



# Partners in Caring

FROM CONNECTICUT CHILDREN'S MEDICAL CENTER FOUNDATION



*Ada Wilson, 15, reacts to Virtual Reality (VR) technology now available at Connecticut Children's. VR is used both as a coping mechanism for pain and as a distraction for children undergoing certain medical procedures.*

## Virtual Reality a New Reality AT CONNECTICUT CHILDREN'S

When Ada Wilson undergoes hospitalization or lengthy follow-up visits at Connecticut Children's, she can escape for a while into virtual reality with games like "Pebbles the Penguin," "Asteroid Miner" and "Mindfulness Meditation."

Ada, the 15-year-old daughter of Julie and Markes Wilson of Windsor, has been hospitalized numerous times since 2015 for complications related to cystic fibrosis—a progressive, hereditary disease that causes persistent lung infections—and has found virtual reality (VR) games to be a great way to take her mind off blood draws and other exams—and hospitalization overall.

"I've tried a lot of distractions for procedures, but these are really good," said Ada, watching a game of "Pebbles the Penguin" unfold through a VR headset. "These goggles are super easy to use. You can choose longer, lively games or shorter games. For a procedure, it can be very helpful."

**"SOMETIMES PATIENTS JUST FEEL LIKE THEY NEED TO ESCAPE THE ROOM. VR IS ANOTHER TOOL IN OUR TOOLBOX FOR HELPING KIDS COPE."**

~ Lauren Smizer, child life specialist

"She uses it while she's here on precautions," her mother, Julie, said. "It helps her feel like she's somewhere else."

Ada, who underwent a resection of her lower right lung in October 2015 and may eventually undergo a double-lung transplant, was introduced to the VR software earlier this year by Lauren Smizer, a child life specialist at Connecticut Children's.

"Ada got so comfortable with the goggles, she decided to use them for distraction," said Lauren, who met Ada during one of her admissions in February 2017. "VR is huge in children's hospitals right now," she added. "Sometimes patients just feel like they need to escape the room. VR is another tool in our toolbox for helping kids cope."

### Donor Gift Makes VR Possible

Indeed, no one enjoys being stuck with a needle, let alone having someone set a broken arm or touch a serious laceration. But thanks to a generous gift from Paula Sisti and her children, Connecticut Children's can now offer patients, like Ada, an option to make all of those discomforts easier and provide a distraction to look forward to.

*(continued on page 2)*

## Virtual Reality a New Reality (continued from page 1)

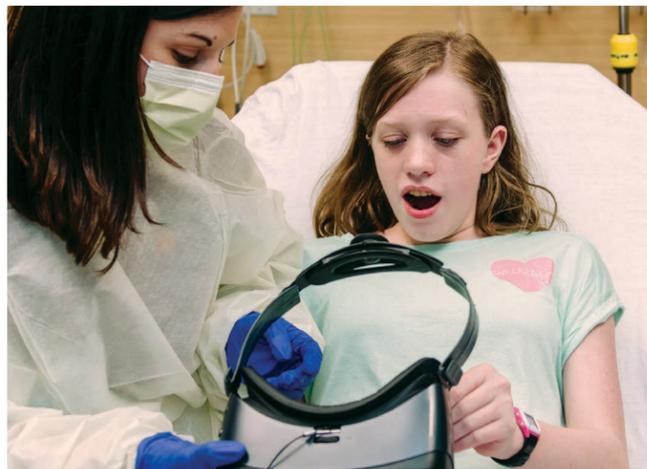
"It's exciting to see VR being used by children across the hospital for managing pain and to distract them in times of high stress," said William Zempsey, MD, Division Head of Pain & Palliative Care at Connecticut Children's. "So far, hundreds of kids have used the goggles to ease their pain, relax before a procedure or be distracted during a procedure. We currently have 10 headsets and are planning to add a number of cardboard goggles that would let us reach many more kids."

The VR equipment, bought with the Sisti family's support, consists of a set of goggles, a smartphone-like device that holds the software and has a screen on which a game plays, and a hand-held controller. The goggles render the image in 3D, and the software itself is designed to place the child in another world that can be explored by turning the head or eyes.

For example, child life specialists at Connecticut Children's, who administer the VR program, use a meditation app that helps address a child's anxiety. Once the child puts the goggles on, he finds himself on a mountaintop with a nearby waterfall and a field of flowers and butterflies. The child can look up and see the sky or down at the flowers or turn his head to see what's behind him. In conventional games and in movies, the viewer stays motionless and the scene moves, but in VR, it's the opposite: The patient moves and the world stays in place, just as it does in the real world. That's what makes VR so immersive and compelling. And it's why it is so effective in distracting a child.

"Soon, we'll be using VR as part of a biofeedback program that will help young people with chronic pain," Dr. Zempsey said. "For example, kids with chronic headache will have sensors on their scalp and using the VR goggles, they will learn how to relax certain muscles to reduce pain."

"The Sistis' donation was essential to getting this program going," Dr. Zempsey noted. "We wouldn't be where we are without them."



Pictured here with Dr. William Zempsey, Division Head of Pain & Palliative Care (second from left), are Kevin Sisti, with his mother, Paula, and sisters Abigail Sisti and Kristina Wilson. (Not pictured: Samantha Sisti)

## The Gift that Keeps on Giving

The Sistis—Paula and her children, Kevin, Abigail, Kristina and Samantha—made their gift to establish a virtual reality program at Connecticut Children's in memory of Paula's husband, Kevin, who passed away in 2016. Her son, Kevin, had a business interest in film and had experienced what VR could do, so when his father became sick, he wanted to use it.

"My husband had been diagnosed terminally ill with cancer," Paula said, "and my son thought it would be really exciting for my husband to be able to go on a safari, which he wouldn't otherwise be able to do. So, Kevin was able to bring him to a safari through virtual reality. The pleasure watching my husband's face was incredible. The helplessness that you feel when your loved one is in pain is so overwhelming, and to be able to witness that, well, I have no words; I just couldn't believe it. My mother was ill at the same time, and my son brought

the goggles over to my mom's house, and virtually brought her home back in Sicily, to the church where she was married, to the street she was born on, right to the door."

Seeing how much VR helped their family, the Sistis wanted to share its benefits with children. "We want to give the kids something else to focus on," Abigail said. "If we get even one smile, it will be worth it."

For the Wilson family, having VR technology available for Ada and other pediatric patients who will benefit from its use is just one more reason why Connecticut Children's is the right place for their children's care. "We spend a lot of time here, and they do a fabulous job of making it just like home," Ada's mother said.

*Child life specialist Lauren Smizer shows Ada how to use the VR equipment, which was made possible by a gift from the Sisti family.*

**If you would like to support the VR program at Connecticut Children's, please contact the Foundation at 860.837.5700.**

**"SO FAR, HUNDREDS OF KIDS HAVE USED THE GOGGLES TO EASE THEIR PAIN, RELAX BEFORE A PROCEDURE OR BE DISTRACTED DURING A PROCEDURE."**

*~William Zempsey, MD*

## Fairfield County Connections

# Rare Arthritis Won't Sideline Westport Teen

As a soccer player, Madeline Barney never dreamed that a rare form of arthritis would one day try to sideline her game—or her health.

But in September 2018, the 13-year-old Westport resident developed a condition so unusual that it concerned her parents, Caroline and Craig, and eventually brought the Fairfield County family to Connecticut Children's in Hartford for expert care.

## Madeline's Journey

"It started with a rash on her hand," her mother, Caroline, recalled. "Then it left. We thought, 'No big deal.' But then it came back and left again. When it came back a third time, she had a fever, and we took her to the doctor. Her fever spiked to 104 degrees."

"The rash would move all over her body," Caroline explained. "Our pediatrician called Dr. Lawrence Zemel, a rheumatologist at Connecticut Children's, and we were told to bring her in immediately."

At Connecticut Children's, Dr. Zemel diagnosed Madeline with a rare form of arthritis called systemic juvenile idiopathic arthritis or SJIA, which is one of several rheumatic diseases affecting children.

Madeline experienced joint pain and swelling, making tasks like dressing herself or eating difficult.

"The joint pain flared up in different areas, including her ankles, knees and wrists," her father, Craig, recalled. "At its worst, when we went to see Dr. Zemel for the first time, her whole body was achy and she couldn't really walk without help."

Then her condition took an unexpected turn. "She developed MAS—or macrophage activation syndrome—which is a complication of SJIA," Craig explained.

Macrophages are part of the body's natural defense system for fighting infection. But MAS causes the immune system to shift into overdrive, causing life-threatening inflammation.

Madeline was hospitalized at Connecticut Children's for three days in October 2018 and underwent a bone marrow biopsy and many other tests.

"We knew we were in the right place," Caroline said.

## Arthritis and Children

Juvenile arthritis—a term for many autoimmune and inflammatory conditions or pediatric rheumatic diseases that can develop in kids under 16 years of age—affects nearly 300,000 children in the United States.

"About 10 percent of children with juvenile arthritis have the type of arthritis that Madeline has, and only about 10 percent with this rare form of arthritis develop MAS, like she did," said Dr. Zemel, who heads the Division of Rheumatology.

"The typical treatments are anti-inflammatory medications, including nonsteroidals and steroids," Dr. Zemel said. "We also added a newer biologic drug that blocks the cytokines that are active in this condition and are responsible for inflammation."

"This type of arthritis is pretty interruptive," Dr. Zemel noted. "Madeline's a swimmer, she plays soccer, but she couldn't do sports, she couldn't concentrate, she couldn't go to school. But we were very fortunate to see her fairly early. We recognized her condition early, so it didn't get too severe."

## Expert Care Close to Home

"When I was sick, I couldn't do anything," said Madeline, who spent nearly two months last fall sidelined on the couch. "I didn't attempt to leave the house."

Since then, she has been weaned off most of her medications and says she feels a lot better. She is back in school, finishing out her eighth-grade year, and is back on the soccer field, playing the game she loves.

For the Barney family—which includes another daughter, Lucy, 11, and Beacher, a playful goldendoodle—having a world-class children's hospital in Connecticut has been a godsend. And now that there are satellite locations, including offices in Shelton and Stamford, they can take Madeline for follow-up visits with Dr. Zemel with relatively little travel time.

"Our biggest takeaway is that we were confident in the medical care we were getting, and we were also struck by the compassion," Caroline said. "There's something about being at a hospital dedicated to children that makes a big difference."

*To learn about Connecticut Children's rheumatology services or to find the Connecticut Children's location closest to you, please visit [www.connecticutchildrens.org](http://www.connecticutchildrens.org).*



Madeline at a follow-up visit with Dr. Lawrence Zemel in Connecticut Children's Shelton office.

One distinctive feature of the new Infusion Center is a digital environment that not only provides entertainment and distraction during treatment, but also gives the child a sense of control over his or her environment.



## Spotlight on Connecticut Children's

### World-Class Infusion Center Opens in Farmington

You could hear the collective gasp as attendees at the ribbon cutting for Connecticut Children's new Infusion Center entered the facility April 25. That's because there is nothing like this anywhere. It bears little resemblance to a medical facility, looking more like something out of Disneyland.

The new center at 10 Birdseye Road in Farmington is all the more impressive when you compare it to the old infusion space on the Hartford campus, where patients were treated in a 343-square-foot room equipped with six infusion chairs, a space that opened more than 20 years ago with 20 percent of the patient volume.

"The old infusion center was small, crowded and noisy—sensory overload," said Jeffrey Hyams, MD, the Director of the Center for Pediatric Inflammatory Bowel Disease and the holder of The Mandell-Braunstein Family Endowed Chair for Pediatric Inflammatory Bowel Disease. "What we wanted to do with this space is the exact opposite."

Connecticut Children's donors came to the rescue, generously funding the construction of a world-class Infusion Center, which is as whimsical as it is functional.

#### Designed with Kids in Mind

The reception area alone is eye-popping to look at, with nature-inspired colors, textures and shapes and scarcely a straight line or flat surface to be seen. Whether it's the pendant lights that look like they're dew drops or the bas-relief birch forest or the multilayered ceiling, everything is designed to distract,

engage and delight a young eye. It may be the first waiting room that makes you want to wait longer.

Then there is the treatment area, a large space with a circular central desk and treatment rooms around the perimeter. Your eyes are likely to be drawn to the huge, colorful acrylic tree in the center of the room—a tree that glows from within. There are three styles of patient rooms that the kids will get to choose from. One is a tent motif, with kid-sized passages between rooms; the second is a cabin style, with blackout shades and a bed for patients needing lengthy infusions; and the third looks like an Airstream trailer. Each offers a different level of sociability, so patients can choose to interact with other patients or enjoy privacy.

"We really wanted to create a space that varied the patients' experience, so that they can discover something new with every visit, and even look forward to their next appointment," said Karri May, the Manager of Planning, Design and Construction. "There's such attention to detail in the smallest things, I have no doubt patients and their families will notice a different element of adventure with every visit."

#### A Measure of Control

To make the space even more special, each treatment room has a video screen, on which the kids can explore a virtual world. Each child creates a Pathfinder—a character that represents the child in the game. That character moves through several landscapes collecting colored fireflies as it goes, putting each color of firefly into a different jar. Once a jar is full, the child can remove the cover and release that color of firefly.

As the fireflies fly off, the color of the acrylic tree changes to match their color, giving children a measure of control over their infusion environment.

The new Center opened to patients on April 30.

**RIBBON-CUTTING CEREMONY:** Donors, patient families, board members and area dignitaries gathered for a tour and ribbon-cutting ceremony at Connecticut Children's new Infusion Center in Farmington April 25. Among those on hand to celebrate the completion of the awe-inspiring facility were (from left): Jim Shmerling, DHA, FACHE, CEO and President of Connecticut Children's; Infusion Center Steering Committee members Matthew and Christine Bromberg; Chloe Lang, a patient advocate for Connecticut Children's Infusion Center; and Jeffrey Hyams, MD, the Director of the Center for Pediatric Inflammatory Bowel Disease, and the holder of The Mandell-Braunstein Family Endowed Chair for Pediatric Inflammatory Bowel Disease.



### Chloe Lang's New Leading Role in Infusion Therapy

When Connecticut Children's new Infusion Center at 10 Birdseye Road in Farmington had its ceremonial ribbon cutting on April 25, 17-year-old Chloe Lang was there as the patient representative, which is only fitting, because she's been getting regular infusions at Connecticut Children's for five years and is a public advocate for the Infusion Center.

In fact, as part of the new center's opening, she's just made a video about the infusion process to help new patients better understand what it's like from a patient's point of view.

But then, Chloe is pretty comfortable in the spotlight: When she was 10, she was an international television personality, playing the lead character on a wildly popular children's program called "LazyTown." The show, which was filmed in Iceland and shown around the world, revolved around Chloe's character, Stephanie, who comes to live with her uncle in LazyTown and spends her time trying to get her out-of-shape neighbors to live a more active lifestyle.

And the whole time she was filming that show, Chloe was struggling with ulcerative colitis, a debilitating form of inflammatory bowel disease.

#### Chloe's Journey

"It started out as really bad stomachaches," Chloe says, "to the point where I couldn't stand or walk. Sometimes I would be in the middle of a scene and I would just say 'Stop; I can't do this anymore,' and I would sit down and curl up. The director would

say, 'What are you doing? We have a budget, we have to finish on time. Get up and finish your scene.' It went on like that for a while until I finished that season and I went home and started going to all these doctors and trying to figure it out."

"She had two ER visits a week apart," her mother, Tina, says, "and at the second ER visit she actually collapsed. She was down to 79 pounds. Because of the trauma that happened to her body, her hair was falling out in clumps—which was itself traumatic."



Chloe Lang, a patient and accomplished actress, is an advocate for Connecticut Children's Infusion Center.

#### A New Script

Finally, Chloe was referred to Connecticut Children's, where Jeffrey Hyams, MD, the Director of the Center for Pediatric Inflammatory Bowel Disease, diagnosed her with ulcerative colitis and began the process of finding the most effective treatment.

Today, Chloe is a senior in high school, pursuing a very active career singing, dancing and acting. Her music videos are gaining traction on YouTube, she's landing acting jobs in New York City and this fall she will attend Pace University, where she plans to study entertainment management.

That exciting life is made possible, in part, by the infusions she gets regularly at Connecticut Children's. "I'm excited to get my first infusion here," Chloe told those in attendance at the ribbon-cutting ceremony. "I want to bring all my friends here to see it."

To view the video, visit [connecticutchildrensfoundation.org/chloe](http://connecticutchildrensfoundation.org/chloe).



## Our Kids & Causes

### “Tee It Up” with Coach Geno

Hall of Fame Coach Geno Auriemma is “teeing it up” for Connecticut Children’s at the 17th annual “Fore the Kids Charity Golf Tournament” on Monday, June 24.

Tournament proceeds will fund the purchase of a new transport isolette—a self-contained, high-performance transport incubator to be used by Connecticut Children’s Neonatal Intensive Care Unit (NICU). Last year, more than 300 critically ill newborns were transported to Connecticut Children’s from regional hospitals, and this new isolette will enhance the care provided to these patients en route to Connecticut Children’s.

Proceeds from the event will also fund the purchase of a highly specialized spinal surgery table for patients undergoing complex spine surgeries. Orthopedic surgeons can more easily position, rotate and stabilize patients using this highly specialized device, providing positive outcomes to children with spinal issues and deformities.

Learn more at [give.connecticutchildrens.org/geno](http://give.connecticutchildrens.org/geno).

## Gifts From the Heart

### Endowed Chair Honors Neurosurgeons

Friends, colleagues and supporters of the Division of Neurosurgery gathered on March 5 to celebrate the lifetime achievements of Paul Kanev, MD, and install Jonathan Martin, MD, as the inaugural chair holder of **The Paul M. Kanev, MD, Endowed Chair of Pediatric Neurosurgery**.

Former colleagues from as far away as Atlanta attended the event, held at the New Britain Museum of Art, to honor Dr. Kanev, the beloved physician that many affectionately refer to as “Santa Claus’ brother.” Connecticut Children’s staff members shared their fond memories of the talented neurosurgeon and captivated the audience with tales of his dedication and perseverance.

Dr. Kanev took to the podium to candidly share what Connecticut Children’s has meant to him, but more importantly the role his colleagues have played in his career.

Established by two generous, anonymous donors, the Endowed Chair of Pediatric Neurosurgery is the first of its kind at Connecticut Children’s. It will provide Dr. Martin and future Neurosurgery Division Heads funding to address the greatest needs of their division and afford the greatest benefit to their patients.



*Dr. Jonathan Martin (left) was installed as the inaugural chair holder of The Paul M. Kanev, MD, Endowed Chair of Pediatric Neurosurgery, named in honor of Dr. Kanev.*

## Concorso’s Coming to Town

On Sunday, June 23, **Concorso Ferrari & Friends** is returning to West Hartford. Now in its 19th year, Concorso Ferrari & Friends is the signature automobile event for Southern New England, attracting more than 10,000 spectators and car enthusiasts annually while raising awareness and critical support for Connecticut Children’s.

Concorso celebrates all makes and models of Italian automobiles—from vintage Alfa Romeos, Fiats and Lamborghinis to the supercars of Ferrari, Pagani and Maserati. From 10 am to 3 pm, sponsors, car owners and spectators can visit the many unique shops and restaurants on LaSalle Road in West Hartford while viewing the wide array of autos and listening to music and driver interviews featured throughout the day.

The highlight of the event, the Patient Parade, kicks off at 10 am with 40 Connecticut Children’s patients chauffeured from Connecticut Children’s in Farmington to LaSalle Road in West Hartford, where they will receive a rock-star-worthy welcome.

Proceeds from the 2019 event will benefit the Family Support Fund, which covers critical expenses not covered by insurance.

Visit [give.connecticutchildrens.org/concorso](http://give.connecticutchildrens.org/concorso) to learn more.



## Children’s Miracle Network Hospitals

### UConn HuskyTHON Celebrates 20 Years of Giving

When the University of Connecticut’s annual HuskyTHON dance marathon broke the \$1 million mark last year, it seemed like an impossible achievement. However, this year they surpassed that by raising \$1,328,402.19—an incredible 30-percent increase. HuskyTHON is a yearlong effort coordinated by the students at UConn that culminated in the 18-hour dance marathon February 23-24 on the UConn campus.

This outstanding achievement was all the more satisfying for the students because this year marked the 20th anniversary of their first dance marathon, then called the UConn Midnight Marathon, and it brought their overall total



*Connecticut Children’s patient Kiley Sullivan received a red-carpet welcome during HuskyTHON.*

to more than \$6.2 million, all going to support Connecticut Children’s.

More than 3,000 students took part this year, along with 44 Connecticut Children’s patients and their families, who were the center of attention throughout.

### 2019 CONNECTICUT CHAMPION CHILD NAMED

Four-year-old Gavin David has been named the 2019 Children’s Miracle Network Hospitals Connecticut Champion Child.



*Gavin David*

In front of a crowd of local partners who generously support Connecticut Children’s through Children’s Miracle Network Hospitals, Gavin charmed the crowd with his charismatic nature and playful grin during a program held in his honor April 3.

At first glance, it’s hard to believe that Gavin is fighting leukemia and was diagnosed at 2 years and 4 months of age. At the conclusion of his treatment, he will have endured more than 40 months of chemotherapy and nearly 60 days as an inpatient at Connecticut Children’s.

Gavin, who is always excited to see his doctors and nurses, loves pizza and hopes to become a LEGO® builder someday.

### PLAN TO JOIN US!

|   |   |   |  |   |
|---|---|---|--|---|
| <b>May 1-May 31</b><br><b>Costco Campaign</b><br>Brookfield, Enfield, Milford, New Britain, Waterbury | <b>June 10-July 7</b><br><b>Walmart &amp; Sam’s Club Campaign</b><br>All Walmart and Sam’s Club Locations in the Region | <b>Thurs., July 25</b><br><b>Dairy Queen’s Miracle Treat Day</b><br>Participating Locations | <b>Aug. 2-Aug. 4</b><br><b>Ace Hardware Bucket Days</b><br>Participating Locations | <b>Tues., Aug 6</b><br><b>Marriott Root Beer Float Day</b><br>Participating Locations |
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*For more information, please visit [give.connecticutchildrens.org/shop](http://give.connecticutchildrens.org/shop).*

## QTHON Tops \$1 Million Over 8 Years

More than 1,700 students from Quinnipiac University joined forces on the dance floor March 23, raising over \$332,000 for Connecticut Children’s and bringing their eight-year cumulative giving total to more than \$1 million.

The 8th Annual QTHON, a Miracle Network Dance Marathon, surpassed all previous fundraising records in a yearlong effort that culminated in the 10-hour dance marathon to benefit patient care at Connecticut Children’s. The festivities on Quinnipiac’s Mount Carmel campus ended at midnight when the year’s fundraising total of \$332,567.12 was revealed.



*At the end of the evening, Quinnipiac students revealed their fundraising total.*

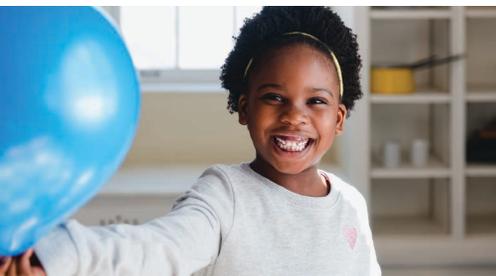


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*Partners in Caring* is a quarterly publication of Connecticut Children's Foundation, highlighting the amazing work that takes place at Connecticut Children's and our generous donors who help make it happen. To be added or removed from our mailing list, please contact [updateinfo@connecticutchildrens.org](mailto:updateinfo@connecticutchildrens.org)



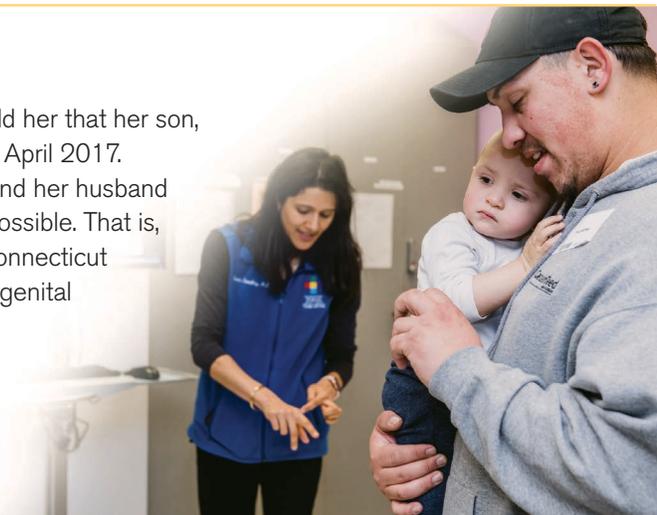
## Greatest Need Children's Fund

At Connecticut Children's, caring for children and their families is what we do best. Last year, more than 108,000 patients from across the region and around the world came to Connecticut Children's for world-class care. Your support of the **Greatest Need Children's Fund** allows us to direct funds to the areas of our mission that provide the greatest impact to our patients. If you would like to help, please call the Foundation at 860.837.5700 or make a gift online at [give.connecticutchildrens.org/partners](http://give.connecticutchildrens.org/partners).

## New Thumb, New Possibilities

Ashley Denison remembers the worry that washed over her when doctors told her that her son, Julian, had no thumb on his left hand just moments after he was delivered in April 2017. "How would he hold a ball, play sports or do anything?" she wondered. She and her husband just wanted their son to be happy, but now they weren't sure that would be possible. That is, until they met with Sonia Chaudry, MD, a pediatric orthopedic surgeon at Connecticut Children's, the only pediatric hand surgeon in Connecticut specializing in congenital hand anomalies and microvascular surgery.

To find out how Dr. Chaudry created a new thumb for Julian, please visit [connecticutchildrensfoundation.org/julian](http://connecticutchildrensfoundation.org/julian).



## CALENDAR OF EVENTS

**Wed., May 22**  
**Birdies & Horsepower**  
Farmington, CT

**Mon., June 10**  
**Manchester Chapter of UNICO Golf Tournament**  
Manchester, CT

**Wed., June 12**  
**Abitz & Angel Memorial Golf Tournament**  
Blackledge Country Club,  
Hebron, CT

**Thurs., June 13**  
**Allied Printing Services Golf Tournament**  
Farmington, CT

**Fri., June 14**  
**Burt Process Golf**  
Lyman Orchards  
Middlefield, CT

**Sat., June 15**  
**Belcan Scramble**  
Grassmere Country Club  
Enfield, CT

**Sun., June 23**  
**Concorso Ferrari & Friends**  
LaSalle Road  
West Hartford, CT

**Mon., June 24**  
**Geno Auriemma's Fore the Kids Charity Golf Tournament**  
West Hartford, CT

**Thurs., June 27**  
**Golf Fore the Kids Jacob Osit Memorial Golf Tournament**  
Hebron, CT

**Fri., June 28**  
**The Hartford Personal Lines Golf Tournament**  
Avon, CT

**Fri., July 12**  
**IBEW Charity Golf Tournament**  
Bristol, CT

**Mon, Aug. 5**  
**Robby Brisco Open Golf Tournament**  
Avon, CT

For more information, please visit [give.connecticutchildrens.org/calendar](http://give.connecticutchildrens.org/calendar).