

STRONG KIDS



UR MEDICINE'S GOLISANO CHILDREN'S HOSPITAL NEWS

2017 VOL. II



Meet the 2017
Miracle Kids

Dear Friends



It is hard to believe that this is my last letter to you as Pediatrician-in-Chief of Golisano Children's Hospital at UR Medicine. I am so proud of what we have achieved together and what you have allowed me the privilege of leaving to the children and families of Rochester and Western NY. It is true we have built one

of the most beautiful and most patient- and family-friendly hospitals for children in the U.S. But we have built so much more!

We have launched divisions of pediatric sleep medicine, pediatric hospitalist medicine, pediatric palliative care, and pediatric allergy-immunology. We have launched the careers of dozens of physician-scientists and academic clinicians with our National Institutes of Health-awarded Fellowship and Junior Faculty research programs. We have sustained the #1 Med-Peds residency program and among the most competitive and sought-after Pediatrics residency programs in the U.S. We have built a clinic that serves the needs of children and families with autism and intellectual disabilities and have co-located child neurology, child psychiatry, and developmental and behavioral pediatrics services. We have vastly reduced the incidence of intravenous line infections, catheter-associated infections, and post-operative infections. We are nationally known for our innovative approaches to scoliosis and craniofacial disorders, and our NICU, PICU, PCICU, cardiology, and cardiothoracic surgery services serve children from Buffalo to Syracuse and beyond.

We are ranked #15 in the country for NIH funding, with unique programs in infections of the immunocompromised host, food allergy, precursor cell biology, childhood anemia, asthma, and lung biology and biochemistry. In the past 11 years, we have named new Division Chiefs in Pediatric Gastroenterology, Developmental & Behavioral Pediatrics, Pediatric Cardiology, Pediatric Orthopedics, Pediatric Palliative Care, Pediatric Plastic Surgery, Pediatric Ophthalmology, Pediatric Otolaryngology, Neonatology, Pediatric Critical Care Medicine, Pediatric Hospitalist Medicine, General Pediatrics, Pediatric Allergy/Immunology, Adolescent Medicine, and, most recently, Pediatric Pulmonology. These people come to Rochester and stay because of our outstanding faculty, staff, and facilities; the dedication of this community to its children and families; and our enviable quality of life and spirit of giving.

I know I can count on all of you to welcome Golisano Children's Hospital's new leader when he or she is named and to help everyone who serves our community's children and families continue to elevate the level of clinical care, research, education, and community service available in Rochester. I am excited for their future and for what my children call "Mom's next adventure" – an adventure that, I hope, will bring me back to the intensive involvement in the neuropharmacology research and national leadership in mentoring that has always been my passion.

Wishing you all the best,

*Nina F. Schor, M.D., Ph.D.
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21st Annual Golisano Children's Hospital Stroll for Strong Kids & 5K Run

Join us on
Saturday,
June 3rd!



Every year, thousands of friends of Golisano Children's Hospital make their way into Genesee Valley Park for the Stroll for Strong Kids Walk and 5K Run. This year, they'll all be swimming — in a manner of speaking! The 21st annual Stroll for Strong Kids will be themed "Under the Sea," and participants are encouraged to dress in their best nautical outfits while they run in the 5K race, walk with family and friends, or both. Abbott's, once again, will be the event's presenting sponsor.

"The children and the families — they're both the reason that we host the stroll, and the reason that it's so successful," said Stephanie Sheets, assistant director of community affairs.

This year's Stroll will be the first since the passing of founder Don McNelly. McNelly, an avid marathon runner who passed away in February at the age of 96, created the event more than two decades ago.

"At the time, we didn't realize what the Stroll would turn into, but today, it's an incredible event," said Scott Rasmussen, Senior Assistant Vice President of Golisano Children's Hospital Advancement. "Don really did help a lot of sick kids over the years, and he took a lot of personal pride in that."

About 11,000 people participated in the Stroll in 2016, making it another record-setting year. This year's Stroll will kick off with the 5K run at 8:30 a.m., with the Stroll beginning at 10:30 a.m. Parking will be available off of Kendrick Road.

Stroll features

- 1.5 mile family-friendly walk around the park
- 5K Run on a USATF Certified 5K Course (\$30 registration fee to participate; \$40 the day of the event)
- Bounce houses, carnival games and other entertainment for the kids
- Many fun activities for the entire family
- Lunch provided for all participants
- Incentives for additional fundraising

To register for the 21st Annual Stroll for Strong Kids visit:
www.urmc.rochester.edu/childrens-hospital/giving/events/stroll.aspx



Miracle Kid

Ian Galek

Christa Galek climbed into the ambulance next to her 20-month-old son, still in a haze at how quickly it had all happened.

“Take him to Rochester!” shouted her mother-in-law.

“He won’t make it to Rochester,” replied a paramedic.

The exchange pulled her violently back to reality, as Christa became fully aware of the seriousness of her son’s condition. Quickly, the doors closed, and the ambulance sped off to the hospital.



A Rapid Onset

Ian Galek had been lethargic throughout most of the past day. He wasn't eating much, and he was napping more often. He'd thrown up the night before. His digestion seemed off.

"He just seemed like a regular sick kid," said Christa, a resident of Savannah, Wayne County, who had watched Ian's three older siblings battle a standard variety of childhood ailments as they grew up.

But after putting Ian to bed earlier that evening, she and her husband Seth went in to check on him. His color had changed. He wasn't responsive; his parents would later learn that he'd gone into shock.

Paramedics took him to Newark-Wayne Community Hospital, where he was stabilized before Mercy Flight brought him to Golisano Children's Hospital. Once in the pediatric intensive care unit (PICU), doctors and nurses worked to keep him alive. They couldn't pinpoint what type of infection was causing his drastic decline, so they began treatment with a heavy dose of antibiotics.

But despite their best efforts, Ian's heart and lungs were failing. He was moved from a standard ventilator to an oscillator, and his condition continued to worsen over the next two days. The last resort was to treat him with extracorporeal membrane oxygenation (ECMO), in which a mechanical device would act as Ian's heart and lungs while, hopefully, his body worked to repair itself.

"They told us at the beginning that ECMO would be the last thing they could do for him," said Christa. "But it seemed like we got there really quickly."

Long Odds

Doctors estimate that those who become sick enough to need ECMO have, at best, a 50 percent chance of survival. But the speed of Ian's decline, coupled with his Down Syndrome — which can lead to additional health concerns — made his odds even longer.

"Given what he was facing, Ian's chances were probably worse than fifty-fifty," said Louis Daugherty, M.D., Associate Professor of Pediatrics and Clinical Care, who treated Ian along with several of his colleagues in the PICU, including Emily Nazarian, M.D., and Heather Reyes, M.D.

Ian's body swelled up to more than twice its normal size, a consequence of the ECMO treatment. Dialysis drew some of the excess water away, but nowhere near enough to bring him back to his regular size.

"He was a size 4 diaper, but they couldn't even fit a size 6 on him," said Christa.

After a week, he developed a skin tear on his arm from the swelling. For any healthy person, the tear would have been negligible.

But blood clots are a major concern for ECMO patients, as they can clog the machinery, so Ian was on a steady dose of blood thinners. This turned a simple cut into a potentially life-threatening emergency.



Ian with his parents, Seth and Christa, and siblings, Cecilia, Elihu, and Lorelei.

Join us for the 21st Annual Golisano Children's Hospital Golf Classic on August 28, 2017.

A great day of golf on three private courses again this year: *Monroe Golf Club, Country Club of Rochester, and Oak Hill West.*

For more information or to register please call **(585) 273-5948** or visit **www.givetokids.urmc.edu**.

“Normally, a clot forms and the cut heals itself, but a patient on blood thinners will continue to bleed. Attempting to sew it up could have made it worse,” said Daugherty.

Instead, care providers in the PICU took half-hour shifts applying manual pressure to the cut. Finally, the bleeding stopped.

But the incident underscored the dangers of ECMO treatment, as blood thinners also increase the risk of stroke, among other serious side effects. So after spending 11 days attached to the ECMO machine, Ian's physicians were getting antsy.

“Every day you're on ECMO is an additional risk,” said Daugherty. “So as soon as we felt Ian could survive without it, we tried to get him off of it.”

Recovery

It took three tries in all. After each of the first two attempts, Ian's heart wasn't strong enough to remain off ECMO for more than a few moments.

But finally, on the third try: success.

“One of the doctors came in and said that he made it through,” said Christa. “We were crying and my husband was out in the hallways shaking everyone's hands.”

Ian would need continued sedation for six days, but his body kept working to repair itself from the ravages of the infection. His physicians now believe parainfluenza virus triggered a second infection which led to his rapid decline.

“Ian is a strong, resilient kid, and I don't think enough can be said about his parents, either,” said Daugherty. “We did what we could, the machines did what they could, but his parents' support was incredible.”

Several months later, Ian would suffer a minor stroke, which was perhaps a consequence of the ECMO treatment. But from this, too, he would recover, and remarkably, he's shown almost no long-term effects of his ordeal.

Now 2 years old, Ian's personality and development have returned.

“He has occupational and physical and speech therapists, and they all just say ‘He's back,’” said Christa. “He's made it back to where he was before and has started to move past it. It's incredible.”

“Ian's sickness was the biggest trial of our lives, and we did a lot of praying,” said Seth Galek. “The miracle of his survival, we feel, was a gift from God, which was embodied in the amazing care we received in Rochester.”



Miracle Kid

Lauren Gumtow

Emerging from the procedure with eight pins affixed to her skull, Lauren Gumtow awoke beside her new walker, which was attached to the metal halo around her forehead.

But as the anesthesia wore off, the 6-year-old took note of her newfound equipment and realized it might give her an unanticipated edge in combat. She smiled at her mother.

“Want to fight?”

The procedure, in January 2014, was just another step for Lauren, who had been diagnosed with severe scoliosis three years earlier. But her bright attitude helped her family get through the toughest times, and just three months after the halo was put into place, Lauren would become one of the first scoliosis patients in the United States to be outfitted with a special new growing rod.

The new device, installed at UR Medicine’s Golisano Children’s Hospital in April, can be lengthened magnetically as a child grows, and will drastically reduce the number of surgeries Lauren needs while she makes her way toward recovery.





Lauren with her parents, Kelly and Matthew, and older sister Rylie.

The Journey

Born in 2007, Lauren was just 2 days old when she was diagnosed with tetralogy of Fallot, a congenital heart defect which results in low oxygenation of the blood. George Alfieris, M.D., director of pediatric cardiac surgery at Golisano Children's Hospital, performed her open heart surgery in October 2007.

"So she's really had the journey," said Kelly Gumtow, Lauren's mother.

At age 3, Lauren began to show signs of scoliosis, and she returned to Golisano Children's Hospital where she began meeting with James Sanders, M.D., chief of the Division of Pediatric Orthopaedics. Though Lauren was only 3 years old at the time, Sanders knew that her scoliosis was acute enough that treatment needed to progress quickly.

"The curve was so severe that, if untreated, it was highly likely to eventually cause her lungs to fail," Sanders said.

Sanders knew that a brace wouldn't be enough to correct the spine curve, but he was hoping to keep the scoliosis under control until Lauren was old enough for a growing rod surgery. After a series of casts to help limit the spine curve, Sanders placed Lauren in a Milwaukee brace, a device flexible enough to allow her to continue being a kid.

"She's just a girly girl. She loves dressing up, putting on makeup, playing with her sister," Kelly Gumtow said. "It's emotional at times,

because you never stop asking 'Why?' But it's been very humbling because she's such a trooper. Nothing gets her down."

Eventually, as expected, Lauren's scoliosis started to worsen, necessitating the halo traction procedure. Pins were placed in her skull and a halo was attached to a walker, which stayed with Lauren wherever she went.

Halo traction, which uses weights to apply steady upward pressure on the head, attempts to pull the spine into a straighter position. It worked well for Lauren, allowing her to breathe more easily, but the restrictions that accompanied it made it tough for her to do the same things she used to do.

"Basically, she couldn't be a kid," said Matt Gumtow, Lauren's father. "She couldn't play with her sister, lie on the floor, lie on the couch – the simple things you take for granted."

Growing Rod

Lauren's parents set up a table for her in the living room where she could play with her toys from her walker or wheelchair. She grew fond of the Disney movie *Frozen*, and the television shows *Doc McStuffins* and *Sofia the First*. And soon, she was able to start going back to school at Washington West Elementary in Olean. The school was very supportive of Lauren's needs, allowing her grandfather to accompany her to class every day, and her mother, the school counselor, was never far away.

By April 2014, it was time for the growing



rod to be installed. But while traditional growing rods need to be lengthened every six months — requiring an additional surgery for every adjustment — Lauren received a newly-approved device that uses a magnetic motor to allow doctors to make adjustments externally.

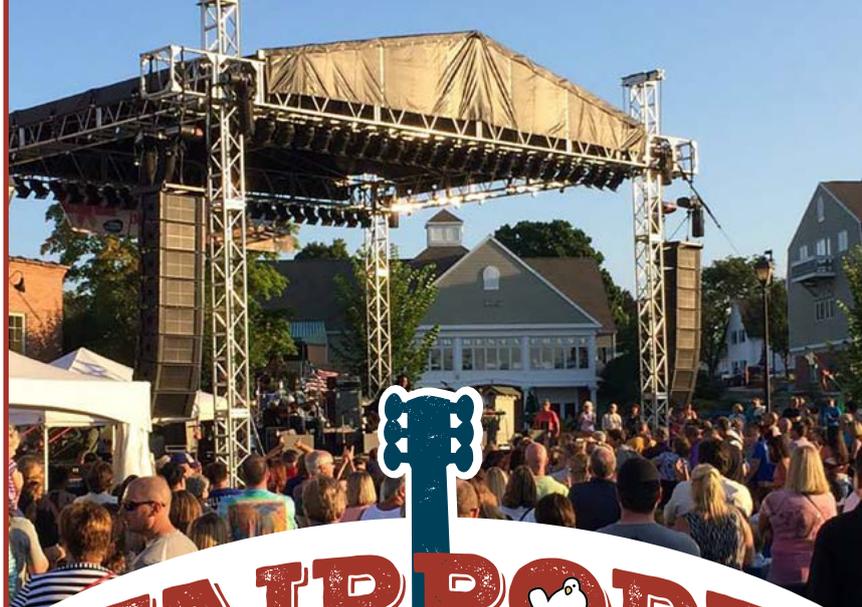
The magnetic growing rod, called the MAGEC System, has been used successfully in Europe for several years, but was only approved by the United States Food and Drug Administration in February. Lauren’s surgery made Golisano Children’s Hospital just the second hospital in the country to install one of the devices since its approval.

“Surgery is traumatic for children, and every time you open up the skin, particularly through an old scar, you increase your risk of infection,” Sanders said. “So anything we can do to try to continue the spine’s growth but decrease the amount of surgeries is a very good thing.”

Now 10 years old, Lauren has received 13 lengthenings of her growing rod, all done in a simple outpatient procedure using the MAGEC remote. She’s now playing soccer, and her confidence is growing on a daily basis.

Lauren will need an additional surgery at some point soon to switch the rod out with a larger model, but that only underscores the fact that she’s growing so well now, said her mother.

“It’s put life in perspective. It’s put our family in perspective,” Kelly Gumtow said. “I think it’s made us stronger.”



FAIRPORT

Music Festival

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Come party with us in the Village of Fairport on August 25 and 26, 2017. The Fairport Music Festival, which takes place on Liftbridge Lane, will feature music and food from local restaurants. It promises to be a fun-filled weekend that offers music on three stages from over 20 bands and entertainers, and tons of kids’ activities.

All proceeds go to Golisano Children’s Hospital at Strong.

To date, with your generosity, we have raised over \$1.1 million for Golisano Children’s Hospital. Thank you for helping us help the kids!



Miracle Kid

Arianna Stewart

The average grapefruit usually grows to about 12 centimeters in diameter. The average size of a baby girl's liver is four to five centimeters. But somehow, six-month-old Arianna Stewart had a tumor the size of a grapefruit growing in her liver.



Arianna with her parents, Brandon and Vanessa, and her older sister, Leila.

A Parent's Intuition

Arianna was living a seemingly typical life as an infant. She was growing and eating, but her parents sensed that something was wrong. She had a lump that had formed on her stomach and her parents were monitoring it closely.

"There was a little bump next to her belly button that bothered us from the day she was born," said her father, Brandon Stewart. "Every meeting that we had with our pediatrician we were told it was a herniated muscle and not to be worried."

Brandon and his wife, Vanessa, continued to do their due-diligence, researching potential causes of the bump. At each appointment, they were sure to check in with their pediatrician and ask about what could be causing it. By the time of Arianna's six-month check-up, the Stewarts wanted some answers. Their pediatrician referred them for an ultrasound at UR Medicine's Golisano Children's Hospital.

After arranging care for their other daughter, Leila, they brought Arianna in for her ultrasound. Then, all they could do was head home and wait for the results. The minutes seemed to blur together from there.

"I remember getting the phone call saying that Arianna had a growth on her liver that could be cancerous," said Brandon. "As an employee at Strong Memorial Hospital, I've seen kids hooked up with IVs and you never think for one minute that it might hit home, but it did."

A Divine Sign

The next day, Arianna would undergo more tests — an MRI, CT scan and blood tests. Little did the Stewarts know that was the day their lives would change forever. Arianna's AFP, a tumor marker used to help detect and diagnose cancer of the liver, was elevated to 257,000, whereas the average child her age has a range of 0-7.

Arianna was diagnosed with hepatoblastoma, a rare tumor accounting for just one percent of pediatric cancer diagnoses.

"The pooching of Arianna's stomach actually had nothing to do with what we found in her liver," said David Korones, M.D., Arianna's oncologist. "It was kind of like a divine sign — something that led to early detection of the tumor. Had it been found later, it would have been a major problem that could have flipped her odds from a very curable to a very-hard-to-cure cancer."

Arianna's liver tumor was quite large — making the treatment and surgical removal of the tumor especially difficult. But fortunately, it had been entirely confined to Arianna's liver, and had not spread to other areas of her body.

"It could have been a different story. If it had grown to involve several different areas of the liver, it might not have been able to be removed — which is the only way to cure it," Korones said. "If that had happened, the only way they could have cured it would have been to remove her liver and give her a transplant, which is pretty high risk while being treated for cancer."

Treatment

“You have to put this into context, this was a beautiful six-month-old baby who wasn’t having a problem in the world,” Korones said. “Brandon and Vanessa were kind of numb, but what impressed me is that even as devastated and shell-shocked as they were, they still had the presence of mind to ask really good, really challenging questions.”

Korones consulted with other centers prior to administering Arianna’s treatment. He talked with Walter Pegoli, M.D., Chief of Pediatric Surgery at Golisano Children’s Hospital, and formed a game-plan for her care, which included giving Arianna six rounds of chemotherapy, two or three rounds before the surgery, and three or four rounds after the surgery.

Without chemotherapy, Pegoli couldn’t attempt to remove the tumor — Arianna wouldn’t have had enough liver to survive. They explored all options, even a primary resection and a liver transplant, but in a child as small as Arianna, it was not feasible.

“The toughest part about giving a child chemotherapy — and Arianna was on the strongest, most intense chemotherapy — is that in order to get better, she had to get sicker,” Korones said. “She responded so well that Walter could do the surgery after two rounds of chemotherapy.”

Surgery

One of the largest risks for a hepatoblastoma resection is being unable to remove the entire tumor. Arianna’s tumor in particular was bulky and in close proximity to major vessels of the vascular structure that feed or drain the liver. After two rounds of chemotherapy, Arianna’s tumor had shrunk in size by 50 percent, and Pegoli could attempt to remove the tumor.

“The entire day was very nerve-racking. It was the longest day ever,” Brandon said. “It’s a blur now, and it was a blur then — our minds were racing.”

“It was a pretty big tumor that involved a very large portion of the right lobe of her liver and also extended into the left side,” said Pegoli. “We ended up having to do a pretty major liver resection in close proximity to some of her major arteries.”

One of the major concerns for children like Arianna is that the remaining portion might not be up to the job. Pegoli also worried about infection and the leaking of bile from her liver edge. He also had to make sure he wasn’t leaving any of the tumor behind.

“The toughest part about giving a child chemotherapy... is that in order to get better, she had to get sicker,” Korones said. “She responded so well that Walter could do the surgery after two rounds of chemotherapy.”



Today

The Stewarts brought Arianna in for four more inpatient chemotherapy treatments after her surgery. Statistics gathered by Korones supported the completion of six rounds of inpatient chemotherapy to fully fend off the tumor.

Arianna rang the “End of Chemo Bell” on July 26, 2016, signifying Arianna’s triumph over cancer. Surrounded by her family, she was declared cancer-free. She turns two years old on July 6, 2017.

“Staying here at Golisano was one of the best decisions because we were able to keep our support group around us – not just for us, but for Leila and Arianna,” Brandon said. “7North became like our home, so much so that Arianna learned how to walk at the hospital.”



Miracle Kid

Ben Tulgan

Ben Tulgan catches himself on the edge of the couch before turning back to the photographer who has captured his attention. The camera is just a foot away. Clearly within reach.

Steadying himself with his right arm, he leans over and swats at the lens. A miss. He nearly loses his balance as his mother, watching from nearby, starts to giggle. Casting her a puzzled look at first, his face quickly brightens, and he joins her in laughter.

“We were unlucky for a lot of reasons,” said Sasha Tulgan. “But looking at him, we really feel, so, so lucky. He’s happy, he laughs a lot, he sleeps through the night. He’s just so easy.”

If anyone deserves a bit of relief, it’s the Tulgans, who spent an astounding 147 days in the Golisano Children’s Hospital Neonatal Intensive Care Unit (NICU). That tenure made Ben the oldest baby on the unit when he was finally discharged in January 2016.

Today, Ben is carefree and cheerful, and shows almost no wear and tear from his long stint in the children’s hospital. But for a time, his parents weren’t sure they would ever bring him home.



Ben with his parents, Adam and Sasha.

An Early Start

Sasha Tulgan was coming back from vacation, just 24 weeks pregnant, when her water broke outside of Albany. She traveled with her husband, Adam, to the nearest hospital, and though she wasn't in labor, physicians were initially unwilling to discharge her.

But the Tulgans wanted to get back to Rochester.

"We knew it was a high-risk situation – it would basically be a three-hour ambulance ride," said Sasha. "But we knew we would be there for some time. We wanted to be close to home."

Fortunately, they made it back without issue, and physicians in Rochester began monitoring baby Ben's heartbeat round the clock. The goal was to keep him in the womb for as long as possible, as every additional day would give him an added chance to grow and develop. As it turned out, Ben got an extra two weeks inside before his heart rate slowed, forcing doctors to initiate delivery.

Any child that survives a birth at 26 weeks is a fighter, for certain. Adam Tulgan's strongest memory of this time was just how small his son looked at first — how a wedding band fit around Ben's entire hand.

But what came next for Ben is what makes him a true miracle: At birth, doctors discovered that he was hydropic, meaning there was excess water in his system. Usually, this means organs are failing.

"There are a variety of conditions that lead to hydrops, and depending on the cause, the mortality rate is between 50 and 98 percent — and that's for children who are born at full term," said Patricia Chess, M.D., Professor of Neonatology at Golisano Children's Hospital.

Upon delivery, Ben wasn't breathing or showing any signs of movement. His heart rate was low. He was so unstable that he couldn't be treated with the standard dose of surfactant — which helps premature infants' lungs develop — and had to be placed on high-frequency ventilation. His muscles weren't being properly oxygenated, and his kidneys weren't functioning well.

Despite the bleak outlook, Chess promised the Tulgans that she would do everything she possibly could.

"Dr. Chess has an extraordinary ability to convey a sense of optimism and reassurance," said Sasha. "She didn't sugarcoat anything — she was very direct. But we felt we could relax when she was there, because it was clear how deeply she cared. She was always in it with us."

Emotional Rollercoaster

After a few days, Ben was relatively stable, and he continued to improve for about three weeks. But he needed treatment for an unclosed hole in his aorta — a condition called Patent Ductus Arteriosus — and the treatment caused his already-weakened kidneys to shut down entirely. If

Ben's body couldn't start producing urine, he would die, doctors said.

On the day they met, Chess told the Tulgans that any NICU stay is a rollercoaster ride, but that she would check in on them, and would tell them when it was time to really start worrying. Now was that time, she said.

"That was the scariest moment for us — when she said it was serious and nobody knew what was going to happen," said Sasha. "Before Dr. Chess left the hospital, she gave us her cell-phone, home phone, pager, everything. Then she emailed us at 2 a.m. after she checked his labs from home, to tell us what a positive result it was."

Ben was rallying as his kidneys kicked into gear, but he wasn't out of the woods yet. The hole in his aorta still hadn't closed, and despite his fragile condition, physicians recommended going forward with a reparative surgery.

Again, Ben pulled through. "He's a resilient little guy," said Chess.

Going Home

Other trials would follow. By the time he left the NICU, Ben had undergone a total of two surgeries, nine blood transfusions, and dozens of X-rays. Concerns arose daily about new organ systems: premie eye disease, kidney reflux, feeding issues, respiratory challenges. But every time, he pushed past the medical obstacles in his path and continued to grow.

By the end of his near-five-month stay, doctors and nurses had become so familiar with him that they began to dote, bringing him onesies back from their vacations and dressing him up for holidays, often while his parents were at work.

His parents brought him home on Jan. 28, 2016, two weeks before his father's birthday.

"Taking Ben home days before my birthday was the best present I could have asked for," said Adam Tungan.

Now, over a year later, Ben has blossomed into a happy toddler, and is on pace with where his development would be, had he been delivered at full term. After being discharged, he hasn't been readmitted even a single time to the hospital.

But his parents, both employees of the University of Rochester, do find themselves in close proximity to the NICU now and then.

"Given the challenges and how challenging the whole experience was, we are amazed that our associations with the place are only positive," said Sasha. "It's a place you never want to get to know, but for those who do, it is a very special experience."

"Dr. Chess has an extraordinary ability to convey a sense of optimism and reassurance," said Sasha. "She didn't sugarcoat anything — she was very direct. But we felt we could relax when she was there, because we felt like she cared as much as we did!"



Miracle Kid

Judah Dantonio

It's a feeling that Nick and Liz Dantonio will never forget. Loud beeps and alarms coming from the nursery where they delivered their first-born, Judah.

Doctors rushing toward the newborns.

Worriedness on the nurses' faces as they scrambled to help the doctors.

Nick asking the care staff at United Memorial Hospital, "Is it Judah?"

Fear. Panic.

Warsaw, Wyoming County, residents Nick and Liz were elated after Judah's birth just 24 hours earlier. Now, they were left wondering what went wrong. The prenatal ultrasounds were perfect. Judah was delivered at 40 weeks, on time and on schedule. Not even 24 hours later, he was struggling to breathe and was being transported from Batavia to a hospital in Buffalo for more testing.

The diagnosis: hypoplastic left heart syndrome (HLHS); a birth defect that affects blood flow through the heart because the left side of the heart doesn't form correctly. It's one of the most complex cardiac defects seen in newborns and is very challenging to treat — his heart only had one pumping chamber, the right ventricle. Without treatment, HLHS is fatal, often within the first hours or days of life because the left side of the heart cannot support blood circulation to the body's organs.

Judah would then be transported to UR Medicine's Golisano Children's Hospital, his third hospital in as many days, where he'd need surgery at just five-days-old.

Nick and Liz had 70 miles between hospitals to discuss their emotions and come up with a game-plan for their son. To this day, they look back and credit the ride for their success as a couple and as a family.

"We made a promise that we wouldn't turn our backs on God, on each other, and that we would do whatever we could for Judah," said Nick. "We later added another promise to rejoice for every baby we saw go home before Judah."

Upon arrival at Golisano Children's Hospital, they met with George Alferis, M.D., where they were given a care plan from him and his team. The Dantonios were told that Judah would likely require three surgical procedures to reconstruct his heart and that eventually he may need a heart transplant. The first surgery Alferis would execute shortly after their discussion.

"Judah was a very sick baby and it felt like he was constantly taking a step backwards," said Regina Cable, a nurse practitioner on the pediatric cardiology team. "We were not sure he'd survive when we saw him for the first clinic visit."

Alferis and his team performed Judah's first surgery aimed at rebuilding his aorta, creating one open outflow from his heart and adding blood-flow to his lungs. The surgery is a complex procedure — at that point, his heart was roughly the size of a walnut, further complicating matters.

"Surgery days are the hardest days — emotionally and physically — they're just exhausting," Nick said. "I can't believe how much it took out of us."

"He always had a smile on his face," Nick said. "There were countless times his energy and happiness made us forget what our family was going through."



Judah began the recovery process, which usually takes a month or two to complete. But that wasn't the case for Judah — his chest remained open for two weeks after surgery because of swelling. He needed a breathing tube and was on a ventilator for a prolonged period of time to help him breathe easier. Judah's lungs were struggling to provide air to his body. Physicians had removed the breathing tube for a couple hours, but every time they did, he would need to be re-intubated. After undergoing a bronchoscopy, a procedure done to see what Judah's airways looked like, it was decided that he needed a tracheostomy. He also required a gastrostomy tube for feeding because he was having trouble gaining weight.

"A tracheostomy and ventilator are almost unheard of in Judah's population," said Cable. "Taking a baby home with a trach and a vent is very stressful on its own, on top of caring for a child with HLHS, it's almost more than anyone could handle."

"That was one of the hardest things, with a tracheostomy and a ventilator, now, when we eventually would get home, we would need 16-hour nursing in the house," Nick said. "We went back to our first discussion we had in the car: it didn't matter what it cost, we would do whatever it takes to give him the best chance to be healthy and grow old."



Judah with his parents, Nick and Liz, and his sister, Giana.

Within hours of his tracheostomy the Dantonios noticed an immediate difference in Judah's personality. He was beginning to turn the corner and was on the road to health. After five months spent in the pediatric cardiac intensive care unit (PCICU), Judah was finally heading home.

"He always had a smile on his face," Nick said. "There were countless times his energy and happiness made us forget what our family was going through."

The second of Judah's three surgeries took place on October 28, 2013. This procedure, called the Glenn, was performed to reroute blood circulation and reduce his ventricular workload. He was discharged from the second surgery on his first birthday, just 17 days after the procedure.

In February, 2015, Judah returned to Golisano Children's Hospital after Nick and Liz noticed Judah had symptoms of pneumonia. However, tests revealed he had a respiratory infection impacting his heart function. During ultrasounds, providers noticed that his single right ventricle was severely depressed, leading the cardiology team to be concerned for his future. Conversation ensued about referring Judah for heart transplantation.

Since 2015, Judah has done very well clinically. His function of the single right ventricle

has improved with the help of several medications, allowing for his tracheostomy to be removed.

"As far as kids with his heart condition, he has had one of the more complex courses, yet he and his parents have always been so positive. I am so happy with how well he is doing currently," said Carol Wittlieb-Weber, M.D., a pediatric cardiologist at Golisano Children's Hospital. "He's just a happy, adorable little kid who is lucky to have such amazing parents. They're a pleasure to take care of."

Judah is growing and loving life as a four-year-old boy. He's seen by Wittlieb-Weber once every three months and they're constantly working together to evaluate the best treatment options for Judah.

But for the Dantonios, they count each day as a blessing.

"There have been a few times during this journey where I've been sitting by his hospital bedside thinking, 'Is this it?' 'Is this where it ends?'" Nick said. "Our faith has been a big part of why we were able to go through this and come out thriving in our relationship and as a family."

And their family is about to get bigger — Judah and his sister, Giana, are about to welcome a third sibling, a sister, into the world this April.

2017 Miracle Maker Award Recipients

Outstanding Commitment by an Individual

Nina Schor



It won't be difficult to find the mark that Nina Schor left at UR Medicine's Golisano Children's Hospital – just take a walk down Crittenden Boulevard and look north at the new children's hospital, which stands nine stories tall. Her impact, however, has spread far beyond the new tower. Schor stressed the importance of a standalone children's hospital and has drawn top-tier pediatricians to Rochester to work and improve the care and outcome of patients.

Schor has become the face of Golisano Children's Hospital since starting as the Chair of the Department of Pediatrics in 2006.

The unprecedented growth seen from the Department of Pediatrics, along with the creation of divisions such as palliative care, allergy, sleep medicine and hospitalist medicine further exemplify the importance of the work she did for the kids of Golisano Children's Hospital. We'll miss you, Dr. Schor.

"To get an award for what has been an honor and a labor of love is icing on a delicious cake," said Schor.

Outstanding Commitment by a Community Group

Battle of the Beaks



A rivalry between Nazareth and St. John Fisher College has turned out to be a fruitful fundraiser for Golisano Children's Hospital. In the ten-year history of their competition, student athletes at both colleges have combined to raise more than \$120,000 for the children's hospital.

Battle of the Beaks, a tradition pitting both of the college's basketball teams against one another, features both men's and women's games. Nazareth students' efforts typically include T-shirt sales at various events throughout the year, a student-athlete semi-formal, and an annual Winter Walk.

"Being part of the Battle of the Beaks gives students, faculty, and staff a chance to give back to a place that has touched the lives of many members of the campus community," said Becky

Fahy, Ph.D., associate professor in psychology at Nazareth College and a Battle of the Beaks committee member. "Many of us have had children who were treated at the hospital or were treated there ourselves when we were kids. Students see that they are a part of something much larger than themselves and are proud of the fact that they can make a difference in the lives of the children who they visit in the hospital. The events are the result of a fun and collaborative effort of students, staff, and faculty."

The 2016 Battle of the Beaks committee raised \$13,299 for the kids at Golisano Children's Hospital.

2017 Miracle Maker Award Recipients

Outstanding Commitment by a Community Partner

Lauren Dixon and Mike Schwabl



For more than a decade, Dixon Schwabl has partnered with the children's hospital to produce video pieces for our annual Gala, the first of which, Mike Schwabl, president of Dixon Schwabl, recalls shooting for our neonatal intensive care unit (NICU). He said that the impact it made on him, meeting the families that were getting treatment in the NICU, and seeing what the hospital meant to so many, is what keeps him coming back.

"We are so honored to receive this Miracle Maker Award, but there's no doubt in our hearts that the true miracle makers are the doctors, nurses, and staff of Golisano Children's Hospital," said Mike Schwabl. "It is a joy to support this incredible team and we encourage everyone to join us in rallying around their efforts to make our community second to none in healthcare."

Dixon Schwabl, a Rochester marketing and communications agency, also participates in Extra Life, a 24-hour gaming marathon to support Children's Miracle Network Hospitals. Through individual and group fundraising, the Dixon Schwabl team raised nearly \$3,000 in 2016 to benefit Golisano Children's Hospital.

Outstanding Commitment by Grateful Parents

Jennifer and Vinnie Esposito



Grace Esposito was born in September 2011 with a congenital diaphragmatic hernia pushing her heart out of place and leaving little room for her lungs to grow and form. "Amazing Grace" fought on for a year and a half, enduring five surgeries and spending a week on a heart-lung bypass machine, before losing her fight in February 2013.

Long before she was born, Grace's parents, Jennifer Johnson and Vinnie Esposito, gave back to Golisano Children's Hospital. During their time at the children's hospital, Jennifer, Vinnie, and Jennifer's colleagues at 13WHAM led the creation of Grace's Garden, committing \$350,000 to the outdoor garden, which provides patients a healing change of scenery during their stay at the children's hospital. They

also fulfilled a \$100,000 pledge along with Rochester-area Kiwanis clubs for a NICU room in Grace's name. Jennifer, who serves on the children's hospital's Board of Directors in addition to her role as a reporter and anchor at 13WHAM, has also joined several other local media members to host the children's hospital radiothon, which annually raises several hundred thousand dollars for the care of children.

"We're so glad that Grace's story has inspired others during their battles," said Jennifer. "We welcome the opportunity to be around a group of people and families who may have been through the worst with the loss of a child and still support the hospital like we choose to do."



Children's
Miracle Network
Hospitals

Special thanks to our Children's Miracle Network Hospitals (CMNH) Sponsors. Over \$600,000 was raised in 2016 through the support and dedication of the employees and management of our local sponsors. Below are some of the companies that helped contribute to this success:



Ace Hardware

Through their round up program and in store promotions, over \$2,700 was raised through the Ace Hardware stores in our region.

ALEX AND ANI

Alex and Ani

Over \$5,100 was raised through in-store promotions and the sale of a specialty Unicorn bracelet created especially for CMNH. Thanks to our new partner for their generous support.

chico's



Chico's, White House/Black Market and Soma

Through in-store donations and the sale of a specially-created necklace, these stores contributed over \$2,500 in 2016. Please visit these stores April 5 – May 31 as they continue their fundraising initiatives for Golisano Children's Hospital with the sale of Miracle Scarves in Chico's and Miracle Charm Bracelet in White House/Black Market.



Dairy Queen

Our Dairy Queen locations served up some sweet treats during Miracle Treat Day where \$1 from every blizzard sold benefited Golisano Children's Hospital. Through their tremendous support, more than \$19,000 was raised!



Great Clips

Through the generosity of their balloon icon sales, the three area Great Clips raised almost \$3,000 for the children in our region.



IHOP



Through their CMNH balloon icon sales and the annual Pancake Day, our two local restaurants raised almost \$3,000 for the children's hospital. The staff at IHOP truly make a difference when it comes to helping kids!



Kinney Drugs

With just one location in our region, Kinney Drugs did a great job raising more than \$1,100 through their in-store balloon sales.



Ollie's Bargain Outlet

Every April, the two area Ollie's enlist the support of their employees to help raise funds. More than \$2,000 was raised in 2016.



Speedway

A sponsor for the last two years, Speedway has been enthusiastic and energetic. Last year, they raised almost \$25,000 through a variety of fundraisers in their stores.



Valvoline Instant Oil Change

More than \$6,100 was raised through the incredible support of our local Valvoline locations. The employees and management did an incredible job selling miracle balloons during the month of November. Thank you Valvoline!



Walmart and Sam's Club

Our largest corporate sponsor, the area Walmart and Sam's Club associates and management truly put their heart into their six-week fundraising campaign. From hot dog sales to kissing pigs and horses, the management and associates get very creative in their efforts to help the children in our region. Special thanks to the high fundraising stores during the six-week campaign: Canandaigua Walmart and Henrietta Sam's Club, and to the overall high fundraising store: Geneseo Walmart. Our sincere thanks to everyone who helped raise over \$230,000 in 2016.



Extra Life

Since its inception in 2008, Extra Life, a 24-hour gaming marathon, has raised more than \$30 million for local CMN Hospitals. Locally, more than \$26,000 was raised by close to 130 gamers who played a variety of games during the Extra Life marathon. The 2017 Extra Life date is Saturday, November 4. For more information, visit www.extra-life.org.



Thank you!

We are very grateful to all of our generous financial community donors!

Rochester Business Charitable Golf Tournament

WNY Optics/Photonics Golf Tournament

Bill Frisbie Memorial Golf Tournament

Monroe County Sheriff PBA's Charity Golf
Tournament

Spirit of Children

Anthony Poselovich Memorial Foundation

Greece Arcadia HS Boys Baseball

Paige O'Brien

Esther Winter & Canalside Music Together, Inc.

Nick's Fight to be Healed

Kayla Wheeler

Pittsford Central Schools

The Rainbow Classic

Tia's Hope

Walworth Lions Club

More Than A Game Foundation

Prince Elite Hockey

Jaxson & Emme Zampell

Paychex Employees

Battle of the Beaks

Cub Scout Pack 126

Mendon Center Elementary Newspaper Club

Fastrac Markets

Olivia & Reese Davis

The Leonard Family

Mom's Club Henrietta East

Pennies for Penelope

Lauren's Legacy

The Kane Family

Upcoming Community Events

June 3, Stroll for Strong Kids

Genesee Valley Park, 1000 East River Road

The 5K race will begin at 8:30 a.m., followed by the walk at 10:30 a.m. The event will continue until 1 p.m. with family-friendly activities, including over a dozen bounce houses, carnival games, photo booths, and much more! The event is presented by Abbott's Frozen Custard. Register, create a team, and fundraise on the Stroll for Strong Kids. Visit: www.givetokids.urmc.edu/stroll.

June 10, Team Ali-Gaiter Clambake

Honeoye Falls Fireman's Training Grounds, 321 Monroe St.

From 2 p.m. to 7 p.m. attendees will enjoy clams, pulled pork, hot dogs, salads, desserts and drinks. There will also be live music, raffles, bounce houses, costume characters and pony rides. Tickets are available in advance and at the door. For more details, please contact Jackie Klube at (585) 704-4124.

July 17, RBC Golf Tournament

Country Club of Rochester (CCR)

The Rochester Business Classic (RBC) is a charity golf event tournament hosted by the Rochester Businessman's Charitable Organization (RBCO). One of the beneficiaries is Crosby's Fund which benefits Golisano Children's Hospital. For information, please contact Kristi Wenner at kwenner718@gmail.com.

July 27, Miracle Treat Day

Dairy Queen

For every blizzard treat sold at participating Dairy Queen locations, \$1 will be donated to Golisano Children's Hospital. Dairy Queen will also be selling Miracle Balloons leading up to Miracle Treat Day.

Aug. 13, Bill Frisbie Memorial Golf Tournament

Hillendale Golf Course

The Bill Frisbie Memorial Golf Tournament will benefit Golisano Children's Hospital Pediatric Cancer Research specifically GCH's Bright Eyes Fund. It's a scramble format with a shotgun start at 9 a.m. The cost is \$260 per four person team. Entry Fee Includes: 18 Holes With Cart, Coffee & Doughnuts, BBQ at 2 p.m., Longest Drive and Closest To the Pin for Men and Ladies. Hole Sponsors or for more information please Contact Mark Taber at 607-387-9549.

Aug. 19, Rochester Gran Fondo

Blue Cross Arena

We are thrilled to announce the second year of the Rochester Gran Fondo! This new VIP experience charity ride will have the unique feature of being held in conjunction with the Criterium! Help support a wonderful cause and enjoy an amazing event! Participants will enjoy rides designed for different levels of ability followed by exclusive track-side viewing of the Criterium from the atrium of the Blue Cross arena. We welcome both cyclists and spectators to join us at this special event on the 2017 cycling calendar. Visit: <https://rochestergranfondo.com>.

Aug. 25 & 26, Fairport Music Fest

Liftbridge Lane, Fairport

This fun-filled event, located along Fairport's Liftbridge Lane, is great for the whole family! Enjoy two days of good music and food for a great cause. Fairport Music Fest has impacted Golisano Children's Hospital in a number of ways and is committed to supporting Pediatric Cardiac Surgical Room. Visit: <http://www.fairportmusicfestival.com>.

Aug. 28, Golisano Children's Hospital Golf Classic

Monroe Country Club; Country Club of Rochester; Oak Hill

Golfers from across the Finger Lakes region will come together to play for kids at the 19th annual Golf Classic. Save the date and stay tuned for more information!

Save the Date 2017

Oct. 21 – Golisano Children's Hospital Gala

Riverside Convention Center

Visit: givetokids.urmc.edu/gala for information

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Save the Date
30th Annual Golisano Children's Hospital Gala
Saturday, October 21st

Joseph A. Floreano Rochester Riverside Convention Center
6pm – Midnight • Honorary Chairs, Kim and Steve McCluski

The event, themed *An Enchanted Garden*, features a live and silent auction, dinner, and entertainment.

Sponsorships available starting at \$1,500 and tickets are \$250 per person. Proceeds from the Gala benefit Golisano Children's Hospital.

For more information visit www.givetokids.urmc.edu/gala or call (585)273-5948

Black tie preferred.

givetokids.urmc.edu/gala