

LEADERS IN *Care*

STORIES OF THE MOST AMAZING CARE ANYWHERE
SUMMER 2020

Fun in the Sun

Shriners Hospitals
for Children has
tips for keeping
summer safe,
as well as fun
programs for kids
of all abilities.



Shriners Hospitals
for Children®

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ABOUT SHRINERS HOSPITALS FOR CHILDREN



OUR MISSION

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



WHO DO WE TREAT?



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

WHAT ARE OUR PEDIATRIC SPECIALTIES?



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

GROUNDBREAKING RESEARCH



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

CONTINUING EDUCATION



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



THE SHRINERS FRATERNITY

Shriners International, a fraternity based on fun, fellowship and the Masonic principles of brotherly love, relief and truth, founded Shriners Hospitals for Children as its official philanthropy in 1922. What began as one hospital is now a 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 I'm sure you know, creating a magazine takes a tremendous amount of time. As I write this message for our summer edition, we are all living in the midst of a health care crisis unlike anything we have ever experienced. The COVID-19 pandemic



has brought tragedy, upheaval, fear and seemingly limitless turmoil and change to all our lives.

While I don't know as I'm writing what the situation will be when you read this, I do know one thing:

Shriners Hospitals for Children are places of determination, resiliency and hope. No matter how difficult the future may become, our dedication and commitment to our mission of making a difference in the lives of children, and improving the world around us, will remain steadfast.

Nearly 100 years ago, the Shriners fraternity responded to the aftereffects of a polio

epidemic by creating Shriners Hospitals for Children, which has become one of the largest, most respected and revered pediatric health care systems in the world. We know that spirit of determination and compassion still lives in the hearts of everyone connected to Shriners Hospitals for Children and will see us through this crisis, and on to an even stronger future. We are, and will be, here for you.

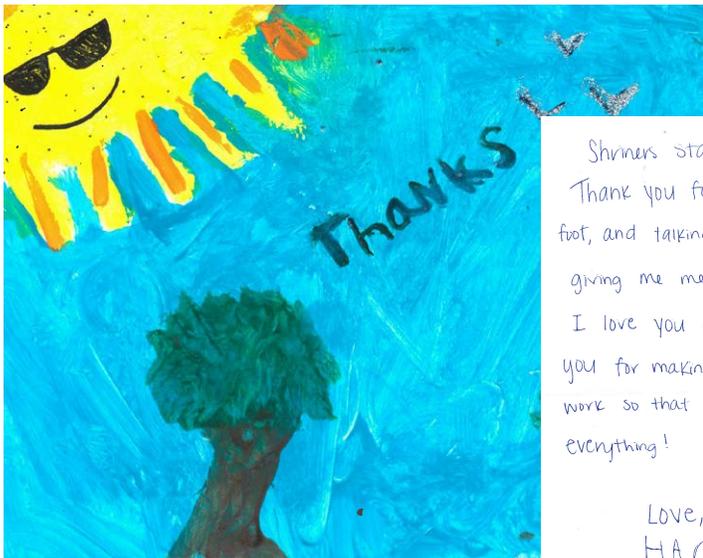
One of the hallmarks of Shriners Hospitals for Children is a concern for the overall well-being of our patients. We provide programs that build confidence and self-esteem, teach skills that will last a lifetime, and offer opportunities for fun and new experiences. We share some of those efforts on the following pages and hope you both enjoy and are inspired by them, especially during this difficult time.

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

 **TELL US WHAT YOU THINK** Take our reader survey and enter to win a \$50 gift card. Visit [leaders2.questionpro.com](https://www.leaders2.questionpro.com).

PATIENT PERSPECTIVES

PATIENTS OF Shriners Hospitals for Children — Portland show their thanks for the excellent care they received.



Shriners staff,
Thank you for wrapping my foot, and talking with me, and giving me medicine, and I love you nurses! Thank you for making my thumb work so that I can do everything!

Love,
HAMILSON
(Henny)

SUMMER 2020

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ON THE COVER: Ray'quan enjoys summer fun at Camp Ytiliba, a program of Shriners Hospitals for Children — Cincinnati. Photo by Jenny Beck.



The new Sports Medicine Consortium will allow multiple sites to combine expertise and patient data for better quality of care.

Sports Medicine Consortium Enhances Care and Research

Collaboration positions Shriners Hospitals for Children to become a leader in the field

Pediatric sports medicine is a rapidly expanding field. This is driven in part by an overall increase in the incidence of sports injuries in children. For example, the incidence of anterior cruciate ligament (ACL) ruptures has increased substantially over the last several years.

Many individual Shriners Hospitals locations have initiated their own sports medicine programs. Corinna Franklin, M.D., an orthopaedic surgeon at Shriners Hospitals for Children — Philadelphia, led a team that obtained a development grant to begin the process of unifying the health care system's sports medicine and motion analysis programs in order to provide collaboration throughout the system and strengthen our presence in this field.

Last year, with this grant, the Shriners Sports Medicine Consortium was established. Sports medicine programs from 10 of our sites – including Philadelphia and Erie, Pennsylvania; Chicago, Illinois; Pasadena, California; and Houston, Texas, are represented in the Consortium, which comprises a multidisciplinary team of physicians, therapists and motion analysis staff from across the health care system. Combining the expertise and patient data from each of the sites will allow us to provide a consistent and comprehensive level of quality care, as well as drive biomechanical sports medicine research.

Since the Consortium's establishment, considerable progress has been made. Various research protocols, as well as a motion analysis clinical protocol, have been developed. In addition, work is being done to standardize the method used within our health care system to safely return athletes to sports, establish patient-reported outcome measures and create a standardized sports-intake form. Over the next two years, the Consortium will establish the infrastructure for data collection, methods for querying and analyzing data, and pilot data for larger studies. These steps will help the Shriners Sports Medicine Consortium become a worldwide leader in pediatric sports medicine. 📌

Chicago Physical Therapist Selected as Fellow



Jennifer Schottler, MPT

The American Spinal Injury Association (ASIA) has selected Jennifer Schottler, MPT, as a Fellow. Schottler is a physical therapist currently working as a clinical research coordinator at Shriners Hospitals for Children — Chicago. She has worked on a variety of clinical research studies involving children and adolescents with spinal cord injuries and scoliosis. She previously worked in the hospital's rehabilitation department as the spinal cord injury lead, evaluating and treating patients.

Fellowship in ASIA is given in recognition of distinguished accomplishments within the fields of spinal cord injury research, clinical practice, education and advocacy, and for a longstanding membership of service to the society. 📌

📖 **TO READ MORE** about the latest news and developments at Shriners Hospitals for Children, please visit shrinershospitalsforchildren.org.

pioneers IN PEDIATRICS

EVERYDAY EXCELLENCE IN SPECIALTY TREATMENTS AND RESEARCH

NAVIGATING CARE FOR CP

Motion analysis and specialized centers expand the possibilities for cerebral palsy treatment

Aidan, a patient of Shriners Hospitals for Children — Chicago, stays active with custom leg braces.

In the U.S., approximately one in every 300 children is born with cerebral palsy (CP), the most common cause of movement and mobility disabilities in children. CP is an umbrella diagnosis for a wide range of neuromuscular disorders affecting movement, muscle tone, balance and coordination – with wide-ranging effects, from mild gross-motor delays or difficulty, to complete disability requiring total care.

Each year, Shriners Hospitals for Children cares for thousands of children with CP. Here are examples of the innovative treatments improving our patients' lives.

Motion analysis

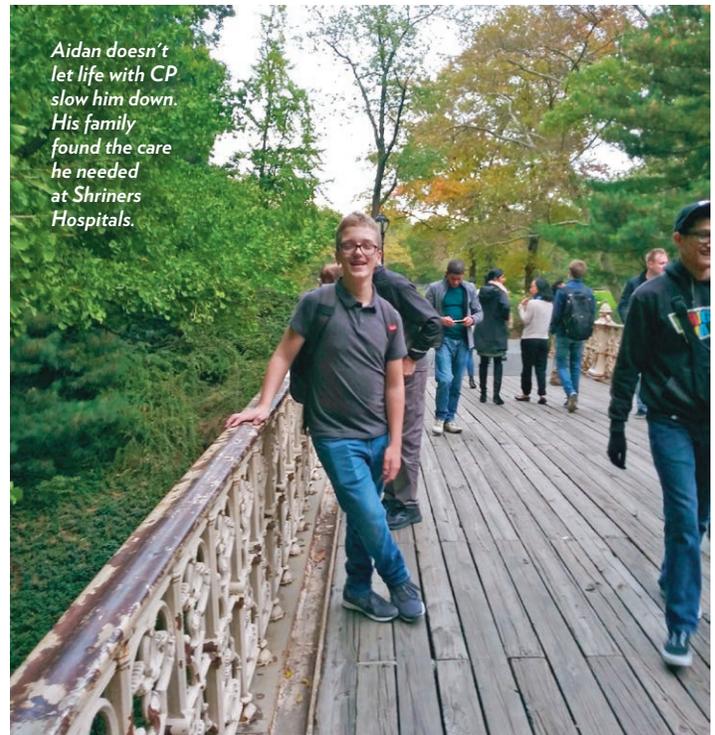
Shriners Hospitals for Children is an internationally recognized leader in clinical motion analysis, available at 14 of our locations. In the motion analysis centers, high-speed cameras, reflective markers, force platforms and muscle sensors work together to record and measure how a child with a mobility impairment moves. The technology of the motion analysis centers provides a way to collect detailed data that helps to give a more complete picture of how and why a patient's muscles, joints and bones are interacting. >>

“If I’m not at home I’m wearing them. If I didn’t wear braces, I wouldn’t have muscle control in my ankles. I wouldn’t be able to walk long distances.” – AIDAN

“At Shriners Hospitals for Children, care decisions for children with cerebral palsy are often driven by the analysis of objective, quantitative data, including information provided by the motion analysis centers,” said Jon Davids, M.D., assistant chief of orthopaedics and director of the Cerebral Palsy Center of Excellence at Shriners Hospitals for Children — Northern California. The information is used to guide clinical decisions and develop treatment protocols, which ultimately leads to improvements in patient outcomes.

Tuned bracing

Aidan, who has a milder form of diplegic (affecting the legs) CP, rides a bike to his suburban Chicago high school, even in the winter. He doesn’t let snow or rain alter his plans and wears ankle foot orthoses (AFOs) on both legs when he’s on his bike and in school. “If I’m not at home I’m wearing them. If I didn’t wear braces, I wouldn’t



have muscle control in my ankles. I wouldn’t be able to walk long distances,” said Aidan.

Aidan’s active lifestyle makes traditional braces a challenge. His mom, Ann, said Aidan would break braces frequently as a child while receiving care at another hospital. After Aidan was 5, Ann felt his care wasn’t showing progress. The family found the care they were looking for at Shriners Hospitals for Children — Chicago, where Aidan has received a series of customized – or tuned – AFOs throughout a large growth spurt. “The Shriners Hospitals team really listens to Aidan talk about the expectations he has because he is highly active among kids that wear braces,” said Ann.

Aidan’s braces are fitted by Nancy Scullion, PT, MPT, PCS, a senior physical therapist who has been treating children with CP at Shriners Hospitals for more than two decades.



Nancy Scullion, PT, MPT, PCS

Scullion is researching the benefits of tuned bracing in children with CP who may have atypical gait patterns or challenges with standard brace prescriptions.

“Typical bracing forces the foot to stay in a ‘neutral’ alignment while sacrificing range of motion from other structures that support the foot, ankle and knee joints,” Scullion said. “Tuned orthotics accept range of motion limitations at the ankle but accommodate and improve ground reaction forces at the knee and hip.”

In an initial small study funded by Shriners Hospitals, researchers will conduct instrumented three-dimensional gait analysis in the motion analysis center on patients wearing their traditional AFOs. Then, they will receive a customized, tuned brace to use for one month, after which a second gait analysis will be conducted. Researchers hope the customized, tuned AFO will show a more normalized walking pattern. Based on early results, Scullion expects

Cerebral Palsy Treatments at Shriners Hospitals

Shriners Hospitals for Children offers a comprehensive range of treatments for children with CP, available at most of our orthopaedic locations, including:

- Orthotic and other assistive devices to help maintain body alignment and provide stability in walking
- Serial casting and Botox injections to relax muscle tone and facilitate needed stretching
- Appropriate wheelchairs when patients need them
- Physical and occupational therapy
- Various orthopaedic and neurosurgical interventions

further benefits: “Tuned bracing can improve joint mechanics in the knees during walking; a frequent area of dysfunction in children with diplegic CP. Also, custom bracing can increase step and stride lengths in ambulatory children with CP. Additionally, tuned-brace wearers have reported improved standing balance compared to bare-foot or traditional bracing.”

SEMLS

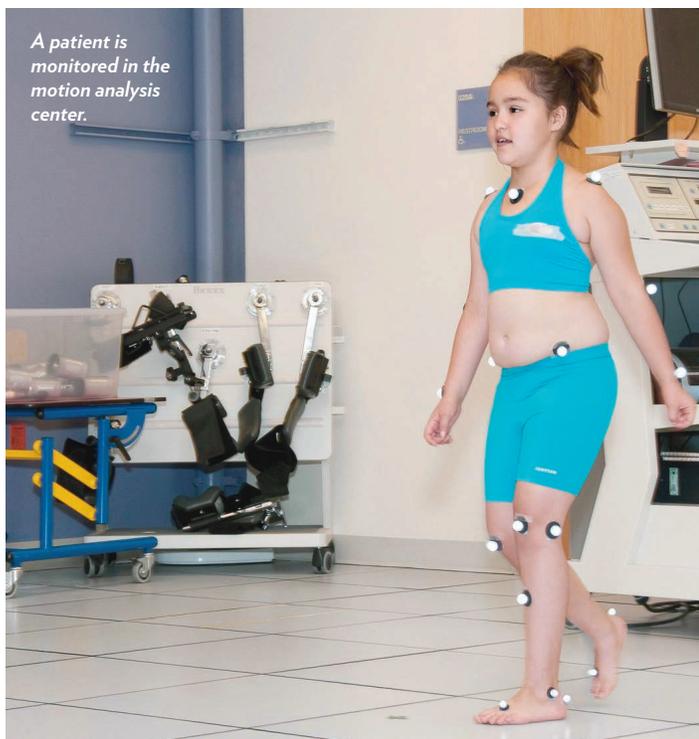
Patients with CP may require multiple surgical procedures to correct all their gait deviations (walking and standing). Prior to the use of computerized motion analysis, a series of single-level surgeries was the standard of care for these children. The frequent surgeries were stressful for the patients and families, and often, the outcomes were less than optimal due to the inability to quantify and objectively evaluate the child’s multilevel gait abnormalities.

Today, gait deviations are often corrected with one surgery, known as single event multilevel surgery (SEMLS), which is now considered to be the standard of care for improving gait and function in ambulatory children with CP. Jane Wick, perioperative nurse at Shriners Hospitals for Children — Portland, explains the advantages of this procedure: “The benefits are immense. SEMLS includes a single anesthetic, less casting, earlier mobilization, faster recovery and a shorter rehabilitative period.”

Follow-up examination and gait analysis allow the members of the clinical team to evaluate the functional outcomes of SEMLS and provide a plan for maintenance or continued improvement, which may include continued physical or occupational therapy or bracing. “The largest benefit of SEMLS is increasing both the functionality and quality of life for our patients with cerebral palsy,” said Wick.

A designated center

Shriners Hospitals for Children takes pride in offering multidisciplinary care in one location, making obtaining complete and quality



care for their children much easier for parents and guardians.

Our Northern California location has established the Cerebral Palsy Center of Excellence for its patients with CP. Here, patients benefit from a comprehensive care program including motion analysis, spasticity management, complex surgical procedures, integrated orthotic management and rehabilitation. Patients also benefit from clinical trials and research led by physicians and scientists determined to improve outcomes for this patient population.

For example, many children with CP may develop hip dysplasia, in which the socket of the hip joint doesn’t fully cover the ball portion of the upper thighbone, so the hip joint can become partially or completely dislocated. Hip dysplasia limits range of motion and is a common cause of pain for these patients. Surgery can help restore mobility and prevent pain later in life. “Earlier surgeries are more successful and can eliminate the need for complex surgery typically used in treating those diagnosed with hip dysplasia as teens,” said Dr. Davids. “Previously, doctors waited until the hip dysplasia was painful before offering treatment, but now we know that earlier diagnosis and treatment leads to better outcomes.”

Shriners Hospitals for Children — Northern California has partnered with other key regional pediatric orthopaedic providers to improve detection, preserve function and reduce pain for patients.

“At Shriners Hospitals for Children, we are committed to maximizing our patients’ function and quality of life through objective analysis and appropriate proactive care,” said Dr. Davids. 🏥

Today, gait deviations are often treated with one surgery, known as SEMLS. This technique is now considered to be the standard of care.



Keeping Summer Safe

How to avoid burn injuries and other summer hazards

“I never knew how horrible burns were, how even the simple act of cleaning the wound causes excruciating pain. We are so grateful for what Shriners Hospitals did for us.”

— REAGAN'S MOM

TAKE YOUR CHILD to a doctor or hospital immediately if he or she is injured in a fire. To learn more about how Shriners Hospitals for Children treats pediatric burns, visit shrinershospitalsforchildren.org/shc/pediatric-burns.

It was supposed to be a fun family outing – a summer camping trip with parents, siblings and cousins piling into the car and heading from their Cincinnati-area home to Columbus, Ohio. But what started as a fun-filled family vacation, ended in injury.

‘It all happened in a flash’

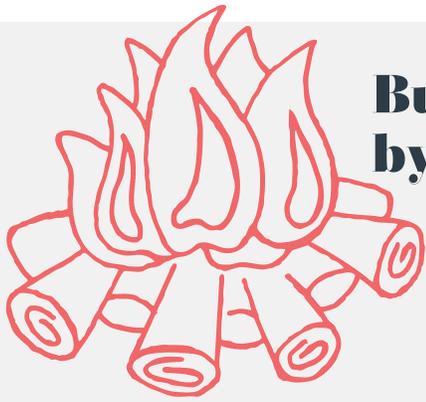
After a dinner of hot dogs and s’mores cooked over a campfire, the happy crew played until bedtime, then headed to their tents for the night. But in the increasing darkness, it was difficult to see the metal fire ring encircling the smoldering hot coals. Six-year-old Reagan stumbled and fell into the ring and onto the embers, sustaining second- and third-degree burns on the backs of both legs.

Her father, Ryan, grabbed her and took her straight to the nearest local hospital. “It all happened in a flash,” he recalled later. After initial treatment, the nurse asked where they would like to take Reagan for continuing care. Reagan’s mom, Erin, immediately requested Shriners Hospitals for Children — Cincinnati; she had a friend



Reagan is back to her normal routine after healing from burns to both legs.





Burn Injuries by the Numbers

24%

of all burn injuries occur in children under the age of 15.¹

Younger children are more likely to sustain injuries from scald burns that are **caused by hot liquids or steam**, while older children are more likely to sustain injuries from flame burns that are caused by **direct contact with fire**.²

Every day, over **300** children ages 0 to 19 are treated in emergency rooms for burn-related injuries.²



Unintentional fire or burn injuries were the **5th** leading cause of injury deaths in the United States in 2015 for children age **1-4**, and the **3rd** for those age **5-9**.¹

¹ https://ameriburn.org/wp-content/uploads/2017/12/nbaw-factsheet_121417-1.pdf

² <https://www.cdc.gov/safecild/burns/index.html>

whose daughter had been treated for a coffee scald and knew it was the best destination for pediatric burns. They had an appointment two days later.

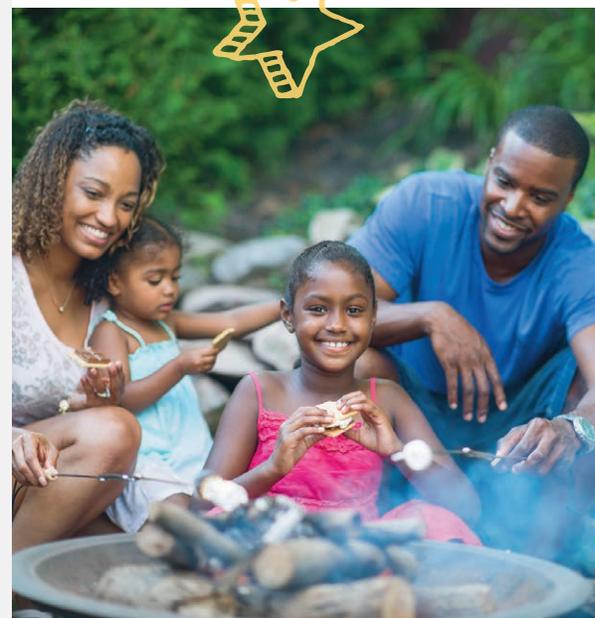
Fortunately, Reagan's injuries were relatively mild and the family only had to make a few visits over a two-week period.

"With four children, we have had bumps, bruises and even stitches, but we never experienced anything like we did with Reagan's accident," Erin said. "I never knew how horrible burns were, how even the simple act of cleaning the wound causes excruciating pain. We are so grateful for what Shriners Hospitals did for us."

Fire safety, simplified

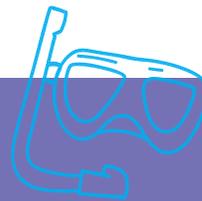
Accidents can happen to anyone. Reagan is proof. Her dad is a firefighter, and she and the other children were well versed in fire safety rules. While campfires are an all-too-common cause of burn injuries in children, there are many other fire-related risks in the summertime. Fortunately, there are simple precautions you can take to avoid burns.

- Teach kids to never play with matches, gasoline, lighter fluid or lighters. Make a habit of placing these items up and away from young children.
- Do not leave children unattended near grills, campfires, fire pits or bonfires. Always have a bucket of water or fire extinguisher nearby whenever there is a burning fire.
- While home fireworks can seem fun, for safety's sake, it's best not to use them. >>



The extreme temperature of even a simple sparkler can lead to direct, deep-boring contact burns when touched or stepped on, extensive burns when clothing or hair ignites, and eye injuries when little hot flecks fly off the tip into the unprotected eye.

More Safety Tips



IN AND NEAR WATER

- Teach children to never swim alone or go near water without an adult present.
- Give children your undivided attention when they are swimming or are near any body of water.
- Always jump in feet-first to check the depth before diving into any body of water.
- Never dive in the shallow end of a pool or into above-ground pools.
- Always have your children wear a Coast Guard approved, properly-fitted life jacket while on a boat, around an open body of water or when participating in water sports.

AT PARKS AND PLAYGROUNDS

- Take your children to playgrounds with shock-absorbing surfaces under the equipment.
- Teach kids to go down the slide feet-first, one child at a time.
- Remind children to swing sitting down. Encourage them to wait until the swing stops before getting off.
- Make sure kids always wear their helmets when riding their bikes or scooters.
- Make sure kids wear shoes to protect feet from cuts, scrapes and splinters, and sunscreen to protect from sunburns and harmful ultra-violet rays.



Leave fireworks to the pros

Colleen M. Ryan, M.D., of Shriners Hospitals for Children – Boston, has important advice about why we should leave fireworks to the pros:

Summertime conjures up memories of backyard barbecues, trips to the beach and watching fireworks. But for dozens of families, these occasions are a reminder of something else entirely: panicked 911 calls, tearful trips to the hospital, and long, painful recoveries from burns sustained by mishandling amateur fireworks. The injuries caused by these products can leave physical and mental scars requiring years of treatment.

At the Shriners Hospitals for Children locations that specialize in burn injuries, we treat children with burns ranging from small injuries that can be treated on an outpatient basis to catastrophic, life-threatening injuries. The pace often picks up during the summer, especially around the Fourth of July, when kids are around more fire hazards, including fireworks.

In Massachusetts, for example, the Office of the State Fire

Marshal reports that 38% of fireworks-related burn injuries reported by hospitals from 2010 to 2019 were to children under age 18. Almost 24% involved children under age 10. These statistics are reflected around the country.

There are no “safe” fireworks. Most people do not realize that sparklers can burn at 1,200 degrees Fahrenheit or higher. The extreme temperature of even this simple firework can lead to direct, deep-boring contact burns when touched or stepped on, extensive burns when clothing or hair ignites, and eye injuries when little hot flecks fly off the tip into the unprotected eye. As parents, we go to great lengths to protect our children from dangers with

everyday things like car seats and bicycle helmets. Fireworks safety should be a basic component of child-safety parenting practices.

Our goal at Shriners Hospitals for Children is always to keep kids safe. Our children look to us to be the example. Let’s lead by example this summer and leave the fireworks to the professionals. 🇺🇸



Colleen M. Ryan, M.D.

champions IN HEALING

A FAMILY-CENTERED APPROACH TO COMPASSIONATE CARE

CAMPS OF CONFIDENCE

Programs offered by Shriners Hospitals for Children build positive perspectives

Self-assurance. Bravery. Perseverance. When you have these things, you can believe in yourself and in your dreams – and do amazing things.

Consequently, supporting and building patients' self-esteem is part of the work and mission of Shriners Hospitals for Children.

One of the ways Shriners Hospitals does this is through camps, which may be held on-site at the hospitals or in the local communities we serve. They offer activities and experiences ranging from therapeutic horseback riding to skiing adventures. Some camps are designed to encourage patients with specific challenges or conditions, such as hand deficiencies, burns and spinal cord injuries, while others are for a wider range of patients. Like all services and programs at Shriners Hospitals for Children, camp programs are provided regardless of the families' ability to pay.

While this year's programs may be adjusted to fit the "new normal" of a world with coronavirus, we are proud of the experiences they've provided to countless patients and look forward to the memories yet to be created.

Here are just some of the incredible camp programs Shriners Hospitals offers. >>

Participating in camp activities like horseback riding can help promote self-esteem.



At Camp Smile, Jonah receives therapies and spends time with other kids who have similar challenges.

Camp Smile

Jonah, 7, was born with Pierre Robin Syndrome, a condition in which the jaw is very recessed, the tongue is farther back, sometimes blocking the airway, and there is an opening in the mouth known as cleft palate. After spending time in the NICU and undergoing corrective surgeries at another hospital, Jonah also had velopharyngeal insufficiency (VPI), where his soft palate didn't quite close to separate his oral and nasal cavities. It affected the way he learned to speak.

Jonah's surgeon recommended the family go to Shriners Hospitals for Children — Chicago and be seen by the cleft team. In this specialized program, families see up to 12 specialists in a single visit. Jonah received care from a surgical and follow-up team for several years. Speech Language Pathologist Sarah Richards explained his speech difficulty in simple terms: "Jonah learned to make speech sounds incorrectly to accommodate his VPI." He receives speech therapy at school and home.

Jonah also received intensive therapy at Camp Smile, a program hosted by the Chicago Shriners

Hospital designed for patients ages 5 to 13 who are diagnosed with cleft lip/palate and/or craniofacial differences. The camp uses a theater theme where speech therapists and psychologists help patients improve speech and self-confidence skills outside of direct therapy.

During the camp, Jonah's self-confidence also improved. "It was really good for him to be exposed to other kids who have challenges similar to him," Jennifer said. "He also opens up easily and talks about his feelings in a therapy type environment, so the psychology piece of the camp was great for him."

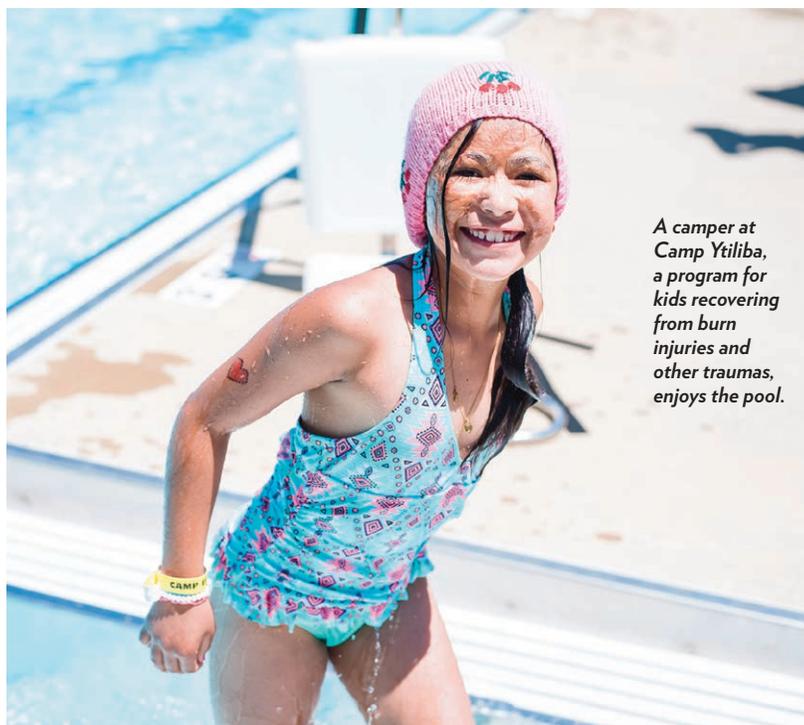
Camp Ytiliba

For 30 years, Shriners Hospitals for Children — Cincinnati has hosted a special weeklong overnight camp for its patients with burns and other traumas or disorders.

Camp Ytiliba (pronounced ya-TIL-eh-ba, the name is "ability" spelled backward and was created by the campers years ago), gives kids ages 9 to 16 a chance to be around others who understand their experience, to make new friends, and to have fun doing things like horseback riding, swimming, fishing and zip lining. Camp Ytiliba, which is held at a local YMCA camp, is designed to build self-esteem and confidence, giving the campers a time when they don't need to be concerned about appearance, scrutiny or bullying by others.

Lauren is a junior counselor who spent three years at Camp Ytiliba. Lauren sustained burns over 40% of her body at age 6. She is now a graduate of the University of Cincinnati. "Kids might be missing fingers or toes, but no one makes fun; they aren't out of

Camp Ytiliba gives kids ages 9 to 16 a chance to be around others who understand their experience.



A camper at Camp Ytiliba, a program for kids recovering from burn injuries and other traumas, enjoys the pool.



During Hand Camp, patients have the opportunity to go horseback riding and try archery, rock wall climbing and fishing.

place,” said Lauren, explaining why she volunteered. “I love seeing them do things they might otherwise not be able to do. One year, a girl with no fingers climbed the rock wall; another who has lost both arms was able to ride a horse. People cheered. It’s rewarding for me to be a part of that.”

Camp Un-Limb-ited

Daniela’s mother will never forget the first year of Un-Limb-ited camp. When she picked her daughter up from the airport, Daniela told her mother the experience was the first time in her life she was able to be herself.

Daniela, who was born with fibula hemimelia, had her right leg amputated below the knee at Shriners Hospitals for Children — Salt Lake City when she was 9 months old. Daniela also had several surgeries and physical therapy over the years at the hospital, and received several prosthetic legs.

The hospital-related experience that had the most impact on her was attending the annual summer and winter Un-Limb-ited camps, which are open to teenage Shriners Hospitals patients who have a limb difference. In the summer version, participants traverse through the Utah wilderness on a river trip, and in the winter session, campers spend the week on a mountain in Park City, Utah, learning to ski and snowboard.

“Every year was memorable,” Daniela said, “but since that first time, I definitely enjoyed being myself and not having to hide. I didn’t have to worry about judgment or stares. I’m very grateful to Shriners Hospitals for giving me the chance to accept and love myself.”

Hand Camp

Hand Camp, a program of Shriners Hospitals for Children — St. Louis, is one of only a few of its kind in the nation. The weekend retreat, for children ages 6 to 12 with hand or upper limb differences and their families, is a place for attendees to meet others facing the same challenges and participate in all the fun activities that camp offers.

The camp is staffed by multiple hospital departments, including occupational therapy (which also organizes the program), recreational therapy/child life, nursing and care management. Many of the activities are run by YMCA camp counselors at the YMCA Camp Lakewood in Potosi, Missouri.

During Hand Camp, patients have the opportunity to go horseback riding and try archery, rock wall climbing and fishing, as well as take part in team-building games and learn from older patients who are junior counselors. Camp also offers special group meetings for parents and siblings for support, learning and sharing.

The difference these programs make in the lives of our patients can be stunning. 🧡

 **PLEASE CHECK** for updated information about this year’s camps at shrinershospitalsforchildren.org.



Keeley Swete provides music therapy to patients at the Portland Shriners Hospital.

Music Makes a Difference

Music programs at Shriners Hospitals can bring a smile, boost confidence and even ease patients' fears

Music therapy is used to address patients' ancillary goals such as socialization, communication and impulse control.

Music can make a tremendous difference in patients' recoveries. Shriners Hospitals for Children offer a variety of musical opportunities, including music therapy programs. Here are two examples of the power of music within our hospitals.

Promoting healing, one patient at a time

The music therapy program at Shriners Hospitals for Children — Portland is conducted by Keeley Swete under the direction of the hospital's child life specialists. Swete is a visiting consultant and owner of Singing Tree Music Therapy. She has been a regular visitor to the hospital's inpatient unit for the past four years and conducts music therapy sessions with our patients twice a week. Every session is tailored to fit each patient's needs and addresses their long-term goals.

Music therapy can be beneficial during and after medical procedures, and may be used to help patients with pain management, sleep issues, agitation or disorientation. Music therapy is also used to address patients' ancillary goals such as socialization, communication and impulse control. In addition, it provides an opportunity for self-expression and can boost self-confidence.

"Our music therapist, Keeley, has become a special part of the child life and patient care team," said Cindy Millard, certified child life specialist at the Portland Shriners Hospital. "She has taught us that music is a universal language that resonates with our patients of various abilities and ages; that music is therapeutic. Patients with limited verbal skills are able to connect with her in amazing ways. There are several patients who ask for Keeley every time they are admitted to the inpatient unit."

+Online Exclusive

Our teams are there to help not only the families we serve, but also families outside of our care. Many of our locations have created educational videos to assist during the challenging time of the coronavirus pandemic. Visit [myleadersincare.com/support-at-home](https://www.myleadersincare.com/support-at-home) to view these videos.



Earning applause from patients and staff

The four strings of the Hawaiian ‘ukulele possess a magical ability to elicit a smile from visitors from around the world. Be it through a pluck or a strum, the notes produced by this iconic instrument have the ability to soothe, invigorate and heal.

At Shriners Hospitals for Children – Honolulu, we recognize the importance of the ‘ukulele, not only to our local island culture, but also to our patients’ healing, and we have incorporated the instrument into several initiatives.

Our ‘ukulele program is a coordinated effort between the hospital and various local musicians who volunteer weekly to help make our patients smile through the power of music.

“It is one of the most rewarding things I’ve ever done in my life. To see the joy that music brings to the children is the ultimate reward,” said instructor Zanuck Lindsey, a member of the ‘Ukulele Guild of Hawai‘i.

The majority of volunteers are musicians with local organizations such as the ‘Ukulele Guild of Hawai‘i and Make ‘Em Smile, but other entertainers also get involved. In the past, we’ve had a few break-dancers and even a puppeteer lend their talents to the program.

“The musicians who play ‘ukulele have been great role models for our patients, and they have all expressed great joy in teaching and engaging with our patients,” said

Recreation Therapy Manager Helene Freni-Rogers, noting that Make ‘Em Smile recently donated several new ‘ukulele to the hospital so that patients can practice on their own time.

“We have a handful of teens who are learning how to play. On any given afternoon, you can see and hear them jamming in the rec therapy area,” Freni-Rogers added.

“This is the first time I’ve learned how to play an instrument,” said an 18-year-old patient. “When I play the ‘ukulele, I stop thinking about my pain.”

The program encourages appreciation for music and builds patients’ confidence and interpersonal skills, which can be seen when patients perform – with beaming smiles – at special events, including our annual May Day program and tea parties hosted by the Ladies’ Oriental Shrine of North America.

“Music is therapeutic and is definitely a part of their overall healing process,” Freni-Rogers said. “Many patients return home with a newfound interest and love for the ‘ukulele instrument and the love and joy that can be shared and gained from its music.” 🎵

Our ‘ukulele program is a coordinated effort between the hospital and various local musicians who volunteer on a weekly basis to help make our patients smile through the power of music.

Patients at the Honolulu Shriners Hospital have the unique opportunity to learn the ‘ukulele.



Talking to Kids About Their Medical Care

An age-by-age guide

By Lydia Barhight, Ph.D.

Psychologist, Shriners Hospitals for Children — Chicago

Discussions around medical care can be sensitive and emotional, especially when kids are facing a new illness or injury. Parents might wonder how to tell a young child that he will be having surgery. A teenager with a new spinal cord injury might ask her parents if she'll be able to walk again.

There's no "right" or "wrong" way to approach these conversations; however, it can be helpful to think about your child's age and developmental level. Here is an age-by-age guide to having these discussions.

Very young children (0-2) and preschoolers (3-5)

Even very young children pick up on the emotions, behaviors and language of adults around them. Showing a full range of emotions is normal and healthy, but it helps to be aware of the cues that you are sending.

- Use simple, direct language. Tell them what to expect during doctor's visits and treatments.
- For older preschoolers, share simple facts such as the name of their medical condition, and help them learn the terminology about their care. Be honest, but filter out what is not necessary or too complex.
- Young children are comforted by routines. Keep things consistent when you can.

Middle childhood (6-12)

Some school-age children are curious about their medical condition. Others might not even think about it on a daily basis. It's important to meet children where they are and follow their lead.

- Talk to children about how to answer questions they might get from peers. Planning ahead and coming up with a script can give them confidence to answer difficult questions.
- Seek out stories of others. It can be powerful for children to know about others who have similar conditions.
- Continue to be honest. Providing inaccurate information to make a child feel better can have lasting consequences.



- Let them know that it is good for them to ask questions or share their feelings. Explain that sometimes, things are just hard, and remove the pressure to find the "bright side."

Teenagers and young adults (13-18)

It's typical for teenagers to give great weight to peer relationships. So it's particularly important to have discussions with teens about changes in appearance, physical differences and self-esteem.

- Discuss how their injury or condition might affect their daily activities, such as sports, school activities and spending time with friends.
- Give direct information about their treatment, procedures or diagnosis. This age group is typically better able to understand more complex information about their medical care.
- Consider having them keep a journal for questions that might pop up when they're at home and bring them to medical appointments.
- If they don't want to talk at a certain time, let them know that they can always come back to you later.
- Lead by example and model healthy coping, such as exercising, socializing and getting good sleep. 🧘



Lydia Barhight, Ph.D.

+For More Advice

Every child has his or her own needs, depending on cognitive level, personality, strengths and weaknesses. Never hesitate to ask your health care team for individualized support, visit [apa.org/helpcenter/talking-to-children](https://www.apa.org/helpcenter/talking-to-children).

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EVENTS, NEWS AND INSPIRATION FROM THE SHRINERS COMMUNITY

Child life specialists at Shriners Hospitals for Children — Portland are focused on reducing the stresses associated with staying in the hospital and teaching patients coping skills through opportunities to play, learn and interact with others in an emotionally and socially safe environment. To help accomplish these goals, the Portland Shriners Hospitals' child life specialists began working with Children's Healing Art Project (CHAP) in 2018.

CHAP is a Portland-based organization that brings the healing power of art to children and families facing medical challenges. Once a week, volunteers from CHAP visit our patients, bringing unique supplies and materials to spark creativity and allow patients to express themselves.

"CHAP is able to modify the activities and tools to fit the ability of each patient," said Susan Gallegos, child life specialist at the Portland Shriners Hospital. "They have specific paint brushes to >>

Carleigh, a patient of our Portland hospital, creates a sculpture of one of her favorite characters.

BRINGING ART TO LIFE

CHAP program gives young artists the tools they need to be creative



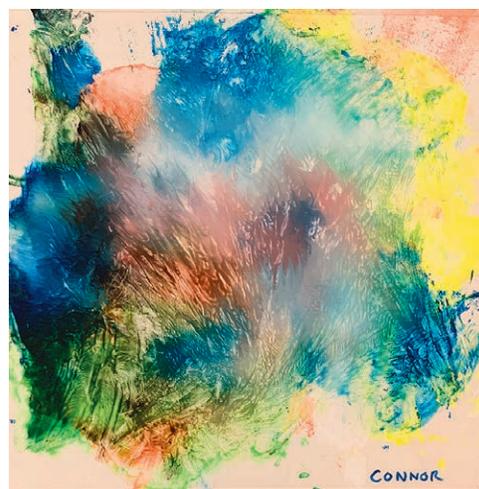
Connor creates a finger-painting using special materials.

use with patients who have limited mobility in their hands and arms. Or, if a child is experiencing sensory issues, CHAP is able to modify activities to ensure the child is comfortable participating.”

For example, Connor, a patient undergoing halo traction treatment at the hospital, is very uncomfortable with substances on his hands. When CHAP representatives proposed the idea of finger-painting, they realized they needed to make some adjustments for Connor. By wrapping a plastic covering over the paper and paint, Connor was able to participate in the activity and push and move the paint through the plastic until he was happy with his creation, without discomfort.

Another patient, Carleigh, who also underwent halo traction, sculpted a replica of Max (the dog in the Dr. Seuss story *How the Grinch Stole Christmas*) during a CHAP session. Carleigh has had a stuffed toy Max since she was born, which inspired her choice. She had a great time in the art session.

“The activities that CHAP offers to our patients are like mental medicine,” said Cindy Millard, child life specialist at the Portland Shriners Hospital. “It distracts them from being in the hospital and helps them heal through play.”



Collaborating for Kids

Shriners Hospitals for Children and Georgia Tech join forces to improve lives

To help young people struggling with conditions such as cerebral palsy, spinal cord injury, clubfoot, scoliosis and osteogenesis imperfecta, Shriners Hospitals for Children and the Georgia Institute of Technology have launched an ambitious collaborative research effort. Their work includes the development of devices to facilitate limb movement and function.

An ambitious affiliation

The new research affiliation brings together the clinical, surgical and scientific expertise of Shriners Hospitals for Children physicians and researchers with Georgia Tech’s expertise in biomedical engineering, robotics and device development. The effort also will leverage the two organizations’ work in big data and artificial intelligence tools for personalized medicine, according to Marc Lalande, Ph.D., vice president of research programs for Shriners Hospitals for Children.

Remarkable robotics

Several joint projects already are underway. Jaydev Desai, professor in the Wallace H. Coulter Department of Biomedical Engineering (BME) at Georgia Tech and Emory University, is working with Scott Kozin, M.D., chief of staff and hand surgeon at Shriners Hospitals for Children — Philadelphia, on a wearable, customized, robotic exoskeleton with voice recognition for kids with cervical spine injury.

“This is a patient-specific system for kids with spinal cord injury,” explained Desai, who is director of the Georgia Center for Medical Robotics and associate director of Georgia Tech’s Institute for

Robotics and Intelligent Machines. “The system is designed to translate voice commands into actions, meaning the exoskeleton will conform to the proper shape and posture of the fingers. The idea is to enhance the child’s ability to perform the activities of daily life.”

Additionally, Aaron Young, assistant professor in the Woodruff School of Mechanical Engineering at Georgia Tech, is working with David Westberry, M.D., pediatric orthopaedic surgeon at Shriners Hospitals for Children — Greenville, on a smart robotic exoskeleton designed to address excessive knee flexion (crouch gait). The condition is common in patients with cerebral palsy and can lead to permanent joint deformity if untreated, as well as reduced independence and mobility.

“Our lab has piloted multiple pediatric projects, but this project represents a quantum leap, taking our work to the next level, in a real-world pediatric care setting. Shriners Hospitals for Children is a perfect fit for us,” said Dongmei Wang, professor of BME at Georgia Tech, where she is director of the Biomedical Informatics and Bioimaging (Bio-MIB) Lab.



Aaron Young, Georgia Tech assistant professor of mechanical engineering, and graduate researcher Pooja Moolchandani inspect a pediatric knee exoskeleton.

PHOTO: ROB FELT, GEORGIA TECH

CELEBRATING A HISTORIC MOMENT

NAME: BOBBI JO

TREATED FOR:
CEREBRAL PALSY

LOCATION: SHRINERS
HOSPITALS FOR
CHILDREN – ST. LOUIS



At a festival in Evansville, Indiana, in 1970, a Shriner helped a young girl who was using wooden crutches. “(He) saw I was having difficulty, so he picked me up and carried me from ride to ride,” Bobbi Jo remembers. That act of kindness was captured by a newspaper photographer. Shriners call the image the “Editorial Without Words” because it so clearly captures the bond between members of Shriners International fraternity and Shriners Hospitals for Children, the health care system they support as their official philanthropy. The Editorial Without Words is the inspiration for the Shriners Hospitals for Children logo and for statues that stand around the world, especially in front of Shriners locations. And this year, we celebrate its 50th anniversary.

“Don’t put limitations on yourself. You may have to improvise and do things differently, but that doesn’t mean you can’t.”
– Bobbi Jo

Bobbi Jo says the treatment she received at Shriners Hospitals for Children made it possible for her to move around without depending on a wheelchair.

In spite of her condition, Bobbi Jo said, she was able to attend college. “It was the first time I was away from home,” she said. “I realized that I could live on my own.”

The Editorial Without Words opened doors for Bobbi Jo. “I never dreamed that I would be traveling, speaking and telling my story,” she said.

Bobbi Jo, now in her 50s, enjoys reading and relaxing with adult coloring books, when she isn’t traveling on behalf of Shriners Hospitals for Children. Her next project: writing a book about her life.

Bobbi Jo, who oversees the prayer ministry at her church, has a message (paraphrased from Psalm 139:1-18; Ephesians 3:20) for others going through challenges: “No matter who you are or what you are going through, God wants to take you on the most amazing journey, weaving together the most beautiful story of you to make a difference in this world – a difference only you can make – if you will let Him!”



Bobbi Jo,
today

LEADERS IN care

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In This Together

Shriners Healthcare for Children — Twin Cities has a message for patients: We may be distant, but we're not apart. Their photo message is one that rings true throughout the Shriners Hospitals for Children system.

Amid the stress and uncertainty during the COVID-19 health care crisis, Shriners Hospitals for Children has been working hard to provide a bright spot of joy – along with important health information – to the world via social media. See some of our #SHCBrightSpot highlights at myleadersincare.com.

+ Online Exclusive

In response to the COVID-19 pandemic, Shriners Hospitals has shown its resilience by using innovation to adapt care, including with Fast Track Video Visits. Learn more at myleadersincare.com/fast-track-telehealth.

LOCATIONS



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

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