



STRONG KIDS NEWS



Meet our Miracle Kids and their families

Hope shines brightly during Miracle Weekend

HOPE KEEPS FAMILIES GOING, DAY IN AND DAY OUT, AS THEY SIT BY THEIR CHILD'S HOSPITAL BED.

It drives clinicians at Golisano Children's Hospital at the University of Rochester Medical Center to work tirelessly to help a child feel better than she felt the day before. And it inspires researchers to explore new possibilities for treatments and cures. Miracle Weekend encapsulates the hope for a better tomorrow that pulses within and throughout Golisano

Children's Hospital.

Five emblems of hope will shine brightly at this year's Miracle Weekend, Friday, June 3, and Saturday, June 4. In this special edition of the Strong Kids newsletter, you'll read the harrowing and heart-wrenching tales of Golisano Children's Hospital five incredible Miracle Kids of 2011. A baby comes into the world without a heartbeat. A toddler from China is given a second chance at life. As a boy's immune system wreaks havoc on itself, his family finds an expert with answers. A teenage girl learns to be true to herself as cancer takes a toll on her body. An adoles-

cent boy finds new hope as a talented surgeon steps up to fix his heart.

Golisano Children's Hospital wouldn't be able to provide the kind of high quality care that saves lives without the generous support of our community of donors. You'll also read about our Miracle Makers in this issue—everyday people, who have shown themselves to be true heroes.

To learn more about Miracle Weekend's Stroll for Strong Kids and News 10 NBC Telethon, turn to page 14 or visit www.givetokids.urmc.edu.

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Dear Friends —

What is it worth to know that, if your child needs critical medical care, you won't have to travel for her to get it? What is it worth to know that a child with a currently incurable disease can participate in a research study today that contributes to developing the cure and perhaps benefit from it tomorrow, right here in Rochester?

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What would you give to know that your child can see healthcare professionals in your neighborhood who will keep him healthy and strong and active into adulthood?

To Pauline Brown, who died this fall at the age of 100 years, it was worth her entire estate. To the child who ran a lemonade stand just off of Park Ave., it was worth spending the hot afternoon outside in the sun throughout the neighborhood's August festival. To the families about whom you read in this Miracle Kids issue, it was priceless. Nothing can compare to the value of a life and the hope and potential of a child. But so much of what we must do to keep healthy children healthy and restore ill children to health requires funds beyond the individual means of the families we serve.

This year, we are hoping to endow critical programs and positions so that we don't have to wonder whether, year-to-year, we will be able to provide these

services and expertise to you and the children of our community. We are hoping to endow our educators and researchers so we can continue to recruit the best medical students, residents and fellows to pediatrics and recruit and retain our truly outstanding researchers to create a better future for our children and their children. We have chosen five signature programs we know need just the "push" an endowment brings to take them from "good" to "great." We will initially focus on our programs in autism, surgery, neonatology/NICU, childhood cancer and childhood heart disease, and we know we can count on all of you to help us build new hope! Please stay up-to-date on our progress at www.givetokids.urmc.edu and watch our next issue of Strong Kids for more information.

With best regards,

Nina F. Schor
Nina F. Schor, M.D., Ph.D.
Pediatrician-in-chief



A warm face and listening ear help CURE families of fear and grief

CHRIS AND RON LUCIEER SAT IN THE WAITING ROOM, TRYING TO KEEP CALM AND COLLECTED AS THEY LISTENED TO THEIR 3 ½-YEAR-OLD DAUGHTER CRY IN OCTOBER 1996. CHRIS, RON AND THEIR DAUGHTER AMANDA HAD SPENT A LONG DAY IN THE CLINIC AT GOLISANO CHILDREN'S HOSPITAL AT THE UNIVERSITY OF ROCHESTER MEDICAL CENTER, GETTING BLOOD WORK AND TESTING. NOW LITTLE AMANDA, WHO HAD ONLY JUST BEEN SENT TO THE HOSPITAL BECAUSE SHE COULD HAVE ACUTE LYMPHOBLASTIC LEUKEMIA (ALL) WAS HAVING A BONE MARROW ASPIRATION AND SPINAL TAP.

A friendly face walked in and quietly introduced herself. "I understand what you're going through," the woman said to the Lucieers. "My son is a cancer survivor." A wave of relief rushed over them. "Wow, it's possible to survive this," Chris thought to herself.

For the past 35 years, CURE Childhood Cancer has leant a warm hand and a listening ear to families of children treated for cancer and blood disorders at Golisano Children's Hospital. Carol Vattimo, the woman who gently offered her support to Chris, has been the friendly face behind of CURE organization for more than 26 of those years.

The non-profit organization has grown into an invaluable platform of support, serving nearly 850 parents and families from the 17-county Finger Lakes region each year. Carol visits with in-patient and out-patient families at Golisano Children's Hospital, providing them with a bag full of simple necessities like toothbrushes, parking passes and, perhaps most importantly, staying with



them for emotional support as long as she is needed. It is not unusual for Carol to stay in hospital rooms with families until 2 or 3 a.m. to be there with them as a close friend and confidante.

Carol works closely with health care professionals to determine who might be in need of extra comfort care and how she can help. Child Life specialists also rely on

Carol to take the parents who need it to get some coffee or fresh air, while they tend to the child's needs, providing them with therapeutic play opportunities.

"It's the tender, loving nature of Carol that makes parents feel so at ease and so able to talk about all the aspects of what they're going through," said Wendy Lane, Golisano Children's Hospital's Child Life program coordinator.

CURE holds gatherings for families of current and former patients, inviting them to help one another through some of the most difficult and trying times of their lives. Parents like Chris Lucieer, whose daughter Amanda is now cancer-free and a senior at Sodus Central High



School, volunteer to serve as parent advocates and often come to CURE functions to support others. In addition to the weekly support group Carol holds for families at the hospital, CURE also hosts also annual memorial services, picnics and other gatherings for families.

"We don't have a cookie cutter approach to helping families," said Brian Wirth, executive director of CURE. The small, localized and nimble organization can customize care in a way that bigger support organizations in the rest of the country cannot.

Whenever Carol meets a new family, she thinks back to her experience and tries to remember where she was at that point in time. Every case is different, but the emotions behind the experiences are similar, she explained. "It changes your priorities...Families just want someone they can share a common bond with."

For the past 35 years, CURE has been the means through which families have found one another and been able to share that common bond. Golisano Children's Hospital is honored to have such a strong and long-standing relationship with CURE — an organization that is driven in the purest sense by hope and compassion for others.

Kicking leukemia gives teen a better sense of self

Katelin awoke on her 14th birthday, Jan. 13, 2010, with a sore throat. She and her mother Adella had fun plans to go shopping and out to dinner to celebrate Katelin's big day, but first, Adella had scheduled an appointment for herself and

her daughter with the family physician. Adella had strep throat and she figured Katelin did too, but they would soon learn that something much more serious was afoot.

Katelin's skin color looked off to the physician and blood work revealed a startling prognosis. Katelin might have leukemia. She needed to get to Golisano Children's Hospital at the University of Rochester Medical Center (URMC) right away.

"I pride myself in staying calm and focused when something stressful happens or if there's an emergency, so at that point, it hadn't really sunk in," Adella said. If you asked Adella's children about the frantic 40-minute drive from Byron to Golisano Children's Hospital though, they might tell you otherwise, she quipped.

Adella's husband John arrived at URMC's Pediatric Emergency Medicine Department soon after Adella, Katelin and Katelin's brother Jacob. The family was told that Katelin probably had a form of cancer called acute myeloid leukemia (AML) which, when it occurs at all, is usually found in older patients.



Photo courtesy: Ken Huth

“The family is incredible,” said Denise Casey, M.D., assistant professor of Pediatric Oncology/Hematology at Golisano Children’s Hospital. “They were just very trusting. Throughout Katie’s entire treatment, they would say, ‘You just let us know what we have to do and we’ll do it.’”

Katelin was given a birthday cupcake in URM’s Department of Pediatric Emergency Medicine before being whisked upstairs for what would be a seven-week stay at Golisano Children’s Hospital. The health care team on 4-1400, which Adella insisted is “where the best nurses in the whole entire world are,” welcomed Katelin to her temporary new home with a birthday cake and balloons.

Katelin had AML with high-risk cytogenic factors, meaning her chromosomes were changing at rates linked with worse outcomes, so she needed very intensive treatment. Katelin briefly faced some complications during her stay and needed to be moved from 4-1400 to the pediatric intensive care unit, where she was given oxygen and fed intravenously. Katelin’s family struggled with seeing Katelin so seriously ill, especially when she had seemed perfectly fine just a few weeks prior. “It was a horrific time,” Katelin’s mom recalled.

The Ivisons found ways to get through the experience together, leaning on their friends and family for help. Adella’s mom flew in from Michigan to help take care of the Ivisons’ other two children Jacob and Cora, while Adella and John took turns taking the 40-minute drive to and from Golisano Children’s Hospital. Friends and neighbors held a fundraiser for Katelin. The family also started a Caring Bridge page and Katelin’s dad attended CURE meetings with other parents of children being treated for cancer.

“Once we got into the hospital, we tried to keep everybody’s life as normal as possible,” Adella said. She was focused on being there for Katelin, but made a point to spend one-on-one time with Jacob and Cora too. She and John each found different ways to cope with the experience. John liked getting the details, whereas Adella like hearing a more general overview. John shared his

experience with others while Adella preferred taking a more private journey. In the end, they made a great team.

“They always had good questions and a positive attitude,” said Casey.

After the first seven weeks and two rounds of chemotherapy, Katelin was able to go home. Katelin surprised her friends by making a special appearance to her eighth grade dance on Valentine’s Day.

Katelin’s health care team and the Ivisons had known from the beginning that a bone marrow transplant would be the best option for Katelin. The family worked closely with Laurie Milner, M.D., associate professor of Pediatric Hematology/Oncology, to find a match and plan Katelin’s pre- and post-transplant therapy.

Katelin’s brother and sister were matches for each other, but not for her. A near match was found on the bone marrow donor registry list, so they decided to schedule the transplant for May 5. Katelin was doing well and in remission at that point, but she was in danger of relapsing without a transplant.

“I don’t know who the donor was. I just know that she was a 20-year-old girl and I just wonder: What 20-year-old would do that? To have to go through all that she did ... this girl is a hero to us,” said Adella.

Katelin’s body fought the transplant at first. She was ill around Thanksgiving and the holidays as well.

“She has a great attitude and bounced back more quickly mentally than physically,” Casey said. “She’s a teenager and they so often think they can take on the world. Her parents are wonderful though and they pulled the reigns in.” Adella and John encouraged their daughter to take things slowly and let herself heal.

Katelin returned to school in January and comes to the hospital every four weeks for check-ups. Her bone marrow transplant was a success and as time goes on, she will continue to get stronger and healthier.

“If attitude has anything to do with a child getting through aggressive treatment, you just knew that Katie was going to be a survivor,” said David Korones, M.D., a pediatric oncologist at Golisano



Photo courtesy: Ken Huth

Children’s Hospital who was on the team that helped treat Katelin. “She faced everything head on and even when things got scary, she had a smile.”

Katelin’s mom explained that she is much more mature and much surer of herself after her experience. She chose to “rock the bald” rather than wearing a wig during her treatment and stopped caring so much about what others thought of her.

“Katie has really come into her own,” said Adella. “She doesn’t waste her time on frivolous stuff ... She knows what she likes.”

Golisano Children’s Hospital is proud to recognize such a resilient, optimistic and inspiring young lady as Katelin Ivison. Watch out world, here she comes.

Baby born without a heartbeat, but her medical team was delivering a miracle



Photo courtesy: Ken Huith

Christy Strobel arrived at Arnot Ogden Medical Center to be induced into labor on April 14, 2010. But when she was hooked up to the monitors, all plans changed and Christy was rushed into the operating room for an emergency c-section. Mike, her husband and Elmira radio personality, didn't even make it into the room in time to see his daughter's arrival.

"She wasn't breathing and she wasn't crying," Christy said. "I remember looking up at Mike and not hearing her crying. No one said anything."

Christy thought Lauren was dead.

Meanwhile, Arnot Ogden physicians and nurses were working hard to revive the 9½-pound baby who was more than a week overdue. Lauren's APGAR score, which assesses a newborn's condition and ranges from 0–10, was 0 at birth. She had no heart beat and took no breaths. Despite chest compressions and being intubated to force air into her lungs, at 5 minutes, she was still 0. No heart beat. No breaths. They gave her epinephrine to kick-start her heart and continued compressions and breathing for her. At 10 minutes, she was still at 0. At 15, 0.

Finally, after 18 minutes, there was a faint and very slow heartbeat. It wasn't normal, but it was something to work with. Often, resuscitation is stopped at 20 minutes when there's no improvement, but something told the Arnot Ogden team to keep going. By 22 minutes, Lauren



Photo courtesy: Ken Huth

had a regular heartbeat, but she still wasn't breathing.

The team came to Christy and Mike and told them Lauren needed to get to Golisano Children's Hospital at the University of Rochester Medical Center now. She needed the specialists there.

Christy was pushed in a wheelchair to see her first-born child in the Neonatal Intensive Care Unit (NICU) before Lauren was taken by ambulance to Rochester. The seriousness of the situation was weighing on Christy. She wanted to go with Lauren, but she had just had major surgery and couldn't be discharged. Her obstetrician, who always has a very calm and professional demeanor, came into the NICU, hugged Christy and started crying.

Christy had to go back to her room, while Mike rushed to Rochester to be with their daughter. Christy's mother stayed with her to help her get discharged from the maternity ward as quickly as possible.

"I was hearing all these babies cry, and my baby was not there," Christy

said. "You just never realize ... you never think this is going to happen."

When Lauren arrived in the NICU at Golisano Children's Hospital, she was immediately placed on a cooling blanket. Arnot Ogden and the transport team had allowed Lauren to stay cool in anticipation of her need for cooling therapy when she arrived at the hospital. Babies whose brains and other organs have been deprived of oxygen during birth may do better when they are kept at 93.2 degrees Fahrenheit for 72 hours if this is started within the first 6 hours after birth.

Ronnie Guillet, M.D., Ph.D., a neonatologist and professor of Pediatrics at Golisano Children's Hospital, helped the hospital become the first in upstate New York to make cooling therapy a standard therapy for babies like Lauren. She was also Lauren's physician when she arrived. Shortly after Lauren was settled into the NICU, on a cooling blanket and on a ventilator to breathe for her, she had an EEG, a test that measures brain activity.

"It couldn't have been any worse unless there was no activity at all,"

Guillet said.

Lauren's EEG showed what is called a "burst suppression" pattern. There were periods of no activity and then bursts of activity. But the inactive periods were long and the bursts were very short. She didn't even respond to pain.

This news hit Christy hard in her hospital room in Arnot Ogden. "I assumed she was gone, and she was just sort of holding on."

The next morning could not come fast enough for the new mother. Christy pushed her providers to get out of the hospital and she and her mother made a beeline for Rochester. Christy's grandfather had died before she was born, and she always associated him with rainbows. About 10 minutes into the drive, she saw a rainbow and felt her grandfather's presence.

"It was very odd because it was completely cloudy. There was this calming force that went over me, and I felt like everything would be OK," Christy said.

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A boy overcomes rare autoimmune disease and is standing strong again



Gordon Guest didn't think too much of it when Joshua, then 3, fell a few times one summer afternoon near their home in Dryden, N.Y. Kids often get clumsy during a growth spurt or when they're tired. He brought Josh home and put him to bed early. But when Josh woke up the next morning, his eyes were pointing different directions and he had no facial expression.

"He just looked like a different kid. He couldn't swallow anything either," Gordon said.

Gordon and Christine rushed their son to their pediatrician who sent Josh to Elmira for an MRI. The MRI didn't reveal anything obvious, like a tumor or bleeding, but he was losing more coordination by the minute, so an ambulance was dispatched from Golisano Children's Hospital at the University of Rochester Medical Center.

Photo courtesy: Ken Huth



Photos courtesy: the Guest family



Photo courtesy: Ken Huth

Josh was rushed to the Pediatric Intensive Care Unit (PICU) because his difficulty walking had progressed with startling rapidity to slurring his speech and having trouble breathing. It was becoming increasingly clear to Gordon and Christine that his condition was very serious.

Christine said Josh had always been very strong, that he could hold himself up on his father's outstretched arms as if they were parallel bars. "To go from a kid who was that strong to a kid who couldn't hold his head up was really scary."

After Josh stopped breathing twice, Gordon and Christine, who had both been emergency medical technicians (EMTs) earlier in life, readily agreed to having Josh intubated and attached to a ventilator. They knew the risks — he could develop pneumonia or become ventilator-dependent and never able to breathe on his own again — but they also knew their little boy would die otherwise.

"Once he was sedated and we were just there with him on a respirator... it

sunk in," Christine said. "You're just helpless."

But the Guests had a lot of support. Friends and family pitched in to take care of Josh's big sister, Julia, who was 6 at the time. Gordon and Christine were invited to stay in the Ronald McDonald House within the Hospital, one floor above the PICU, so that when they could pry themselves from Josh's bedside, they didn't have to go far for some respite, a shower and a bite to eat. Gordon's boss at Intertek, a product testing company, told him to do "whatever it takes" to get Josh well again.

Teams of neurologists, intensivists, nurses, fellows and residents visited Josh constantly, while Josh was kept sedated. On his birthday, Wendy Lane, coordinator of the Child Life program, brought Josh a bag full of presents, but he was so sick that his sister had to open them.

"It was still Joshua's birthday — it didn't matter that he was so sick," Wendy said. "He and his family needed to celebrate and have some normalcy at an extremely difficult time."

Joshua's pediatric neurologists suspected he had a condition called myasthenia gravis, an autoimmune disorder that causes weakness by blocking acetylcholine receptors in the muscles. Essentially, the body's immune system attacks its own muscles. But Josh's blood test for the disease came back negative.

Myasthenia is rare in adults (20 in 10,000 people) and it's far rarer in children. As rare as it is, the University of Rochester Medical Center (URMC) has an expert in the condition who has treated almost a dozen pediatric patients. When Emma Cialfoni, M.D., an associate professor of Neurology, met Joshua, she knew almost immediately that he had myasthenia gravis. About half of kids who have it have negative blood tests. She ordered an electromyography (EMG) test from URMC's experienced EMG lab, which confirmed the diagnosis. A lab with less experience may have misdiagnosed Joshua and led him down the wrong treatment path.

Cialfoni started Josh on steroids
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A bright, lively toddler from China receives a second chance at life



Photo courtesy: Ken Huth

The instant David McAdam and Debbi Napolitano saw Leah at the hotel in China, they knew she was the child they had been waiting for. “She grabbed us and she never let go,” said Debbi, brimming with tears. “It was the most amazing thing ... She knew and we knew that she was always supposed to be our daughter.”

David and Debbi first met their daughter Lenore Isabelle Meiyi McAdam, or Leah, for short, Oct. 1, 2009, in the capitol of her province, Nanning. She lived in an orphanage in the Chinese city of Guping, located in the province of Guangxi. The gorgeous 16-month-old was happy to meet her new parents, but medically, she was in a poor state. Leah had been born with an imperforate anus, which meant she did not have a hole through which excrement could pass out of her body. Leah could not have any solid foods and the formula and crushed watermelon juice that she subsisted on was very painful to pass out of her body.

“I try not to let myself think about what might have happened to her if we hadn’t been lucky enough to adopt her,” Debbi said.

David and Debbi had chosen to adopt a child with special needs. Before committing to the adoption, they had consulted with Walter Pegoli, M.D., chief of pediatric surgery at Golisano Children's Hospital at the University of Rochester Medical Center (URMC), about what the course of treatment would be for their new daughter once they returned to the United States. During their two-week stay in China, they emailed Pegoli several times with questions.

About a week after they arrived back to the States, David and Debbi brought Leah to see Pegoli. He took one look at her and said they needed to get her into surgery right away.

"Basically, I had to reconstruct her backside," Pegoli said.

Pegoli started by doing a colostomy, creating a temporary artificial opening from the colon, the bottom part of the digestive tract. But there was so much backed up in Leah's digestive tract though that a few days later, Pegoli needed to perform an ileostomy, during which Pegoli made an opening at the end of the small intestine, or ileum. It was hard for the new parents to see their daughter undergoing such serious operations, but Debbi and David put their full trust in Pegoli and his medical team, which included Heather Goetzman, C.P.N.P., N.N.P., and Jennifer Maddison, P.N.P.

"Dr. Pegoli did such a good job of telling us what we needed to know. He told us it was his job to take care of the details," David said.

Leah had to be rushed to URMC's Pediatric Emergency Medicine Department on several occasions for dehydration, sores or infections. Regardless of whether it was a serious incident that brought her to the hospital or if Leah's parents just had questions or concerns and were calling from home, Pegoli or someone from his team always got back to them right away with answers.

Leah was in and out of the post-surgical pediatric unit (4-3600) for eight months or so and Debbi and David developed strong relationships with the nursing staff and with other families on the unit — many of whom had been at the hospital longer and more fre-

quently than Leah. The couple was welcomed back like family every time they returned to the unit with Leah.

"They were all just so wonderful," Debbi said, tearfully. "The nurses put up with my hysterics. I was probably the worst behaved I had ever been in my life. You could tell they cared. They went out of their way to answer questions and someone was always there when we called."

Debbi and David had some trouble finding a place that would care for Leah while they were at work, but they were

referred to Tot Spot in Macedon. Leah's complication occurs in only 1 in 5,000 babies, but Tot Spot already cared for two children with similar issues when Leah's parents visited the center. Leah's case was more severe, since she had both a colostomy and ileostomy. Staff members were willing to be trained to tend to Leah's specific needs and Kathy Rideout, Ed.D., P.N.P.-B.C., F.N.A.P., associate dean for Academic Affairs in the School of Nursing, was more than willing to conduct the training.

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Photo courtesy: David McAdam & Debbi Napolitano



Photo courtesy: Ken Huth

Recovery from complicated surgery shows teen has a whole lot of heart



Photo courtesy: Ken Huth

Tracey and Tim Sheehan had run out of options for their son, Ryan, who was born with a complex set of heart defects. His great arteries came from the wrong sides of the heart, his lower chambers were switched, there was a hole between his ventricles and he had a bad mitral valve. He had already undergone three open-heart surgeries to save his life.

But in 2005 Ryan was so weak, he needed a wheelchair to get down the halls at school.

“At that point, I couldn’t stand to see him in a wheelchair anymore,” Tim said. He and Tracey wanted their then-13-year-old to be healthier, and they were determined to get him the care he needed.

“He was so weak and so small,” Tracey said. “He was always at the 5th percentile of height and weight.”

Roger Vermilion, M.D., chief of Pediatric Cardiology at Golisano Children’s Hospital and Ryan’s cardiologist, felt it was time for another heart surgery. Ryan’s previous two surgeries in 1994 and 1999 were performed at The Cleveland Clinic because at the time Rochester didn’t have a surgeon who could do the complicated surgeries Ryan needed. The family wanted to return to Cleveland again for this latest surgery.

“But Cleveland wouldn’t touch him,” Tim said. “They thought he could wait another year or two.”

Ryan’s parents and Dr. Vermilion



Photo courtesy: Ken Huth



Photo courtesy: the Sheehan family

Alfieris knew Ryan needed some inspiration ... in his recovery. He told Ryan that if he could gain another 20 pounds, he would take him for a flight in his airplane. It took a few months, but he did it.



Photo courtesy: Ken Huth

didn't think Ryan had that long to wait. So they turned to the new pediatric cardiac surgeon at Golisano Children's Hospital at the University of Rochester Medical Center, who agreed Ryan needed surgery as soon as possible.

Ryan's set of defects and extensive surgical history are rare, so it was difficult for George Alfieris, M.D., chief of pediatric cardiac surgery, to give the family an exact idea of how the surgery would go. He told the family it was risky and there was a 30 percent chance Ryan wouldn't make it off the operating table.

"I operate on hundreds of kids every year, and Ryan's heart was the most complicated one I'd ever seen. And he

was very sick," Alfieris said. "It was hard to know how he would do."

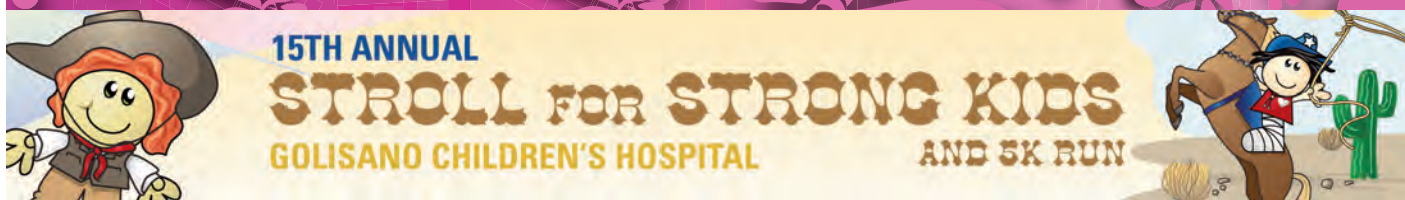
Alfieris had to cut through and clear a lot of scar tissue from the three previous surgeries to get to Ryan's heart. Once inside, Alfieris repaired Ryan's leaking and hardened tricuspid valve that had been making him so sick. He also relieved the heart of some of its burden by performing a bidirectional Glenn shunt procedure, which routes the blood from the upper body past the heart, directly to the lungs for oxygenation. Now his already weak heart had a little less work.

Knowing how difficult it would be to place a pacemaker's leads into Ryan's heart later because of his complicated

arteries, Alfieris and his team did it while they had access. Children like Ryan are at increased risk for developing arrhythmias later in life, but most are able to have them placed years later without open-heart surgery.

Ryan's recovery was not quick. He weighed just 60 pounds when he went home two months later. He was so sick going in and the surgery was so complicated, it took months for Ryan to even catch up to where he was before the surgery. It was very disappointing for Ryan.

Alfieris knew Ryan needed some inspiration to get over the hump in his
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Miracle Weekend: Saddle up for the Stroll for Strong Kids

Just as honor and justice reign supreme in the Wild West, so too will this year's Western-themed Stroll for Strong Kids invite families to saddle up for a greater good. For months leading up to this awe-inspiring event, set for **Saturday, June 4**, families, providers and supporters recruit

family members and friends to build teams in support of the kids at Golisano Children's Hospital at the University of Rochester Medical Center.

Registration on the day of the event will begin at 8 a.m., with the MedVed 5K run starting at the University of Roch-

ester's Fauver Stadium at 9 a.m. and the walk kicking off at the stadium at 10:15 a.m. To sign up for the event and create a personalized fundraising website, visit <http://bit.ly/Stroll2011>. Contact Michael Fahy at (585) 276-5176 or michael.fahy@rochester.edu with any questions.



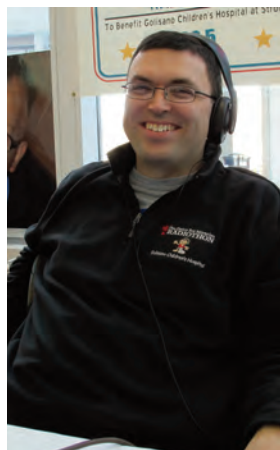
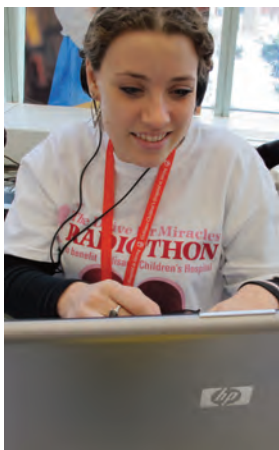
Tune into the CMN Hospitals Telethon on News 10 NBC

Meet the miracles who inspire hope and the people committed to supporting during Golisano Children's Hospital's annual Telethon. During this year's event, scheduled for 7 to 11 p.m. Friday, June 3, and 5 to 8 p.m. **Saturday, June 4**, News 10 NBC will broadcast exclusive interviews with the families of the 2011 Miracle Kids, catch up with local hospital supporters (many of whom have their own incredible stories to share) and speak with health care providers from all over the hospital about the amazing work they do everyday to support and care for our region's children.

To make a pledge of support during Telethon hours, dial (585) 241-KIDS. For more information or to donate online, visit www.givetokids.urmc.edu.



Grateful for sharing and caring during Radiothon



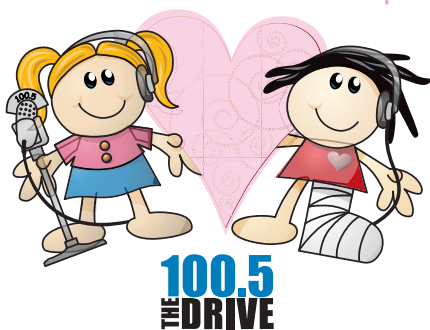
GRANT ENGELSEN SAT CHEERFULLY IN HIS WHEELCHAIR, HOLDING ONTO A NEW, HUGGABLE STUFFED DOG THAT BETSY FINDLAY, DIRECTOR OF GOLISANO CHILDREN'S HOSPITAL'S OFFICE OF ADVANCEMENT, HAD JUST GIVEN HIM.

Grant was on his way home after finishing up cancer treatment and had stopped by the Drive for Miracles Radiothon with his family to say hello.

"Do you want an extra stuffed animal for your sister?" asked Findlay. "That's okay, we can share," the little boy responded.

With those sweet, simple words,

 **The Drive for Miracles
RADIOTHON**
to benefit Golisano Children's Hospital



Grant cut to the heart of what the Drive for Miracles Radiothon is all about — sharing what you have with others. Thanks to a great deal of generosity from the community, the three-day event in February, which was hosted by 100.5 FM The Drive and WHAM 1180, raised nearly \$76,000 for Golisano Children's Hospital at the University of Rochester Medical Center.

Golisano Children's Hospital would like to offer a heartfelt thanks to families who shared their stories and volunteers who shared their time to make the 2011 Radiothon a resounding success. Golisano Children's Hospital is also very grateful for the donors and sponsors who shared their resources, including Tops Friendly Markets, the presenting sponsor; Auction Direct, the vehicle sponsor and Agape Physical Therapy Services, the Miracle Moments sponsor; along with Tim Hortons, Papa Johns and Tops for providing food and beverages to volunteers throughout the event. Special thanks are due to Wisteria Flowers and Gifts for providing beautiful floral arrangements that were sent to the patients when donors made a monthly miracle maker pledge.

To share your stories, time and/or resources with Golisano Children's Hospital, please call (585) 273-5948 or visit www.givetokids.urmc.edu.

Outstanding Commitment by a Community Group

WNY Optics

Family sees value in pediatric care first-hand



AMANDA SCHULMERICH'S LIFE HAS BEEN SAVED TWICE BY GOLISANO CHILDREN'S HOSPITAL AT THE UNIVERSITY OF ROCHESTER MEDICAL CENTER.

She was born seven weeks premature at a little more than 2 pounds and relied on the hospital's attentive neonatal intensive care unit staff to help her grow and gain strength. And at 11-years-old, Amanda was diagnosed with Ewing's Sarcoma, a rare form of cancer that Golisano Children's Hospital doctors treated successfully. Though Amanda no longer comes to Golisano Children's Hospital for care, her family's relationship with the hospital is far from over.

"When Amanda got sick, the hospital became an integral part of our lives," said Ron Schulmerich, Amanda's dad. The Schulmerichs wanted to thank the hospital, so they began holding a golf tournament for the western New York optics industry in 2000. The event was a hit from its first year and has grown immensely since then, attracting optics companies to Rochester from all over the country and the world. The Schulmerichs



will celebrate their 11th annual WNY Optics golf fundraiser for the hospital Thursday, July 21, at Shadow Lake and Shadow Pines golf courses.

"Giving back enriches our lives and it allows us to tell the people in my business about the hospital in a grassroots way," Schulmerich said.

Participants have become very invested in the cause, Ron shared. Friendly rivalries between teams and among individuals have grown over the years. The tradition of finding fun ways to work together to support a charitable cause speaks to the camaraderie and spirit of the industry as a whole, Ron noted. He is grateful for the support of the tournament's participants, who have helped make the event so successful.

"We could never work hard enough to pay the hospital back," Ron said. "The hospital says thank you to us when really it should be reciprocal. We want to continue raising awareness and funds for Golisano Children's Hospital as a way of thanking the staff and administration. In a small way, it helps the phenomenal

work continue to benefit children."

The Schulmerichs have been able to thank the hospital more than they ever could have imagined, and have raised a remarkable total of \$94,039 to benefit Golisano Children's Hospital. When Ron and his wife Diane learned they were receiving a Miracle Maker award, they expressed how humbled and surprised they were.

"We just don't think about what holding the tournament means a whole lot," said Diane Schulmerich. "We're happy to help. That is the intent. I feel like it's something that we can do, so we should do it. Our entire extended family has continued to participate year after year and we couldn't do it without their love and support."

Golisano Children's Hospital is proud to celebrate the dedicated, selfless work of the Schulmerich family, who set out with a simple goal of doing good and wound up making miracles happen in the process. For more information on the WNY Optics Golf Tournament, please email wnyoptics@rochester.rr.com.

Outstanding Commitment by Grateful Parents

Scott & Despina Mitchell

Inspiring many by *Keeping Hope Strong*

THERE ARE NO WORDS TO DESCRIBE THE DIFFICULTY A FAMILY FACES WHEN THEY HEAR THAT THEIR CHILD WILL BE BORN WITH A MEDICAL COMPLICATION.

It's often difficult to cope with such an overwhelming challenge, let alone to see that unexpected obstacle in a positive light. Yet Scott and Despina Mitchell see their son Mason, who was born with a life-threatening diaphragmatic hernia, as a miracle to be celebrated.

"There's something really special about that boy, and I'm not just saying that because I'm his mother," Despina said. "I don't know what it is, but I think it's his spirit. He's so happy and he's able to connect with people in a really amazing way."

Mason had his first surgery about 10 days after he was born, in May 2007. Just before little Mason had received his second surgery to repair his diaphragm in December, Despina asked Scott, "Wouldn't it be great if we could find a way to give back to the hospital, even if it were just one or two thousand dollars?" Scott wholeheartedly agreed. Even though the family was going through a lot, they were determined to try to give back with an event they set for February 2008. Little did they know that just a few years later, the Keeping Hope Strong event would have raised nearly \$60,000 for Golisano Children's Hospital.

The Mitchells have made a real and positive impact for Golisano Children's Hospital in the few short years they have been holding their event. Thanks to the Mitchells, the neonatal intensive care unit where Mason was cared for during his first 56 days of life now has a newly renovated waiting room for families. The Mitchells also purchased pediatric surgical equipment for laparoscopic procedures, which are safer and less invasive for children. At last year's Gala for Golisano Children's Hospital, the family made an incredibly



generous pledge to purchase a new pediatric anesthesiology machine, which is safer and helps children breathe more easily during surgery.

"We're in a position now where we're asked, would you do this again?" said Despina. "The answer is absolutely, we definitely would. We look at this as our destiny. We believe Mason was meant to come to us because we were meant to have these people (from the hospital) in our lives. He has given us the motivation and desire to do something that makes complete sense and has come easily to us."

This year, the Mitchells have been awarded special recognition for their hard work. Children's Miracle Network Hospitals has named Mason Mitchell New York State's Champion and Ambassador. The family will celebrate with other state champions during a trip to Washington D.C. and Orlando in October.

"If anyone is deserving of such an honor, it's the Mitchells," said Betsy Findlay, director of Advancement at Golisano Children's Hospital. "Despina

"We look at this as our destiny. We believe Mason was meant to come to us because we were meant to have these people in our lives. He has given us the motivation and desire to do something that makes complete sense and comes easily to us."

— Despina Mitchell

and Scott never cease to amaze me with their eagerness and willingness to help the hospital by sharing Mason's incredible story and always finding new ways to give back. We're excited to celebrate and honor such a committed, resilient and inspiring family as the Mitchells."

Outstanding Commitment by Individual

Eric Dreyfuss, M.D.

Gift is an act of heroism for local children

AFTER NEARLY HALF A CENTURY OF TREATING CHILDREN WITH ALLERGIES, ERIC DREYFUSS, M.D., CLINICAL ASSISTANT PROFESSOR OF PEDIATRICS AT GOLISANO CHILDREN'S HOSPITAL AT THE UNIVERSITY OF ROCHESTER MEDICAL CENTER, MADE A DECISION OF HEROIC PROPORTIONS, THAT WOULD FOREVER CHANGE THE COURSE OF HISTORY FOR CHILDREN IN OUR REGION.

Dreyfuss established the Founders Fund, committing to make a \$2 million gift that essentially serves as a promise to the Finger Lakes community that children who suffer from allergies will be provided the best possible care for generations to come. With Dreyfuss's gift, he has given Golisano Children's Hospital something invaluable — a sound and definitive investment in the hospital's future.

"We are so very grateful to our friend and colleague, Dr. Eric Dreyfuss," said Nina F. Schor, M.D., pediatrician-in-chief at Golisano Children's Hospital and chair of URMC's Department of Pediatrics. "We are especially grateful as well for the chance it affords us to honor the outstanding founders of the field of pediatric allergy many of whom hailed from right here in Rochester, N.Y."

Thanks to Dreyfuss's charitable contribution, Golisano Children's Hospital's pediatric allergy program can recruit an experienced and reputable chief to see the program through its launch and ensure its stability as it begins to take on research projects. Dreyfuss's gift doesn't stop there. The Founders Fund will also provide training programs for future pediatricians and allergists to offer the best possible care to children with allergies.

"I really wanted to honor my mentors, the people who taught me, and to give back to the university and the community," Dreyfuss said.



Allergies affect one in five Americans. They are life-changing and potentially deadly. To those children whose lives are threatened by asthmatic episodes and to the many others who live in constant fear of ingesting nuts, milk and other various allergens, Dreyfuss's gift is truly an act of heroism.

Asthma, a frequent complication arising from allergens, is the most common chronic illness in childhood and it has been increasing for a number of years, Dreyfuss explained. Allergies affect one in five Americans. They are life-changing and potentially deadly. To those children whose lives are threatened by asthmatic episodes and to the many others who live in constant fear of ingesting nuts, milk and other various allergens, Dreyfuss's gift is truly an act of heroism.

Golisano Children's Hospital prides itself in having a community of committed and caring pediatricians, who remain passionate and driven to improve the lives of children in our region throughout their career. Dreyfuss's selfless and courageous commitment is emblematic of that mindset. Through his gift, Dreyfuss can and will help make miracles happen for the children in our region and for that, we are eternally grateful.

Outstanding Commitment by a CMN Sponsor

IHOP Restaurants

Flipping for chance to help Golisano Children's Hospital

FOR THE PAST SIX YEARS, LOCAL IHOP RESTAURANTS HAVE PARTICIPATED IN NATIONAL PANCAKE DAY, A DAY IN MARCH WHEN IHOP RESTAURANTS ACROSS THE NATION SERVE UP FREE STACKS OF PANCAKES TO CUSTOMERS AND COLLECT DONATIONS FOR LOCAL CHILDREN'S HOSPITALS.

The fundraising event is coordinated by Children's Miracle Network Hospitals, a network of more than 170 hospitals throughout North America committed to helping children.

The two area IHOP restaurants, located at 556 Jefferson Road in Henrietta and 2190 North Goodman St. in Irondequoit, are always enthusiastic about the special day—they go out of their way to help kids. But this year, the restaurants went above and beyond to make a difference for the kids in our region.

When Betsy Findlay, director of Advancement for Golisano Children's Hospital at the University of Rochester Medical Center, totaled up what the restaurants had raised last year, Jason Hargrave, general manager for the IHOP in Henrietta, said, "Oh, we're going to blow those numbers out of the water."

Hargrave fulfilled his promise to Golisano Children's Hospital, doubling the amount the two restaurants had raised from the previous year at his IHOP restaurant alone. The Henrietta restaurant raised \$3,450 and the Irondequoit IHOP raised \$1,181 for the hospital.

The restaurants generated excitement among employees by challenging them to sell one and five dollar Children's Miracle Network Hospitals balloons for the hospital and offering incentives for the most proactive employees. On Pancake Day, the IHOP restaurant employees sported Golisano Children's Hospital t-shirts with the slogan "Making Miracles Happen" and took fun photos with a life-sized Sandy



Strong cut-out for Golisano Children's Hospital's Facebook page.

"They were just so enthusiastic!" Findlay said. "We're so grateful to them for their efforts and are very excited to show them how much we appreciate all that they've done."

Golisano Children's Hospital is pleased to honor the two local IHOP restaurants with this year's Miracle Maker Award for Outstanding Commitment by a CMN Hospitals Sponsor. Their spirit and passion for giving back certainly paid off and serves as an inspiring reminder to us all that a little motivation and creativity can go a long way.

On Pancake Day, the IHOP restaurant employees wore Golisano Children's Hospital t-shirts with the slogan "Making Miracles Happen" and took fun photos with a life-sized Sandy Strong.

Outstanding Commitment by a Corporation

DGA Builders



DGA Builders

Supporting Golisano Children's Hospital from the ground up

GREGORY CRAIG, PRESIDENT OF DGA BUILDERS, FONDLY REMEMBERS THE FIRST TIME HE VOLUNTEERED AT A GOLISANO CHILDREN'S HOSPITAL FUNDRAISING EVENT — THE STROLL FOR STRONG KIDS. IT WAS DARK. IT WAS RAINY. "IT WAS ABSOLUTELY FABULOUS," CRAIG SAID.

The level of commitment DGA Builders has given Golisano Children's Hospital at the University of Rochester Medical Center goes far beyond monetary donations. Gifts from the community are certainly necessary. They help Golisano Children's Hospital operate at the highest level possible when it comes to research, clinical work, education and community outreach. But it is that added personal touch at the ground level that makes DGA Builders a truly stellar community partner.

Craig has volunteered at a variety of events over the years, from being a parking attendant at the Ten Ugly Men Festival to helping with a train for kids at the Fairport Music Festival to setting up chairs and decorations at Golisano Children's Hospital's Gala.

"It's a passion of mine that transferred to a passion of DGA Builders," Craig said. "We started slowly with a few dollars here and by helping out as best we could and we slowly increased our giving and got more involved."

DGA Builders has served as a major sponsor for Golisano Children's Hospital's Gala and Golf Classic events for the past six years. DGA Builders also helped build Golisano Children's Hospital's B&L Wholesale Pediatric Treatment Center, which was renovated in 2008. The Treatment Center provides private rooms and a sunny place space for families coming to the hospital for out-patient treatment like chemotherapy and blood transfusions.

"DGA Builders is an incredible partner for Golisano Children's Hospital," said Scott Rasmussen, assistant vice president of Advancement at Go-



lisano Children's Hospital. "We always know we can rely on Greg and his team to help us hold fundraising events for the hospital. There's no question that DGA Builders is truly invested in helping the hospital help kids."

DGA Builders makes donations to various organizations throughout the community. But the company has a soft spot for Golisano Children's

Hospital and has become increasingly invested in supporting the hospital's mission to provide the best possible care for the children of our region.

"Once you see the help and the good that the hospital is doing for our local community and others, it's pretty important to give our support," said Craig. "It's important for the region and for everyone in the area to have a great hospital for our children."



DGA Builders helped build Golisano Children's Hospital's B&L Wholesale Pediatric Treatment Center.

CMN Hospitals get a new look

Children's hospitals have got to stick together. Golisano Children's Hospital at the University of Rochester Medical Center is one of 170 hospitals across the U.S. and Canada that makes up Children's Miracle Network (CMN) Hospitals. The network is a non-profit organization, dedicated to partnering with businesses and organizations to support local hospitals.

CMN Hospitals decided to renovate its brand this year, refreshing its image and name. In an effort to reflect the hospitals it supports, CMN added the word "Hospitals" to the end of its name.

CMN Hospitals also simplified the look of their signature red and yellow balloons, which you may have seen sold for \$1 at local stores like Tops and Rite Aid to raise funds for Golisano Children's Hospital. For more information on Children's Miracle Network Hospitals, visit <http://childrensmiraclenetworkhospitals.org/>.



The following local Children's Miracle Network Hospitals sponsors are raising funds for Golisano Children's Hospital this year:

Kinney Drugs – March 13 to May 22
Ollie's Bargain Outlet – April 1 to 30
Rite Aid – April 10 to May 28
Walmart and Sam's Club – May 1 to June 11
Chicos, White House/Black Market and Soma's – May 1 to 31
Tops Markets – June 19 to July 2

Children's Miracle Network Hospitals

Other CMN Hospital sponsors who continue to make a difference year-round for our children include:

KE/MAX Realtors
Kiwanis
IHOP
Credit Unions for Kids
Ace Hardware
American Legion

What is Miracle Jeans Day?

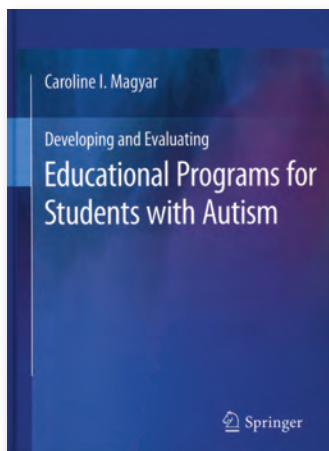
The Miracle Jeans Day concept is simple. Individuals or groups can participate in Miracle Jeans Day by supporting Children's Miracle Network Hospitals with a minimum donation of just \$5. In return, participants can choose from memorable Miracle Jeans Day merchandise to wear with their jeans on **September 14, 2011**. All funds raised go directly to the Golisano Children's Hospital. **Go casual for kids by wearing jeans** to support children in our community. For more information, visit www.miraclejeansday.com

Go casual for kids!

**miracle
JEANS
day**
SEPTEMBER 14, 2011



Book helps educators build effective autism programs



AUTISM PROGRAMS NEED TO BE AS FLEXIBLE AS THEIR STUDENTS ARE DIFFERENT FROM ONE ANOTHER.

No effective one-size-fits-all program exists for educating children on the autism spectrum, but one University of Rochester



Medical Center (URMC) professor has written a book to guide skilled educators in creating, evaluating and modifying programs to fit the needs of their students and the skills of their staff.

Caroline Magyar, Ph.D., associate professor of Pediatrics at URM's Strong Center for Developmental Disabilities, and author of *Developing and Evaluating Educational Programs for Students with Autism* (Springer, 2011), believes the best programs for children with autism are those that are always evolving to meet their needs.

"There are a plethora of packaged curricula that educators can use with their students, but no child with autism is the same as another, so no one program will work for every child. What educators really need are the tools to create effective

programs for the students they have —and the tools to measure whether those programs are working," Magyar said. "This book addresses all of those needs."

Magyar's career working with children on the spectrum began in the classroom and progressed from there to the school- and district-level, and now to the system-level. She consults with schools and organizations across New York state to help them design programs that work for their students and their staff. Her goal is to assist educators to become independent and not need her services any longer.

"They become empowered in the process. I give them the tools to see where they are and what they need to get where they want to go," Magyar said.

Magyar is now working on a field manual to help educators who have less experience designing programs for children with autism.

community spotlight

SMILE Spaghetti Dinner brings joy to families

For the past five years, students in the Communications Sciences and Disorders Association at Nazareth College have held a spaghetti dinner benefit to raise funds for the Cleft and Craniofacial Center at Golisano Children's Hospital at the University of Rochester Medical Center. Families come to the event for a healthy dose of comfort food and children's activities to entertain the little ones. This year's event, which took place April 1, raised about \$2,100 for Golisano Children's Hospital. We would like to thank Mary Sweeney, who heads up efforts to organize this wonderful event for families, along with the many other participants and volunteers who take part every year.



Ski Invitational slopes in favor of Golisano Children's Hospital

Skiing is not just a favorite winter pastime for Paul Tesson and Mark Schwartz. The two have turned a fun outdoors activity with family and friends into a remarkable fundraiser, which has greatly benefitted the children and families who seek care at Golisano Children's Hospital.

The ninth annual ski invitational, which took place on Valentine's Day at Bristol Mountain brings the all-time total of funds raised from this event to an incredible sum of nearly \$320,000. Thank you so much to Tesson, Schwartz and all those who have helped make this event a resounding success year after year. We are very grateful for all that you've done to help the children in our region.



special thanks

- Cobbles Elementary School raised \$1,541 in their Coins for Kids Fundraiser. Thanks!
- Thank you to the Passero and Yazwinski families for donating nearly \$15,000 from this year's 100 Inning Softball Game.
- The Genesee Valley Hunt Races donated \$5,000 to the hospital. Thanks!
- Thank you to ROCBeer and Jaime Barclay for donating \$500.
- We appreciate the \$1,300 donation from Pace Electronics.
- Thanks to those who organized and participated in the Cycle for Hope, which raised nearly \$30,000 for Camp Good Days & Special Times and Golisano Children's Hospital.
- The first-ever Jordan's Journey Benefit Dinner raised \$4,912.50 for the hospital. Thank you!
- The Budda Foundation donated more than \$1,500 in play items for patients. Thanks!
- Thank you to the Mitchells, who raised \$15,110 during Keeping Hope Strong.
- The Acevedo-Garcia family made a donation of \$610, which we greatly appreciate!
- Thank you to the Panera Bread Foundation for their incredible donation of \$10,537. We appreciate your support!
- Thank you to Rebecca Orbach for her generous and personalized donation

through her Bat Mitzvah project. We appreciate your time and effort!

- The Azzarone family donated \$400 from the 16th annual John M. Azzarone Memorial Golf Tournament – Thanks so much!
- Thanks to Ida Wheeler and the rest of the Holiday Showcase organizers for donating more than \$4,000 from the event.
- The 10th annual Rainbow Classic generated \$20,000 from their event. Congratulations on another great year!
- We appreciate the \$13,815 donation from the Spirit of Children – thanks so much!
- Trammel Creative Portraiture donated \$550 from the Holiday Portrait fundraiser. Thanks!
- The Peace of Mind Home Inspection Service donated \$400 to Golisano Children's Hospital. We appreciate your generosity!
- Thank you to the Wayne Central Varsity and JV Girls Basketball teams for their donation through the More Than a Game Foundation.
- Thank you to Maya Grace Richards for donating \$10.01 from her lemonade stand!
- The Churchville Chili FIRST Robotics Team 340 gave a gift of \$1,300 to the hospital.
- We appreciate the donation from the Webster Montessori School of \$325.50

from their Valentine's Bake Sale.

- Thank you to the Van Bortel Ford and Subaru Dealerships for their donation of \$500 from their "Give Back to Those in Need" Campaign.
- Thanks so much to the Photo City Browns Backers for their donation of \$200!
- We appreciate the donation from Rotary Club of Brighton of \$500. Thanks!
- The United Martial Arts Center donated \$200. Thanks!
- We appreciate the Steelers Fan Club of Rochester, which has donated more than \$30,000 to local charities, including Golisano Children's Hospital. Thank you very much!
- Thank you to the students at Webster Schroeder, who donated nearly \$500 from the proceeds of their annual cabaret.
- Thanks to Meghan Sessler, Natalie Pope and Ryleigh Mattle, who donated almost \$1,200 when they asked friends and family to support the hospital in lieu of gifts at their Sweet 16 party!

We'd like to offer many thanks to these folks and to our many generous supporters and event organizers that work so hard to help Golisano Children's Hospital. Thank you!

upcoming events

May 28-31, Roc City Rib Fest, Ontario Beach Park. Seasoned barbeque vendors from across the Northeast will serve up their best racks of ribs at this Memorial Day weekend festival, which benefits Golisano Children's Hospital. Tickets are \$5 and free for children younger than 12. For more information, visit www.roccityribfest.com. If you would like to volunteer, call (585) 273-5948.

July 23, Ten Ugly Men, Genesee Valley Park. The Uglys will host their beloved day-long festival to give back to local charities and celebrate the joy of summer. General admission tickets are \$40 at the door, \$30 in advance and free for children 12 and younger. For information, visit www.tenuglymen.com. Call (585) 273-5948 to volunteer.

Aug. 27, Fairport Music & Food Fest, Lift Bridge Lane. See all that the village of Fairport has to offer with this exciting, family friendly festival. Tickets are \$15 at the door and \$10 in

advance. Children 12 and younger get in free. For info., visit www.fairportmusicfestival.com. To volunteer, call (585) 273-5948.

Golf Events

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

May 25	Golfing for Kids Tournament sponsored by Walmart and Sam's Club
June 20	23rd annual Kiwanis Charity Golf Tournament
June 20	4th annual Cheshire A/V Golf, http://www.egolfevent.com/cheshireclassic .
June 22	B&L Wholesale Golf Tournament
July 21	WNY Optics Golf Tournament
July 26	3rd annual Cheshire A/V Golf
Aug. 1	12th Annual Tim Milgate Golf Fundraiser
Aug. 1	9th Annual Kittelberger Charity Golf Tournament
Aug. 29	Ed Kaufmann Golf Tournament
Aug. 29	15th annual Golisano Children's Hospital Golf Classic

Delivering a Miracle

Lauren Strobel

Continued from page 7

Lauren's survival was still very iffy. Her lack of normal brain activity and the fact that she didn't have a normal heart-beat for 22 minutes prompted the medical team to have a very painful conversation with the family.

Guillet explained to the family that even if Lauren was able to start breathing on her own, it was very possible she would never sit up or speak. She was without oxygen for a very long time, and she might need total care for the rest of her life. Did the family agree that it would be in Lauren's best interest not to resuscitate her if her heart stopped again? Did they feel that it would be in her best interest to stop providing aggressive treatment and instead keep her comfortable until she died?

Lauren was very bloated because of all the fluids she needed pumped into her. She had a half dozen machines hooked up to her, helping her breathe, keeping her cool, monitoring her heart, her oxygen, her temperature. Mike and

Christy couldn't touch her because it was too much stress on her.

"I didn't get to see her eyes," Christy said. "They were always closed. It was just ... a very grave situation."

They decided to keep going and to resuscitate Lauren, if she needed it. They sat next to her and told her all about her room at home. They told her about her puppies. Read her books. But she didn't react to any of it.

On Lauren's 5th day of life, Mike and Christy were about to leave for the Ronald McDonald House to rest when she opened her eyes to look at her parents.

"She looked right at me," Christy said. "It was so wild to see her react. It was so moving."

That night, everything changed. From that moment on, Lauren improved. She worked her way off the ventilator. She started eating, although much of that was through a tube snaked down her nose into her stomach (NG tube). Her EEG at about a week old wasn't much better than her first one, but that didn't stop her or her parents from forging ahead. Lauren started breathing on her own and was able to wean off the ventilator.

On her 9th day of life, Lauren's EEG was much improved.

"She went from practically brain dead to being near normal. We all went from thinking she was gone to, 'She's going to be OK,'" Christy said.

While that was an incredible achievement, Lauren still wasn't drinking from a bottle well. Christy didn't want Lauren to have a tube surgically placed into her stomach. She was determined to get Lauren eating normally or at least getting enough through the NG tube. At 3-weeks-and-3-days-old, Lauren went home with her family, still taking food through the tube and her brain function still some-



Photo courtesy: Ken Huth


"She looked right at me. It was so wild to see her react." That night everything changed. From that moment on, Lauren improved.

what in question, but she was breathing on her own and responding to her parents.


"I believed in her. I thought if I could get her home and really work with her that I could get her feeding. She was so strong and I could be strong, too," Christy said. She said Lauren was likely to have some disabilities but that she would work just as hard to get Lauren all the help she needed.



Three days after getting home, Lauren didn't need her NG tube anymore. Christy enlisted the help of early intervention services, but Lauren started meeting every developmental milestone quickly. At her 6-month-old follow up at Golisano Children's Hospital, her physician said Lauren didn't need to come back. Christy called Guillet down to see Lauren, and she was delighted to see her former patient doing so incredibly well.

"I would never have predicted this," Guillet said. "It's a testament to what cooling therapy can do, but also, what a family and child can accomplish with hard work and determination."



Golisano Children's Hospital would like to announce that we have our own United Way designation number. By selecting **#2530** on your United Way forms, your donation goes directly to the Children's Hospital. In the spirit of community, we ask you to share your gift between Golisano Children's Hospital and United Way's Community Fund. **We thank you for your generosity.**





Standing strong again

Joshua Guest

Continued from page 9

to suppress his immune system and Mestinon to treat his muscle weakness. He had a central line placed in his chest and experts at Wilmot Cancer Center used it for plasmapheresis. Much like dialysis, during plasmapheresis Josh's blood was taken out of his body and the blood's serum was cleaned before putting back the red blood cells. Almost immediately, he started to get stronger. But in order to return to his normal, energetic self, Josh needed his thymus gland surgically removed.

The thymus sits high in the chest, behind the sternum, and plays an important role in building the immune system prenatally and in babies. By about 12-months-old, the gland's work is largely done. In rare cases, it can go haywire, causing the immune system to turn on itself and attack nerves. Plasmapheresis and the medications would help Josh, but what he really needed was a thymectomy.

After 18 days and a couple complications, Joshua could finally breathe on his own. He could take rides down to the indoor-outdoor play area, called the Play Deck, although he tired easily.

"By the time we'd get back, he couldn't hold his head up," Gordon said.

The same muscle weakness that made it hard for Josh to breathe also made it difficult for him to swallow without choking. He was finally cleared to have food. It had been five weeks since he last ate. The family celebrated with a trip to the Seneca Park Zoo. His sister Julia had taken a couple trips to The Strong – National Museum of Play, but this would be Josh's first trip out. The hospital gave Josh a day pass and Child Life sent the family with tickets and a special wagon to pull him around.

On Sept. 14, 2009, six weeks after Josh first got sick, surgeons removed his thymus. Because of its location, he had to have his chest opened as if he were having heart surgery. He struggled with pain afterward, but once his pain was under control, he improved as rapidly as he had gotten sick. Josh was well enough to go home six days later. Within two weeks, Josh was back on his bicycle.

Ciafaloni said Josh has been doing very well. He hasn't needed steroids to suppress his immune system since the summer of 2010. If his immune system continues to behave itself, he'll soon be declared in full remission.

"He's a very affectionate, hugging and smart kid," Ciafaloni said. "And he sure has a contagious smile!"

For all he's been through, that may be the most remarkable thing of all.



Photo courtesy: Ken Huth



SAVE *the* DATE

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A second chance

Leah McAdam

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Leah was behind her developmental milestones when she arrived at the day care center, but she quickly learned how to crawl and then to walk, and she picked up on English too. Although Leah's "plumbing" issues were not completely fixed yet, she was "as happy as can be," Debbi said, because she was no longer in pain. Leah made friends quickly and Debbi joked that she has a more active social life than her parents.

Pegoli performed a third surgical procedure in the beginning of 2010 to reconnect Leah's proper tubes together and create a rectum for Leah. Her surgery, a sagittal anorectoplasty, went well, but little Leah had other plans.

Normally, these procedures are done before an infant can walk or stand, explained Pegoli. But 18-month-old Leah did not want to sit still like a newborn. The little girl fully enjoyed her newfound ability to move about comfortably and bounded around the hospital after the surgery, accidentally tearing her new opening. She was back in surgery several days later with Pegoli, to repair the damage and this time, Leah let herself heal.

Still, she needed another surgery in

April 2010, to reverse the ileostomy and colostomy.

More than a year later, Debbi and David could not be happier. They chalk their success up to the support system they were so fortunate to have during their time of need.

"You think you can go about your job as normal when your child has multiple surgeries, but you just can't," David said.

Debbi Napolitano, Ph.D., and David McAdam, Ph.D., who work as assistant professors for Golisano Children's Hospital's Division of Neurodevelopmental and Behavioral Pediatrics, expressed their appreciation for their colleagues who offered to donate their vacation time to the couple, the resources they had to support them through the adoption process and in finding an appropriate day care center for Leah, the friends and family members who helped out when they could and the medical team at Golisano Children's Hospital.

"Now Leah can be whatever she wants to be in life," David proudly declared. The little miracle has come a long way — and thanks to two very compassionate parents and the medical expertise at Golisano Children's Hospital, when it comes to Leah's future, the sky is the limit.

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A whole lot of heart

Ryan Sheehan

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recovery. He told Ryan that if he could gain another 20 pounds, he would take him for a flight in his airplane. It took a few months, but he did it, and Ryan said the goal of taking that flight with his surgeon helped him focus on getting better.

Alfieris was true to his word and took Ryan up in his airplane, nicknamed Herbie. They flew out over Sodus Bay and over Lake Ontario. Ryan said the plane's cockpit was surrounded in windows and gave him a view he'd never seen before.

"It was surreal. It was awesome," Ryan said.

Vermilion said it's been amazing to see the change in Ryan. He has grown to 5-foot-10-inches and weighs 100 pounds more than he did the day he was discharged. He got the surgery exactly when he needed it, Vermilion said. He's a model for other children with heart defects.

"He's one of the new generation of kids who would've died 15 years ago 'without these surgeries,' Tracey said. We don't know what's in store for him. He could have an arrhythmia or his right ventricle could get enlarged and at that point, it'd be a heart transplant."

But after several points when the family prepared to lose Ryan — rushing Ryan's baptism when he was first diagnosed and once involving a counselor to help his older brother, Tim, deal with Ryan's impending death — his parents, Vermilion and Alfieris were delighted to see him graduate last June and go off to college last fall.

"We never thought he'd be able to go away to school," Tracey said. In fact, Ryan said he didn't think he'd be able to either, but in his first semester, he earned a 3.92 grade point average.

"Dr. Alfieris changed everything. He was able to help me," Ryan said. "And it wasn't like he did the surgery and went on to another patient. He stuck with me and helped me get better after the surgery. He even showed up to my graduation party."

Alfieris doesn't hesitate when he talks about Ryan: "He is a miracle. The biggest miracle of my career."



Photo courtesy: Ken Huth

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