego, are proud to serve.



# Shriners Children's Patient Makes Her Mark on Reality TV

*In All-Round Champion, Momo shows grit and star power*



*Momo is a champion swimmer, and she proves her skills on the competition reality show.*

Meet Momo – an aspiring Paralympian, violinist, creative writer and Shriners Children's patient ambassador. Now, after participating in Season 5 of BYU TV's *All-Round Champion* (ARC) series, she can add reality TV star to her list of accomplishments.

ARC is a series in which elite athletes compete against others in their signature sporting events. During weekly podium ceremonies, medals are awarded to those who excel athletically, and "shout-out" points are given to those exhibiting great sportsmanship. Season 5 was the show's first to feature all para athletes.

Momo, 16, is a champion swimmer who was born with scoliosis and a congenital amputation of her right arm. She was treated at the Shriners Children's locations in St. Louis and Florida.

On the show, Momo was often applauded for her positive attitude, so it's no surprise that she received four different "shout-outs" throughout the season for persistence, infectious energy, tenacity and being "hungry to learn." Whether she was taking on rock climbing or sailing, Momo proved that having a limb difference makes no difference at all.

"Discovering how to adapt to take on challenges is [every para athlete's] bread and butter, and seeing us all grow throughout our time on ARC has taught me to always keep an open mind," Momo said.

**FUN FACT:** Momo's "violin arm" assisted her during wheelchair track week. It was an amazing nod to Momo's versatility and to the Shriners Children's Pediatric Prosthetic and Orthotic Services (POPS) team for empowering her with the arm she needs to thrive in any situation.

Was Momo crowned the season 5 "All-Round Champion?" To find out, stream the show at [BYUtv.org](https://www.byutv.org).

**Whether she was taking on rock climbing or sailing, Momo proved that having a limb difference makes no difference at all.**



On ARC, Momo competes with fellow elite athletes from North America.

PHOTOS: MARK BLINCH, BYUTV

EVERYDAY EXCELLENCE IN SPECIALTY TREATMENTS AND RESEARCH

# It's All in the **GENES**

*Genomics research at Shriners Children's promises to unlock a future of groundbreaking treatment possibilities*

*Scientists at the Shriners Children's Genomics Institute study patients' genetic data.*

**W**earing glasses and a plaid shirt, the director of the Shriners Children's Genomics Institute peers at his computer screen. At the top is a string of capital letters, spelling nothing. Beneath them, lines and bars of varying widths and colors stretch horizontally across the screen. Relaxed yet intent, Kamran Shazand, Ph.D., is looking for patterns. Artificial intelligence has isolated some possibilities for him, but only a person has the knowledge and judgment necessary to make sense of it all. He is analyzing a gene. >>



Kamran Shazand, Ph.D., and Anxhela Gustafson, Ph.D., analyze genetic patterns.



**Together with colleagues around the Shriners Children's healthcare system, these three scientists are doing work that is going to change the world.**



Across the hall, in a smaller room with warmer lighting, Awtum Brashear Lewis, Ph.D., sits before two computer screens, one set up the usual way, the other mounted vertically. Both are filled with lines of code, much like the computers in the *Matrix* movies – the patterns and the meaning are there if you know how to see them. Trained in biology and computer analytics, the bioinformatics specialist is looking at records from the Shriners Children's Research Data Warehouse, hoping to make connections that haven't been made before.

The adjoining room is a laboratory with humming machines and good natural light. Wearing a maroon Shriners Children's shirt, khakis and blue latex gloves, a woman sits at a counter, surrounded by stacks of clear plastic vials. Each contains a 2-milliliter sample of saliva. In front of her is a tray holding a few smaller, open vials. With her long dark hair tucked behind her ears, she is using a tool that seems like a very high-tech turkey baster. Working in a smooth rhythm, she suctions up a drop of liquid, releases it into a small test tube, ejects the used turkey baster tip into the trash, taps a new tip into place and repeats the process. Anxhela Gustafson, Ph.D., is deep in the process of manually extracting DNA from a saliva sample from a Shriners Children's patient or parent.

Here in the headquarters of the Shriners Children's Genomics Institute, located on the campus of the University of South Florida in Tampa, all three of them are "doing science." Together with colleagues around the Shriners Children's healthcare system, they are doing work that is going to change the world.

It is only a matter of time.

## The vision

Shriners Children's is in a unique position to collect and analyze genetic data related to the conditions we treat. That's because not only does the healthcare system care for a large number of patients, but we also have a diverse patient population that comes to us from around the world.

The goal of Shriners Children's genomics research is to discover the genetic causes for diseases and conditions and use the knowledge to create personalized therapies. This genetics-based approach to care is known as precision medicine.

To go from test tubes to treatments for kids is a lengthy process. Just analyzing the genomic samples takes thousands of hours a year. Years of testing occur before clinical trials with patients can begin. Precision medicine is the destination, but working in medical research requires enjoying the journey.

## A quick science lesson

Strands of DNA are made of four chemical units, which are identified by the letters A, T, G and C – the capital letters at the top of Shazand's computer screen. Many of these units strung together make up a gene. A gene gives our cells the instructions to make proteins, and the

proteins make it possible for our bodies to function. Our genome is our complete set of DNA, and every person's is unique.

Sometimes our genetic code makes mistakes. It may mix up the chemical units – placing a T where G should be, for example – or inserting an extra piece where it doesn't belong (turning a sequence that should be GCT to GCCT, perhaps). Sometimes these errors have little or no consequence to our health. Other times, they cause life-threatening or life-changing conditions. Those are the ones Shriners Children's research is targeting.

## Benefits for patients

Work at the Genomics Institute falls into two categories. One is building the database – collecting genetic samples and sequencing them. The other is using the data to investigate genetic causes of specific conditions.

While some conditions are caused by a change in a single spot in the genome, most are not. However, the changes are often found in a similar area, called a pathway. By identifying pathways and correlating them with symptoms, scientists create information clinicians can use. >>

### TO WATCH

a video about the work at the Institute, visit [bit.ly/GenomicsVideo](https://bit.ly/GenomicsVideo).



*The goal of Shriners Children's genomics research is to discover the genetic causes for diseases and conditions and use the knowledge to create personalized therapies. This genetics-based approach to care is known as precision medicine.*

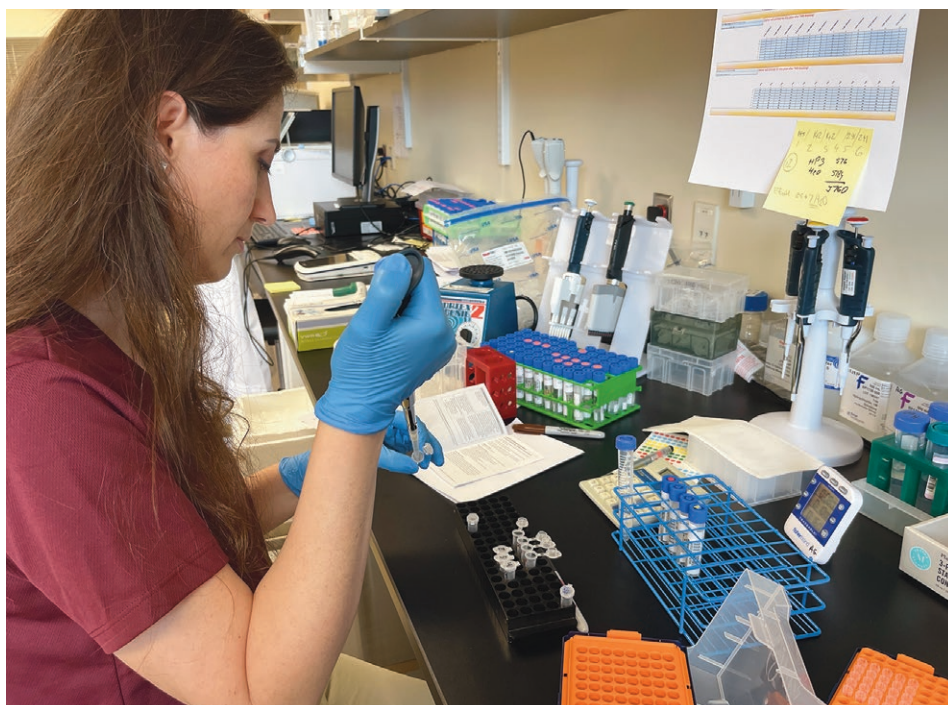


*Libbie has arthrogryposis, a rare condition researchers are learning more about through genomics.*



**When a chunk of the genetic sequence is identified as possibly involved in causing a disorder, it is marked for further investigation and possible testing. It takes a full day's work to analyze one genome.**

*Gustafson processes samples in the lab.*



Take idiopathic scoliosis. A physician may have two patients whose spines look exactly the same yet respond far differently to the same treatment. Genetic researchers are working to identify different pathways associated with scoliosis. In the future, we expect doctors will be able to sequence the two patients' genes, locate the affected pathways, and select different, appropriate treatments for each based on the cause of their scoliosis. That's precision medicine.

Shriners Children's is currently conducting research projects for 10 conditions, including scoliosis, cerebral palsy, arthrogryposis, club foot, and cleft lip and palate, with plans to add more.

### How we get there

The healthcare system is working to sequence 15,000 genomes. That means collecting and processing the samples of 15,000 Shriners Children's patients and parents. Patients give their sample during a visit to their Shriners Children's location or outreach clinic, providing 2 milliliters of saliva in a sterile vial. Samples are labeled only with the donor's sex, condition and clinical symptoms and are then sent to the laboratory in Tampa.

There, they go through an elaborate process to extract the DNA and prepare it for sequencing. The lab recently purchased the latest in sequencing technology. Previously, the machine they used could



*Awtum Brashear Lewis, Ph.D., is a bioinformatics specialist at the Shriners Children's Genomics Institute.*

process 48 samples over a period of three days. The new machine can practically double that.

The sequencer is how we get from spit in a cup to a string of 6.4 billion letters. It takes computer analysis, artificial intelligence and human judgment to arrange the data into forms that can yield insights. That's bioinformatics.

Only then can researchers comb the genes for clues to medical problems. Shazand does the bulk of that, although Gustafson, Brashear Lewis and lead bioinformatician Andrew Quitadamo, Ph.D., who is based in North Carolina, help when they can. When a genetic sequence is identified as a possible link to a disorder, it's marked for further investigation. It takes a full day's work to analyze one genome. With 500 more samples to go, there's a lot of work to be done.

### Worth the wait

Shazand has dedicated his career, and his life, to research. At Shriners Children's, he said, "We want to be part of the international effort in tackling rare pediatric disorders. That is what animates us."

But what drives him to work so hard, knowing tangible results won't be seen in his lifetime? His first grandchild was born in June.

"I have the most beautiful mission," he said. "The father in me is driving this research."

Perhaps today's work will benefit his grandchildren, or his grandchildren's grandchildren?

"I am certain it will," he said. "It's just a matter of time." 🍀



# Fulfilling Our Research Mission

*To change and improve lives, Shriners Children's seeks new knowledge*



Researchers from Shriners Children's and Georgia Institute of Technology come together to share ideas.

**Our goal is to position Shriners Children's as a leader in pediatric research, recognized for our contributions to the advancement of medical knowledge and the improvement of patient care.**

Shriners Children's medical providers are always striving to provide the most innovative and effective treatments. That's why we are so committed to our mission to conduct research.

Today, Shriners Children's patients benefit from research that began decades ago, and we are confident that the research we do now will drive results far into the future. To benefit our patients most, our main research efforts fall within Shriners Children's areas of clinical focus – pediatric orthopedics, burns, and cleft lip and palate. That's in addition to work at the Shriners Children's Genomics Institute (see page 5).

To maximize our impact, we work with renowned research institutions and industry partners to promote research collaborations and leverage funding opportunities. Publications and presentations at national and international conferences enhance the visibility of our research findings. Our goal is to position Shriners Children's as a leader in pediatric research, recognized for our contributions to the advancement of medical knowledge and the improvement of patient care.

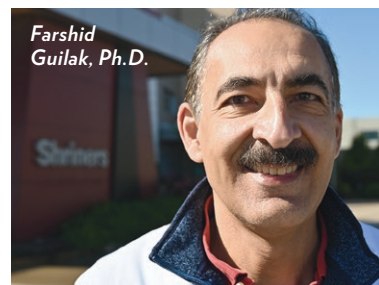
Here are a few research projects underway around Shriners Children's.

## Smart stem cells

Farshid Guilak, Ph.D., director of research at Shriners Children's St. Louis, and his team have discovered a new way to help children and adults who have arthritis: smart stem cells.

The team rewired the genetic circuits in stem cells, so that the cells can sense when a person is about to have a flare-up of juvenile arthritis or rheumatoid arthritis. The cells then make and release substances similar to medications that are injected for arthritis treatment. These biologic >>

Farshid Guilak, Ph.D.







**The number of patients who did not require opioids while the epidural catheter was in place increased from 40% to 62%. The Shriners Children's Spokane medical team continues to use the new epidural catheter.**

agents can control disease flare-ups before they happen and make it possible for patients to be less dependent on high doses of medication.

To keep these smart cells in place, Guilak's team encapsulated the cells within flexible gel rods, made from a seaweed derivative, that are designed to be kept in the body for months at a time. Without the gel rods, the cells only last in the body for 48 hours.

"Our next steps are to determine which drug, or drugs, can be delivered successfully through the gel rods to control symptoms for different forms of arthritis," said Guilak.

## Better pain management

Shriners Children's Spokane collaborates with Washington State University (WSU) Medical School to provide research opportunities for medical students through the Helen Lemieux Scholarship Fund.


This scholarship, administered through the Shriners Children's research department, provides financial support for medical students who participate in four- or eight-week research projects with local faculty. In the summer of 2022, WSU medical student Abby Velarde designed and implemented a research project in collaboration with Lloyd Halpern, M.D., a pediatric anesthesiologist at Shriners Children's Spokane.

The project studied the use of a new type of epidural catheter for certain

20% of children in the general population experience mental health conditions. Youths with a chronic condition or physical disabilities are up to 10% more likely to experience a mental health condition.

At Shriners Children's Chicago, pediatric psychologist Kyle Deane, Ph.D., is leading research to develop the first pediatric measure of appraisals of disability for children with a spinal cord injury.

As Deane explained, appraisals are “how someone makes sense of a stressful event. They can look at it as a loss, as something they find threatening, or as a challenge that they can meet,” he said. “We think that the way a kid thinks about his or her injury really affects functioning.”

The research examines how patients understand, or appraise, their spinal cord injury and whether they have psychosocial issues such as depression, anxiety or post-traumatic stress, or other health conditions such as pressure injuries, sleep difficulties or pain after injury. The goal is to create a tool that quantitatively measures how children think about their spinal cord injury, which may help psychologists and clinicians identify patients at higher risk for negative outcomes. 

patients undergoing spinal fusion surgery. The researchers hypothesized that the new catheter would provide improved pain relief for Shriners Children's patients.

The study found the new epidural catheter reduced the incidence of breakthrough pain (pain that erupts while a patient is already medicated). The number of patients who did not require opioids while the epidural catheter was in place increased from 40% to 62%. The Shriners Children's Spokane medical team continues to use the new epidural catheter.

## Supporting mental health

Mental health is a critical piece of a child's overall healing and wellness. In addition to providing direct patient support, Shriners Children's child psychologists conduct research to improve care. The World Health Organization says about



*Kyle Deane, Ph.D.*



# champions

## IN HEALING

A FAMILY-CENTERED APPROACH TO COMPASSIONATE CARE

The cleft lip and palate treatment journey has many experts who help along the way

# The Long Road to a Smile

April and Michael knew exactly where to turn when an ultrasound indicated their son, Evan, would likely be born with a cleft palate. That's because the family had found compassionate support and medical expertise in the multidisciplinary team of specialists at Shriners Children's when Evan's older sister, Terilyn, had the same diagnosis years before. Many parents like April and Michael trust Shriners Children's and our cleft and craniofacial care teams to repair and restore their child's physical, psychological and social health. >>

Evan is all smiles after years of treatment for his cleft lip and palate.





Scott Rapp, M.D., holds a patient with cleft lip and palate treatment needs.

**“We often see children who need ancillary services like neurology, ophthalmology and orthodontics, so it’s critical that we treat the patient as a complete team.”**

– SCOTT RAPP, M.D.

Each child’s comprehensive care team may include a plastic surgeon, orthodontist, otolaryngologist, speech therapist, dietitian, pediatrician and geneticist, as well as other associated specialists. Often these team members can be seen in the same building, creating a continuity and convenience that parents appreciate.

Evan, who was born with a bilateral cleft lip and palate, had four surgeries in 2018 at Shriners Children’s Chicago, including a two-step repair to his upper lip, repair of his palate and tubes inserted in his ears.

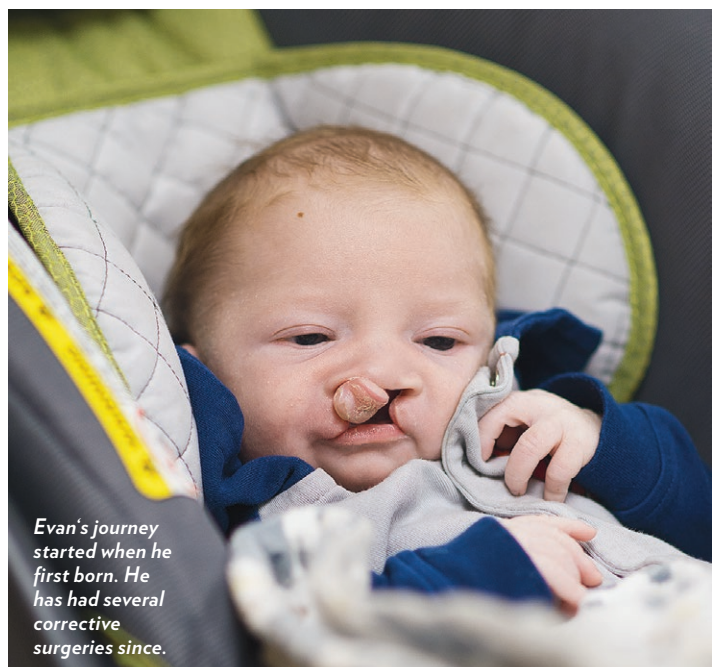


### Carefully planned, team-based procedures

For a patient with a cleft diagnosis, the medical journey can span their entire childhood. Although the cleft palate and lip typically are repaired within the child’s first year, as many as nine surgeries may be needed to the mouth, jaw and nose as a child grows into adulthood. Surgeons at Shriners Children’s guide families in the timing of procedures and surgical approaches that will improve their child’s physical health – their eating, hearing, breathing and speaking – while also creating the best possible appearance.

Each patient receives a customized treatment plan and is cared for by a multi-disciplinary team.

“We often see children who need ancillary services like neurology, ophthalmology and orthodontics, so it’s critical that we treat the patient as a complete team,” said Scott Rapp, M.D., a surgeon at Shriners Children’s Ohio.



Evan’s journey started when he first born. He has had several corrective surgeries since.





## Providing expert care for feeding and speech

Patients often work with speech-language pathologists, since having a hole in the roof of their mouth can cause feeding difficulties and speech challenges.

Babies with a cleft need to use specialized bottles that don't require the use of oral pressure, explained Sarah Richards, MS, CCC-SLP, a speech-language pathologist at Shriners Children's Chicago. At Shriners Children's, we provide these special bottles, in addition to evaluating feeding techniques and success.

Over half of children born with cleft lip and palate will require speech therapy at some point in their lives, typically before age 5. Richards said cleft palate patients may have difficulty with high-pressure consonants like P, B, D or T. "Because the child will come up with clever and inaccurate ways to try to say those sounds, those incorrect early speech patterns will have to be worked on later in speech therapy," she said.

Veronica was 4 when she started weekly speech therapy. First she worked to master her consonants, then she was able to move on to other sounds. "Veronica made tremendous progress," Richards said. After 17 months in therapy, Veronica felt more confident speaking and was no longer shy around adults or kids.

"Shriners Children's Chicago has great doctors and therapists," said Veronica's father. "It is a place to go when your child needs help." >>



*Sarah Richards, MS, CCC-SLP, works with Veronica on her speech.*

## Research Study Sends Science Home

Sleep apnea is common among patients who have a cleft as well as patients who need orthognathic (jaw) surgery. However, diagnosis involves an overnight stay in a sleep lab, which takes the child out of their normal sleep environment and may require significant travel for the family.

"My new study offers an alternative," said Chad Purnell, M.D., a board-certified plastic surgeon at Shriners Children's Chicago who specializes in craniofacial surgery and microsurgery.

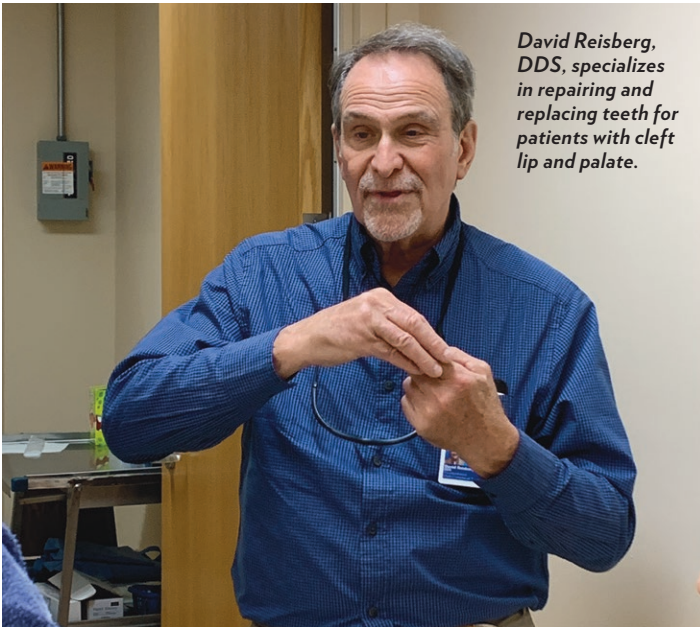
He is collaborating with Georgia Institute of Technology researchers W. Hong Yeo, Ph.D., who conducts research in micro and nano engineering, and May Dongmei Wang, Ph.D., who works in the area of biomedical informatics, using tools to analyze data and train artificial intelligence (AI) software to find patterns.

"We are using at-home sleep studies that use wireless, wearable sensor technology," said Dr. Purnell. "This allows a child to have a sleep study in their own bed where they are comfortable."

Using data from sleep studies and computerized tomography (CT) scans, they hope to train AI to be able to predict sleep apnea from a CT scan or even, someday, a picture.



*Chad Purnell, M.D., (front right) leads a study on improving sleep apnea diagnostics.*



David Reisberg, DDS, specializes in repairing and replacing teeth for patients with cleft lip and palate.

***“If there’s a cleft lip involved, patients are usually missing at least one tooth in the cleft site, sometimes more. And if it’s a bilateral, they may be missing one on each side.”***

– DAVID REISBERG, DDS

For younger patients, Dr. Reisberg may be called on to insert a speech-aid prosthesis. This is an interim prosthetic to plug the hole in the palate, which allows children to speak more typically until they are ready for their final surgical repair.

### Worth the trip

All of this advanced care at Shriners Children’s locations across the country is provided regardless of families’ ability to pay or insurance status. Even with the peace of mind that brings, visiting the Shriners Children’s team every six to 12 months can feel daunting. Still, families say the process is worth it to reach the goal of giving their child a healthy, independent life and a smile they like.

“We thought Evan’s work was perfection – even the two little marks on his lip,” April said. “They are his trademark. We tell him that’s the special little stamp you’re going to have for life.” 📷

### Each child leaves with a smile

Families can expect additional surgeries after the initial flurry of repair procedures during the early years. Between 6 and 9 years old, patients born with cleft lip may need a bone graft to fill in the missing bone in the child’s jawline.

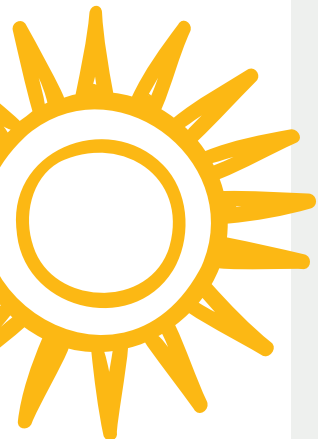
Almost every child with a cleft will also need final corrective surgery after their facial structure is done growing in the late teen years. Once facial bones are in the correct positions, cleft rhinoplasty (a nose and lip surgery) is performed. While nearly all children who have a cleft will need braces (orthodontia), a smaller percentage of teenagers will also need orthognathic surgery – surgery on their jaw.

“If there’s a cleft lip involved, patients are usually missing at least one tooth in the cleft site, sometimes more. And if it’s a bilateral, they may be missing one on each side,” said David Reisberg, DDS, a pediatric dentist at Shriners Children’s Chicago and one of a few hundred specially trained prosthodontists in the country. A prosthodontist specializes in repairing natural teeth and replacing missing teeth.

For Shriners Children’s patients with a cleft, specialists use dental implants with a bone graft to fill the hole. These grafts typically use the patient’s own bone, taken from their hip. “We place the bone graft, and five months later, we do an X-ray to ensure the graft has taken,” said Dr. Reisberg.



Evan’s parents have appreciated every step of his care journey.





# partners IN SERVICE

EVENTS, NEWS AND INSPIRATION FROM THE SHRINERS COMMUNITY

*International Patient Ambassadors share their messages of resilience and life-changing care*

## Becoming the Best Version of

# Me

*Gianna and Juan Diego proudly take on the roles of International Patient Ambassadors.*

**E**very journalist knows if you want the scoop, go right to the source. And there is no better way to get the lowdown on Shriners Children's than to hear it from the patients themselves. Each year thousands of young children and teens receive transformative care at one of the healthcare system's premier locations. Walk through the halls at any of these facilities across the >>



U.S., in Mexico or Canada, and you will be captivated by countless stories of patients thriving after treatment. You'll hear about that special something that sets Shriners Children's apart.

Each year, Shriners Children's selects two International Patient Ambassadors who carry these messages of care that embraces the whole family. They help showcase successful outcomes and illustrate how Shriners Children's patients

gain the confidence to overcome adversity and pursue their dreams. The ambassadors are introduced in July at Imperial Session, an annual convention that brings together Shriners from all over the world.

These resilient and inspirational patients represent the health-care system at signature events throughout the year, including collegiate and professional sporting events and the most widely televised parade in the world, the Tournament of Roses Parade. This July, the 2023–2024 International Patient Ambassadors, Gianna and Juan Diego, took the stage to share their gratitude and excitement about the year ahead.

## Meet Gianna

Gianna was born with a rare condition called proximal femoral focal deficiency (PFFD), which caused her to be missing part of her left femur. Her parents knew they had to find the right specialized care for their daughter and were grateful to learn that the orthopedic team at Shriners Children's Southern California had the expertise to treat PFFD.

Gianna's left leg was shorter than her right one, and she had hip malformations and other congenital deficiencies in her left leg, said Robert Cho, M.D., pediatric orthopedic surgeon and chief of staff at Shriners Children's Southern California. "Gianna did not have a functional knee joint, and she had a nonfunctioning foot that was pointed inward. It would have been essentially impossible for her to walk without amputating and giving her a prosthesis," Dr. Cho said.

Gianna had her first visit at Shriners Children's when she was 3 months old, and at 9 months, she received her first prosthesis. As she grew older, she became aware of her physical differences and at times struggled with her self-image. The prosthetics and rehabilitation teams worked with Gianna to teach her how to adapt and build the skills and confidence to meet her physical challenges. "My Shriners Children's family taught me to never let my leg hold me back from being the best version of myself," she said.

Gianna's father was so impressed with the care his daughter received, he was inspired to become a Shriner and currently serves as chairman of the Board of Governors at Shriners Children's Southern California.

***"My Shriners Children's family taught me to never let my leg hold me back from being the best version of myself."***

– GIANNA



Now Gianna, 15, is an active high school student who is both an artist and an athlete. She especially loves football and dreams of working for the NFL someday. Dr. Cho has every confidence that with her drive and spirit, Gianna can achieve whatever she sets her mind to.





## Meet Juan Diego

Juan Diego, 19, was burned in an electrical accident at his home in Honduras when he was 13. His hands were seriously injured, and he was completely dependent on others for even the most basic tasks. He could not take care of himself, go to school, or draw or play music – two of his passions.

The Ruth Paz Foundation, a non-profit organization in Honduras devoted to providing quality medical services to children, learned about Juan Diego's burn injury and connected him with Shriners Children's. Four months after his injury, he arrived at Shriners Children's Boston. Some of his burn wounds were still open, requiring immediate attention from the acute burn team.

During his 2½ months in Boston in 2018, much of Juan Diego's treatment involved intensive physical and occupational therapy. Occupational therapist Courtney Updegrave fabricated customized splints for his hands, enabling Juan Diego to relearn how to care for himself. He was even able to draw and play the drums again. Juan Diego approached every treatment and every obstacle with a positive attitude.

Juan Diego's care also included reconstructive treatment, through which Joseph Upton, M.D., a plastic surgeon hand specialist, restored sensation and mobility in Juan Diego's hands. Dr. Upton was able to take tissue from another part of Juan Diego's body and build a web space between his thumb and index finger. Juan Diego continues to come to Shriners Children's Boston for reconstructive and laser surgeries.

Now a college student in Honduras studying international relations, Juan Diego is honored to represent Shriners Children's as an International Patient Ambassador. "I want to put into action all of the gratitude I have for Shriners Children's," he said. "I hope my story brings inspiration and hope to others." 🙌

***"I want to put into action all of the gratitude I have for Shriners Children's. I hope my story brings inspiration and hope to others."***

– JUAN DIEGO

### **WATCH IT**

*No Boundaries: The Stories of Gianna and Juan Diego* highlights the remarkable journeys of our 2023–2024 International Patient Ambassadors.





# It Takes Two

*At Shriners Children's St. Louis, hand surgeons operate as a team*

A power team of surgeons at Shriners Children's St. Louis shows that two is better than one, especially when each is fellowship trained, highly specialized and passionate about helping kids thrive.

Lindley Wall, M.D., MSc, and Charles Goldfarb, M.D., both specialize in congenital upper extremity anomalies, traumatic injuries and nerve compression. Dr. Wall has additional expertise in cerebral palsy and brachial plexus birth injury, while Dr. Goldfarb specializes in adolescent athletes and sports injuries.

"The value of being able to work together as two surgeons provides families the next level of care," Dr. Wall said.

## Less time, more attention

Wyatt, who was born with an extra set of thumbs, is one patient who has benefited from this teamwork-makes-the-dream-work approach. Diagnosed with radial polydactyly and triphalangeal thumbs, Wyatt's treatment plan included multiple surgeries.

"In the operating room, performing surgery together allows us to minimize time under anesthesia and to have real-time collaboration about approaches in unique cases," said Dr. Wall. "While we both treat the pediatric upper limb, we each have areas of particular interest, allowing us to provide comprehensive treatment of nearly all conditions impacting the hand and upper limb in children."



Wyatt and his mom, Amanda



Drs. Goldfarb and Wall perform surgery together, minimizing operating time.

For Wyatt's surgery, Dr. Wall worked on one hand while Dr. Goldfarb worked on the other.

"Having two surgical teams working simultaneously limited the anesthesia time by half, which meant it was much easier on Wyatt's little body from a sedation and recovery standpoint," said Wyatt's mother, Amanda. "For us, it was a blessing, as the pacing and worrying time was drastically shortened while getting both of his little hands fixed."



Wyatt shows his repaired thumbs.

**For Wyatt's surgery, Dr. Wall worked on one hand while Dr. Goldfarb worked on the other.**

## Successful outcomes

Today, Wyatt is a third-grader in Wichita, Kansas, and he has some of the best penmanship in his class. To say he's found success thanks to his care at Shriners Children's St. Louis would be an understatement.

Amanda knows Wyatt's ability to thrive is due in part to the doctors' commitment to teamwork.

"Knowing that the two often confer and pull from each other's previous experiences minimizes the unknown and provides such enormous confidence," she said. "When you have a team of experts you can trust, traveling 500 miles each way for appointments and care is worth every mile. You know that your child is in the best hands to ensure their future success."

**TO READ MORE STORIES**

like this one, visit [myleadersincare.com](http://myleadersincare.com).





## SOMETHING TO CHEER FOR

NAME: GABBY

CONDITION: SCOLIOSIS

LOCATION: SHRINERS  
CHILDREN'S NORTHERN  
CALIFORNIA

***“I entered the gym with a new sense of confidence I didn’t even know I had.”***

Gabby, 13, is a dedicated cheerleader who has had her sights set on competing at a national level. But back pain due to scoliosis required that she take a slight detour on the road to S-U-C-C-E-S-S. With her condition rapidly worsening, Gabby was referred to Shriners Children’s Northern California and orthopedic spine surgeon and medical director of the Pediatric Spine Program, Rolando Roberto, M.D.

Gabby learned she was a good candidate for a less invasive surgical procedure called VBT, vertebral body tethering. Although it was a long and complicated surgery, she was released home 48 hours after surgery and cleared for all activity just five weeks later. “I threw my first handspring the day after I was cleared,” said Gabby.

Gabby is grateful to be back in the gym performing all of her favorite moves, including the spike, a balancing move. The spike requires extreme spinal flexibility and is a spectacle when an athlete can pull it off. When a 13-year-old has it mastered after going through spine surgery? Simply amazing.

“My back doesn’t hurt anymore,” said Gabby. “My knees and hips are in alignment so those don’t hurt anymore either, and I can do all the same things as before, plus more. I’m really glad I had the surgery.”

And that national competition? In April, Gabby competed in The Summit Championship Varsity All Star cheerleading tournament, a competition her coach called the “Super Bowl of cheerleading.” There, she helped her team, Korra of Nor Cal Elite All-Stars, win it all.

## MARKETING

Mel Bower  
Chief Marketing and Communications Officer

Kate Brassfield  
Senior Editor and Writer

Richard G. Burke  
Marketing and Communications Committee Chairman

## Contact Shriners Children's

Phone: 813-281-0300

Leaders in Care is published four times a year  
by Shriners Children's. ©2023.

All rights reserved.

Publication management: GLC, part of SPM Group



**Shriners**  
Children's™

PO Box 31356  
Tampa, FL 33631

Shriners Children's [shrinerschildrens.org](https://shrinerschildrens.org)

Non-Profit Org.  
U.S. Postage  
**PAID**  
Shriners  
Children's

SHC-021

# Motion-Picture Power

Do horses lift all four feet off the ground when they run? Finding the answer to this question led to the technology used today to treat children with cerebral palsy (CP) and other orthopedic conditions.

In the early 1860s, California Governor Leland Stanford wanted to settle a debate about how horses run. He turned to photographer Eadweard Muybridge for help. The result was a groundbreaking series of photos that made news around the world and proved Stanford right: Horses did, at times, have all four feet off the ground. The images led to more photographic experiments, including photos of a woman with CP walking. Muybridge eventually became the father of motion pictures.

## Advancements in imagery

Over the decades, advances in computer imaging technology have greatly improved gait analysis – the assessment of how a patient moves. Jon Davids, M.D., director of the Motion Analysis Laboratory and assistant chief of orthopedic surgery at Shriners Children's Northern California, was one of the early pioneers of this technology, becoming a gait analysis research and treatment global leader.

Motion analysis centers in 14 Shriners Children's locations use high-level technology, infrared cameras and advanced computer programming to assess CP patients before and after surgery and other treatments.

It's a chance for young patients to feel like action figures in a movie. First, markers are attached to their bodies to track their movements, and then they're filmed

by infrared cameras as they move and walk. Hollywood uses the same technology to create special effects in films such as *Lord of the Rings*, *Avatar*, *Polar Express* and the newer Marvel movies.



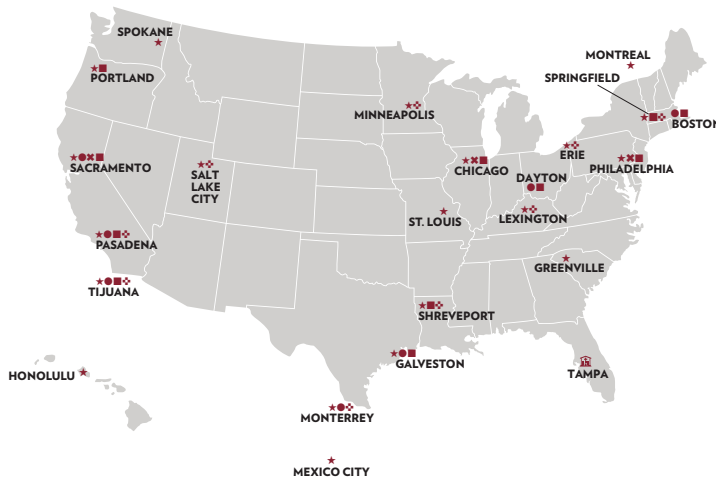
Our motion analysis centers utilize some of the same technology used in major motion pictures.

## Next step: Cellphone videos

What's in store for this incredible technology that started with a series of horse photos? With computer programs, apps and smart phone videos, ongoing patient assessment can be done with fewer trips to the hospital.

"Not everyone can get to a gait lab, but almost everyone has a cellphone, and you can make videos of children walking," Dr. Davids said. "These advances will make life-changing care accessible to many more children, meaning we can help improve many more lives."

## LOCATIONS



- ★ Orthopedics
- Burn care
- ✕ Spinal cord injury
- Cleft lip and palate
- ⊕ Outpatient care only; necessary inpatient care provided at an affiliated facility
- 🏠 Shriners Children's and Shriners International's Headquarters