

STRONG KIDS NEWS



2012 VOL. II



New Children's Hospital design puts children and families first

At first glance, it is apparent that the new Golisano Children's Hospital is designed around the common theme of supporting our patients – and their families. The most exciting features of the new building are the many spaces planned for gathering, playing, resting and finding respite.

The new \$145-million building, located on Crittenden Boulevard and attached to the University of Rochester Medical Center (URMC) and Strong Memorial Hospital, will be eight floors and approximately 245,000 square feet of space dedicated to children and their families.

The groundbreaking is planned for late summer or early fall this year with an expected opening in 2015.

Not only will the building give our patients and their families private rooms, it will include a new hospitality suite that parents can use to shower, eat home-cooked meals as a family or even run a load of laundry.

“Our families are so dedicated to participating in the care of their children while they’re hospitalized that our nurses have to firmly

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DEAR FRIENDS —

I am often asked why, if health care is a business, Golisano Children's Hospital needs to raise funds for what, in other arenas, would be called "operations." "After all," people say, "other corporations don't ask the public for donations to pay their employees or to buy their equipment and supplies. Why should a hospital need to do so?"

I suppose health care is, at some level, a business. But it is not solely a business and it does not operate by the same market forces that govern other business enterprises in the U.S. There are three fundamental differences between children's health care and most businesses that drive the critical need for your generous donations.

First, we cannot allow the financial balance sheet to be the only determinant of the services we offer to the public. If a manufacturer sees that a particular product does not sell well enough to offset the cost of its production, that manufacturer can decide to discontinue production of that product. But imagine going to a hospital with your child and being told that, while there is a treatment for your child's condition, we cannot provide it to your child because it costs more to provide than we can recoup from your insurer.

Second, public demand cannot be the only driver of the services we provide. Most children are healthy. Most important contributions to child health are preventive and drive down demand for "high-end" health care services. Unlike the case for adults, most preventive and screening health care in children does not involve a procedure or sedation or a hospital stay. This is by design because it is in the best interests of children. But this means that the costliest components of child health care – the PICU, the surgeries, the new imaging modalities like PET-MRI scanning, the genetic therapies – are low-volume, low demand propositions. But imagine going to the hospital with your critically ill child and being told he or she cannot have the test or procedure called for because it was not sufficiently in demand to warrant its continuation.

Finally, we alone do not set the charges for our services or reap all of the direct financial benefits of the wonderful work we do. The equation for determination of charges and receipts for health care services is indeed extraordinarily complex in the current fee-for-service environment. And who knows how much longer fee-for-service will be the order of the day! In addition, if we are the very, very best pediatricians and we prevent any child from getting ill, we make or save health, workforce effectiveness, and, yes, money for the community at large, but not for our "business!"

The bottom line, as any of the Miracle Makers and Miracle Kids in this issue can tell you, is that we need you and are so very grateful to you for giving us the ability to do what we do for all of our children. As you read about each of our wonderful children and families, ask yourselves how many of them would still be here today – healthy and happy – if they had to depend on market forces to fund the seeds for their recoveries. As we plan to build a children's hospital for today's and tomorrow's children, we honor our Miracle Kids and their families and our Miracle Makers, and ask that each of you give whatever you can to ensure the health of our community for many, many years to come.

All the best,



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



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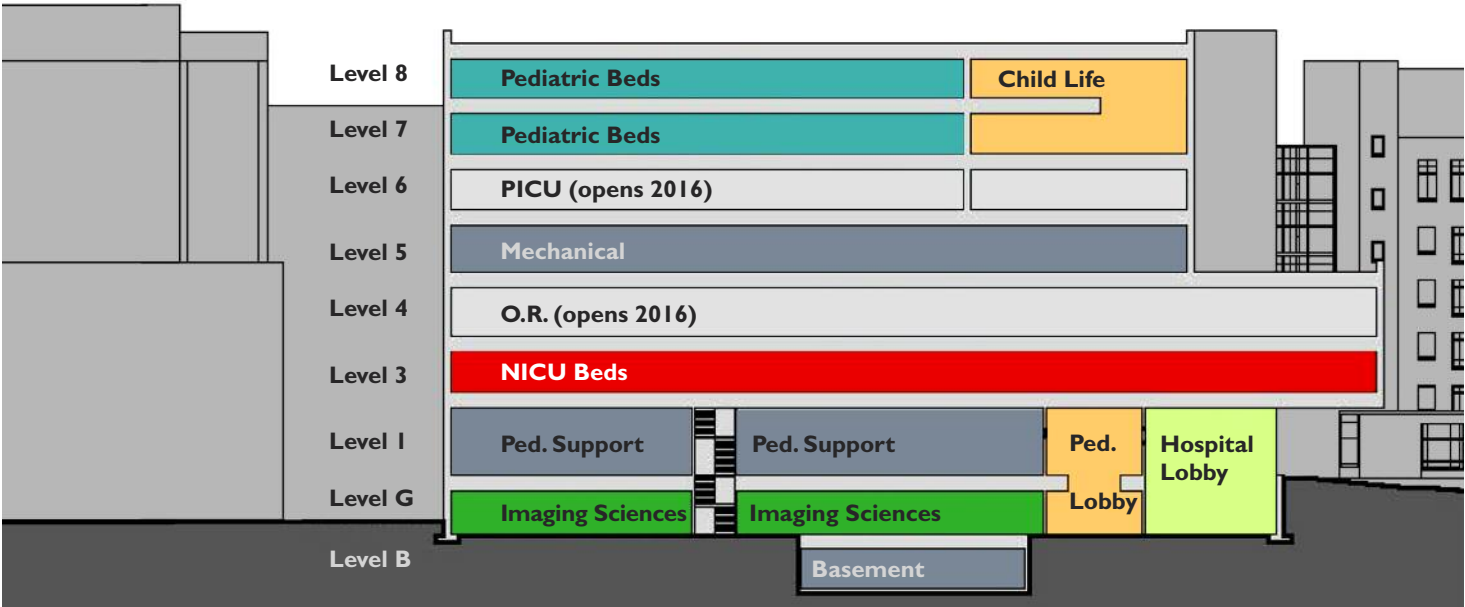
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Side elevation of proposed Children’s Hospital showing floors and space usage



New Children’s Hospital building

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remind them to take care of themselves, too. Having these services so close will make it easier for all our parents to stay rested and nourished,” said Nina F. Schor, pediatrician-in-chief at Golisano Children’s Hospital and chair of URM’s Department of Pediatrics.

A resource library will allow families to learn more about the illness or injury their children have, and a concierge service will assist parents with errands or needs that allow them to focus on their ill or injured child.

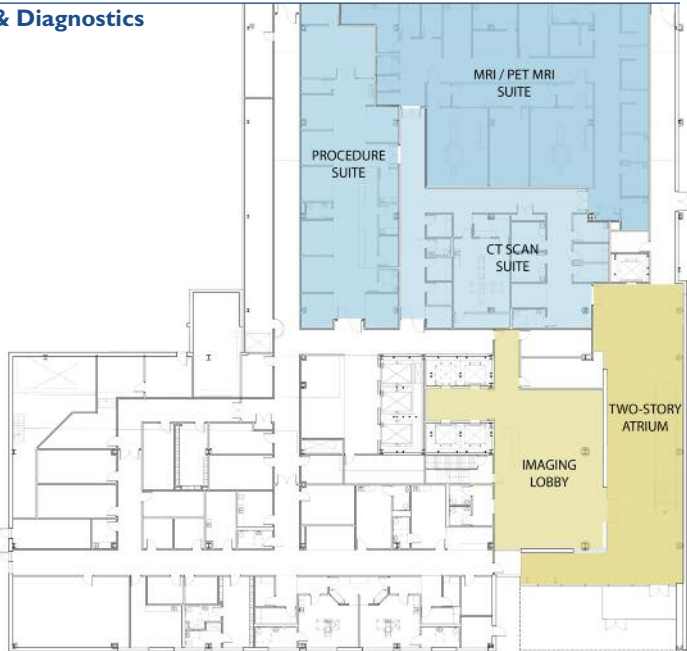
After children go home from Golisano Children’s Hospital, many tell us that the most memorable moments they have are from the playrooms and the playdeck, a large play space filled with natural light. The new hospital will fully embrace this need for play and normalcy with a toddler playroom and a new two-story playdeck on the seventh floor. Above that, on the eighth floor, will be a school room and a teen room that will overlook the playdeck. An outdoor rooftop playspace and a healing garden are also planned.

The two general care floors will each include a respite lounge, allowing parents to rest in a living room-like atmosphere. These rooms will give parents a place to bond with other parents in similar situations, if they choose to.

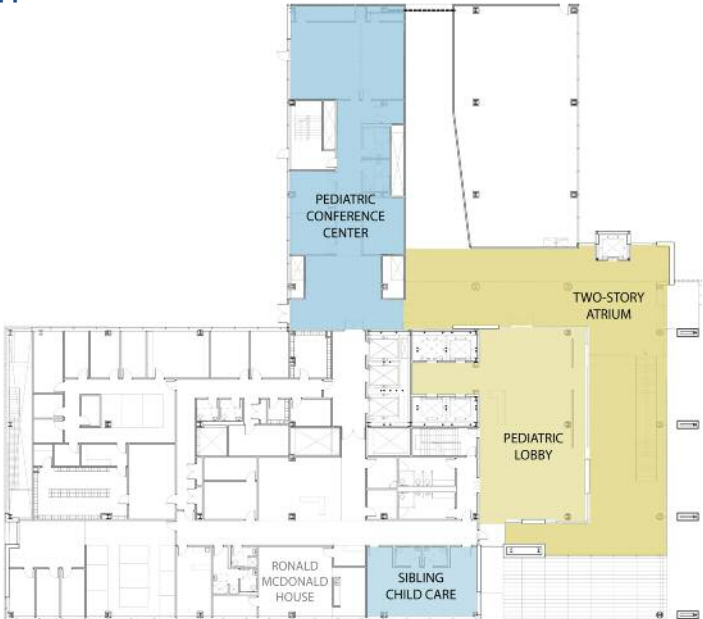
“The new hospital will help us provide state-of-the-art medicine for our region’s children, but our families’ needs reach far beyond the latest technology,” Schor said. “Our children need to play and learn even when they’re sick. Our parents need support, information and, sometimes, they just need

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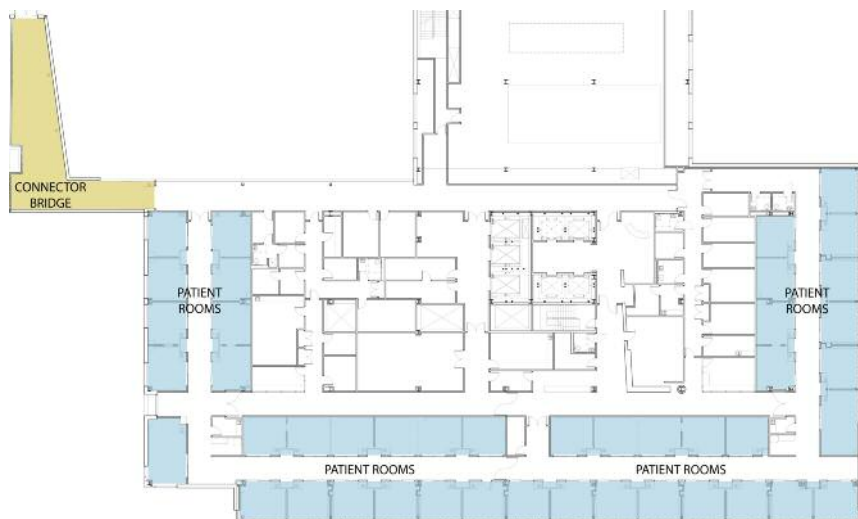
Ground Floor – Imaging & Diagnostics



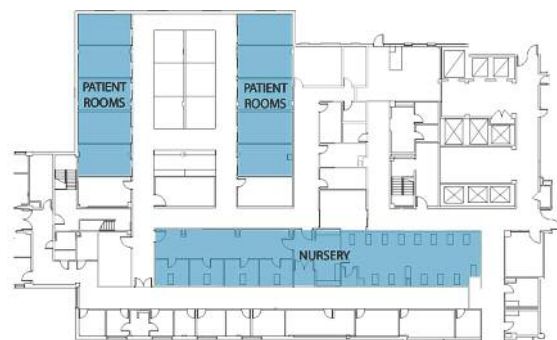
1st Floor – Pediatric Support



3rd Floor – NICU



3rd Floor – Renovated NICU



7th and 8th Floor – Patient Beds



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a shower, a cup of coffee and a little break from the stress of having a sick child.”

The pediatric operating rooms and the Pediatric Cardiac Intensive Care Unit/ Pediatric Intensive Care Unit will open in the new building in 2016. In a later phase of construction, the Ronald McDonald House within the Hospital will also be relocated.

Elizabeth R. McAnarney, M.D., professor and chair emerita of Pediatrics at URM, said her new role as co-chair of the hospital’s campaign has been particularly rewarding.

“This dream of a hospital built from the ground up for our region’s children and their families is becoming a reality,” she said. “We have a considerable amount to do before we can open the doors of the new children’s hospital, but the extensive plans for the new hospital allow us to all fully appreciate what we can do for children when all adults work on behalf of children’s best needs.”

Golisano Children’s Hospital’s \$100 million campaign, which launched publicly in October 2011, supports both a new children’s hospital and major enhancements to pediatric programs. The effort is part of the University of Rochester Medical Center’s \$650 million campaign and the overall \$1.2 billion goal of *The Meliora Challenge: The Campaign for the University of Rochester*.

For a virtual tour of the building,
please visit our interactive website at
www.givetokids.urmc.edu.

For more information on how you
can support the campaign,
please call (585) 273-5948.





MIRACLE WEEKEND COMING JUNE 2-3



Stroll for Strong Kids

Each child carries with them an incredible amount of strength, power and resilience. Every doctor and nurse has the power to heal. And every supporter of Golisano Children's Hospital at the University of Rochester Medical Center is an enormous force for good. This year, the Stroll for Strong Kids is celebrating the superhero within us all – with capes, costumes and plenty of family-friendly fun.

This year's supercharged event, presented by Abbott's Frozen Custard, will take place on Saturday, June 2, on the River Campus at the University of Rochester, located at 252 Elmwood Ave. in Rochester. The 5K race is back in action for its fourth year. Runners should be on their marks and ready to run at super speed at 8:30 a.m. Stroll participants will begin their annual trek at 10:30 a.m. and are welcome to gather at the rugby field next to Fauver Stadium prior to the start time with team-themed t-shirts, banners and an energy level of heroic proportions.

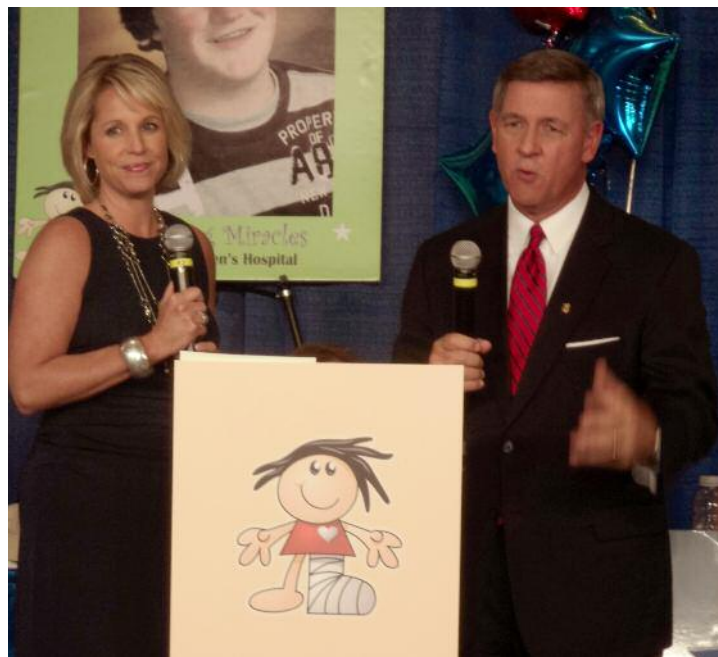
Last year was a record-breaking year, with more than 4,200 participants and more than \$340,000 raised. These numbers are hard to beat, but superheroes can conquer insurmountable odds by leaps and bounds, and by teaming up with our many incredible hospital advocates, we're sure that this year will be even better than the last. To register for the Stroll, please visit <http://bit.ly/stroll2012>.



Children's Miracle Network Hospitals Telethon, Hosted by News 10 NBC

Golisano Children's Hospital is the only hospital in the Rochester and Finger Lakes region devoted solely to the care of children. All donations made through the Telethon stay here to help children suffering from a variety of illnesses and injuries, and support many projects crucial for our children.

Take some time during this year's Telethon, set to air on News 10 NBC from 10 a.m. to 1 p.m. and 6:30 to 11 p.m. Sunday, June 3, to get to know the hospital. You'll get to meet all five of our amazing Miracle Kids and their families, along with some of the warm and wonderful health care providers that serve our community's children. Teams of dedicated hospital supporters committed to making a difference for local kids, and members of the Rochester and Finger Lakes community whose lives have been touched by Golisano Children's Hospital will also appear. To make a gift during the Telethon, call (585) 241-KIDS or give online at <http://bit.ly/GCHgive>.



Meet our 2012 Miracle Kids

As you read through the riveting stories of what this year's five Miracle Kid families have endured and look upon the lovely faces of these precious children, know that they are here, today, because of you. Your support helps us recruit the best and brightest doctors to care for the children

and families who rely on us most. With your help, we're able to purchase state-of-the-art equipment, search for cures and provide the support and resources that our families need. Please enjoy these incredible stories and know that from the bottom of our hearts, we thank you.



Grace Esposito

GIVEN ONE IN FIVE CHANCE OF SURVIVAL, AMAZING GRACE DEFIES THE ODDS

Jennifer Johnson was 18 weeks and five days pregnant when an ultrasound showed something was wrong.

The doctor who ran the ultrasound group called her into his office and broke the news that her baby had a congenital diaphragmatic hernia, or a hole in the diaphragm.

"When I first heard hernia, I thought that it was no biggie," she recalled. "Then he started talking about some operations and that 50 percent of kids with this don't survive, but that was too much for me to comprehend. It wasn't until he said that if the baby survives we'd be in the hospital for months did I think, 'Oh my God.' He said, 'Why don't you call Vinnie?'"

Monroe County Legislator Vinnie Esposito, who had missed the ultrasound appointment to meet an electrician at home, rushed to be by his wife's side. The doctor told them their case was beyond his scope of care

and that they would eventually need treatment at Golisano Children's Hospital at the University of Rochester Medical Center.

Once home, Vinnie and Jennifer tried to wrap their heads around the fact that their very busy, very public lives had just completely changed. Vinnie was running for office at the time. Jennifer, a newscaster for 13WHAM News whose belly was expanding in the spotlight, had to field congratulatory remarks, phone calls and e-mails from both co-workers who knew her and viewers who felt like they did. And they had a 1-year-old daughter, Avery, to think about.

Already emotionally and physically exhausted from the situation, they decided to keep the news to themselves.

The couple switched to a high-risk OB/GYN, toured the hospital's Neonatal Intensive Care Unit (NICU), and learned over the next several ultrasounds that their baby

girl's condition was worse than they had originally thought. The hole in the diaphragm had allowed the intestines, stomach and part of the liver to move into the chest, where her heart and lungs were squished and pushed out of place.

By the time Grace was born, her chances of survival dropped to one in five. She was surviving after her birth with just 20 percent functionality in one lung.

"That's pretty uncommon," said Patricia Chess, M.D., a neonatologist at Golisano Children's Hospital who treated Grace. "We just took it one step at a time and did the best we could. What was going to happen was going to happen – and Grace surprised us all."

The day after Grace was born, a team of doctors and nurses repaired the hole in her diaphragm and put her organs where they belonged. But within hours, the baby's lung

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Nathan VanDeVoorde

MENINGITIS SCARE BRINGS HEALTHY KID TO BRINK OF DEATH

When Julie VanDeVoorde was growing up, a neighbor of hers died of meningitis. So when her 5-year-old son, Nathan, complained that his neck hurt, spiked a high fever and began vomiting, a little voice in the back of her head wondered if these same symptoms meant the same condition.

"My 'mother gut' was telling me that things weren't good," said Julie, who brought him to the pediatrician's office, where multiple tests showed nothing serious. But Nathan was up throughout the night, inconsolable. And by 8 a.m. he had a rash all over his body, his fever had hit 104 degrees, and he felt like he was falling even though he was lying down.

Dave VanDeVoorde yelled for Julie to call 911. "His eyes were like saucers and he started to stumble around the house," he said. "It's hard to describe how helpless I felt and how terrified I was."

About 10 minutes later, when the

ambulance arrived, Nathan was calm and alert, and could even identify the color of his father's brown shirt. But a CT scan, taken immediately after being rushed to the pediatric emergency department at Golisano Children's Hospital at the University of Rochester Medical Center, showed that his brain was swelling, raising the pressure inside his skull to nearly five times the normal force. That's when more than a dozen physicians swarmed in and swooped him into the Pediatric Intensive Care Unit, where they inserted a breathing tube, as well as a catheter into the brain to measure the increased pressure. Within hours, Nathan was in a medically induced coma to help his brain recover from the illness – which by this point had been diagnosed as encephalitis with meningitis, inflammatory diseases of the membranes that surround the brain and spinal cord and are caused by bacterial or

viral infections.

Dave and Julie will never forget the image of their son hooked up to a ventilator in a room packed with beeping machines, wrapped in a cooling blanket, motionless.

"It was a complete, tortuous waiting game by then," said Julie. "The hardest part for me was trying to understand how our child could be so perfect and then so sick in such a short period of time. How does that happen?"

Relatives from in town and out of state rushed to the hospital to be with the family and to help take care of Nathan's 6-year-old sister, Natalie, and 2-year-old brother, Jake.

Over the next 10 days, Dave and Julie also found strength and support from Jeffrey Rubenstein, M.D., professor of Pediatric Critical Care at Golisano Children's Hospital, who was in charge of Nathan's case. "He not only became our physician, he became our

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Arie Beasley

BEAUTIFUL, BUBBLY TODDLER WITH DOWN SYNDROME FACES CANCER HEAD-ON

It seemed like a simple cold at first, when Sandra Beasley took her 2-year-old daughter, Arieona, to the pediatrician and returned home with instructions to administer some ibuprofen. But the next week, when Sandra drove up to her mother-in-law's house to pick up her two children, Arieona, who goes by Arie, didn't run outside with her usual enthusiastic greeting.

She was sitting by the door with her hands on her hips. Her breathing was labored, and her skin was a pale color her mother had never seen before.

"I looked at her hands, then I looked at my hands, then I looked at her hands," recalled Sandra. "I was scared it was serious."

Within 10 minutes, they were back at the pediatrician's office, where they drew blood and immediately sent Arie to Golisano Children's Hospital at the University of Rochester Medical Center. By the time they

arrived, Arie was even more lethargic, and she was soon admitted to the Pediatric Intensive Care Unit.

"When they left us alone, I was like, 'What did I do to deserve this?'" Sandra said. "Every name I could think of for God, I called him. Jehovah-Jireh, Jesus Lord, Master King. And I was even praying to my mom, who passed away more than 20 years ago. I said, 'You sit up there and talk to him. Just don't let him take my baby.'"

Though initial blood tests showed she had low white blood cell, hemoglobin and platelet counts, which suggested a potential bacterial infection, a follow-up bone marrow aspiration confirmed suspicion of acute myeloid leukemia, otherwise known as AML. The disease, which affects approximately 500 children in the U.S. each year, is characterized by white blood cells that accumulate in the bone marrow, interfere with the production of

normal blood cells, and can spread to other parts of the body.

Arie's course of treatment was intense and spread out over seven months. She was hospitalized each month for a seven-day stretch to undergo daily chemotherapy sessions, and had monthly bone marrow aspirations to assess her response to treatment, as well as spinal taps to make sure the leukemia did not spread.

"It was a lot to go through," said Jeffrey R. Andolina, M.D., M.S., an assistant professor of Pediatric Hematology/Oncology at Golisano Children's Hospital. "But she's such an energetic and happy child, and very resilient, so she tolerated things really well."

To overlap with her regular care, Arie's family decided to enroll her in a clinical trial through Children's Oncology Group, a cooperative research network that offers

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Charlie Levin

DETERMINED TO SAVE SON, FAMILY SHOWS A LOT OF HEART

Though Charlie Levin entered the world five weeks early and showed no obvious signs of trouble at birth, his parents, Ken and Meredith, weren't convinced everything was normal.

"He was given the all-clear to go home, but he looked orange," Meredith said. "Like a Muppet."

At 3-months-old, Charlie was vomiting regularly, losing weight and making disconcerting grunting sounds. His parents took him to the pediatrician's office six times in a four-week period. They saw nearly every physician in the Williamsville practice and they all said the same thing, that it was gastroesophageal reflux, a common condition in infants. Ken and Meredith talked with other parents whose children had the condition, but Charlie's symptoms seemed much worse and he wasn't responding to any treatments. When the vomiting worsened and

he started breathing rapidly, they demanded to see another doctor who'd previously been unavailable, one who'd taken care of their daughter, Parker, when she was sick as an infant. The pediatrician took one look at Charlie and said she would meet them at the hospital near their home in Buffalo.

After making arrangements for Ken's mother to pick up Parker from preschool, the family headed to the hospital, where a chest X-ray revealed an enlarged heart. "All we saw was ribs and heart," said Meredith. "You couldn't even see his lungs." Charlie was admitted to the hospital, but by the next day, he needed further testing and treatment, and was transported to Golisano Children's Hospital's Pediatric Cardiac Intensive Care Unit at the University of Rochester Medical Center, where he was diagnosed with hypoplastic left heart syndrome. The left side of Charlie's heart had not fully developed and,

as a result, was unable to pump sufficient blood to his body. That made the right side of his heart have to work much harder, which was why it had become three times its regular size. His aortic arch was so narrow, like a pinched straw, that he was unable to get oxygenated blood to his kidneys, liver, and other vital parts of the body, while too much blood was being sent to his lungs.

Testing done in Golisano Children's Hospital's pediatric catheterization lab, the only one in western New York to offer a full range of interventional procedures for children with congenital heart disease, showed that Charlie was pretty far into congestive heart failure, and he would need a series of open-heart surgeries to save his life.

His particular type of cardiac defect usually presents symptoms in utero or at birth.

"The problem with symptoms showing up
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Gavin Steel

WITH CYSTIC FIBROSIS AND HEART DEFECT, SENECA FALLS BABY FACES UNIQUE SET OF CHALLENGES

Jason and Christie Steel had no reason to suspect they'd need pre-birth genetic screening for their second son. But the set of conditions with which little Gavin was born was so rare that it left many specialists from around the country stumped. Never before had they seen such a unique combination in one baby.

Doctors initially thought that Gavin had only a heart murmur, but his family soon learned he had been born with a Ventricular Septal Defect (VSD). VSD is the most common type of congenital heart defect in newborns and in many cases, the hole between the two lower chambers of the heart closes up on its own. However, Gavin's cardiologist was concerned his VSD might cause problems and thought the hole in his heart would need to be closed with surgery. Meanwhile, news came that Gavin's newborn screening showed that he might have cystic fibrosis. But Gavin

needed to gain weight before getting a sweat test, the definitive test for cystic fibrosis.

Jason and Christie closely monitored how much food he was eating and how often he was going to the bathroom.

"We were even weighing diapers at one point," Christie said.

Despite their efforts, Gavin's weight went down by six ounces, and after four weeks he was admitted to Golisano Children's Hospital at the University of Rochester Medical Center. Gavin's heart failure was controlled with medications and he was evaluated further for possible cystic fibrosis. A stool evaluation showed abnormal digestive enzyme levels consistent with cystic fibrosis. Because Gavin was so small and undernourished, the health care team decided it was best to delay open-heart surgery until he was stronger.

Gavin's body was fighting itself. The cystic fibrosis, eventually confirmed, was preventing

his body from breaking down food enzymes into cellular fat. He was burning up all his energy trying to eat without falling asleep because his heart wasn't working right, leaving him permanently exhausted.

Gavin was put on a high-calorie diet through a feeding pump to gain the weight he needed for surgery. He underwent open-heart surgery just a few weeks later.

"To perform that kind of surgery on a 2-month-old is a reflection of the expertise we have here," said Clement L. Ren, M.D., an associate professor in Pediatrics at Golisano Children's Hospital.

Jason and Christie, who'd been staying at the Ronald McDonald House less than a mile away, were given a chance to hold their baby before the surgery – something they hadn't been able to do for three weeks because Gavin was intubated.

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Grace Esposito

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had collapsed. Vinnie and Jennifer rushed to Grace's room as quickly as they could.

"A whole team of people were working on her," said Jennifer. "She was this awful color and seemed lifeless. It was the hardest thing to see."

They watched for a few minutes before heading to the waiting room, where Dr. Chess approached with an offer to try a tricky procedure that might cause neurodevelopmental issues down the road or might not work at all – or they could just let her go. They had about a minute to make the decision.

"She has proved herself to be a fighter so far," Vinnie responded, "so if any baby is up to the challenge, it's her."

Grace was on heart-lung bypass for about a week, during which her blood had to remain thin enough to race through the tubes that ran from an enormous machine into her neck and heart, but thick enough not to bleed out of her surgical sites. That week, while Avery stayed with relatives, Vinnie and Jennifer stayed at the Ronald McDonald House within the Hospital to be with Grace as much as possible. Within weeks of the bypass, the nub of tissue in the second lung Grace had been born with had grown in size to match the other one.

"Every step along the way, Grace has done as well as she possibly could because she's



tough and the people at that hospital saved her life," Vinnie said. "I can't imagine getting better care than we have gotten from this world-class institution."

Jennifer shook her head in disbelief as she described Dr. Chess as an extremely busy physician, wife, and mother of four who spent countless hours attending to details that had nothing to do with her job description.

"Not only did she take our very medically complicated child and allow her to survive and thrive, but the amount of care and compassion she showed was just unbelievable," said Jennifer, remembering Grace's baptism in the NICU. Dr. Chess had slipped Grace's right

arm through one sleeve of a white baptismal gown she'd found, then with steady hands held a prayer shawl over Grace's body during the entire ceremony, held in a dark room, the only light shining on Grace's face. She also wrote little notes to Vinnie and Jennifer on behalf of their daughter, with messages such as "I love it when you read stories to me" and "When you sing to me, I promise the staff won't laugh at you."

After two-and-a-half months at Golisano Children's Hospital, where she received oxygen support and medication to help lower her blood pressure while her lungs matured, Grace's health progressed by leaps and bounds and she was able to go home three months earlier than expected.

The transition – what Jennifer calls "Chapter Two" – has meant around-the-clock planning and care so that Grace has the necessary food, medicine, medical supplies and scheduled appointments with a host of therapists and nurses. But it has also meant weekend mornings with the entire family in one bed, reveling in finally being all together.

Grace – her name was bumped up after her birth from its original position as a middle name – became somewhat of a celebrity after Vinnie and Jennifer filmed a TV segment about their experience for 13WHAM News. People now often ask, "How's Amazing Grace?"

Her parents are happy to report that she's doing quite well.

"Every time we think there might be another complication, she gets past it in very short order," Vinnie said.

Added Jennifer: "She's a strong little lady."

Nathan VanDeVoorde

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true friend," said Julie.

Nathan's first sign of communication came on the fifth day at the hospital, when he grasped a nurse's hand. The next day, he grasped his parents' hands and opened his eyes every now and then, and the day after that, he turned his head when he recognized Julie's voice and tried to smile. "It was the best feeling," she said. "My baby was back. That's a moment I'll never forget."

The day Nathan went off the ventilator, about 10 physicians came into his room together to help celebrate. "Nathan touched a lot of people and so did his parents," said Dr. Rubenstein. "His recovery was amazing. It was everything we were all hoping to see."

Less than two hours later, Nathan, surrounded by superhero-themed toys and balloons, whispered, "Jake says 'poop,'" and grinned. Everyone in the room, once uncertain whether he would live, let alone talk

again, laughed and cheered that he remembered one of his brother's favorite words.

Day by day, the triumphs continued – and didn't stop even after returning home. Nathan was expected to need months of therapy and rehabilitation, but he was taking his first steps the day after he left the hospital. He had occupational therapy only once, physical therapy just three times, and 17 days later was back in school. The day after that, he rode his bike around the neighborhood.

At follow-up appointments and random visits to the hospital to say hello to those who helped him get better, Nathan spends time in the indoor-outdoor play area, called the Christie Simonetti Play Deck, which had been instrumental in helping him start to move around again. And at night, no matter his mood, he recites the same bedtime prayer: "Dear God, thank you for making people, thank you for a great day, and get everyone better at the hospital. Amen!"

In honor of Nathan's recovery and the strong bond the VanDeVoordes made with the entire staff at Golisano Children's Hospital,

the family organized a party – one that took place months before anyone would've expected, given the circumstances. The celebration turned into a fundraiser that brought in nearly \$5,000 in gifts and donations for the hospital and the Ronald McDonald House, where Julie had slept with Nathan's blanket and pajama top. Dave was especially moved that some of the people who work at the Ronald McDonald House are volunteers. "They folded our laundry, provided food and utensils, and a place to stay since there was no way we were leaving the hospital," he said. "You never think about all those services until you need to use them, then you're so thankful. We are in debt to the hospital and anything we can do to help, we are willing to do."

"Nathan is a special little miracle," said Julie. "He's destined for big things."

Arie Beasley

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the latest and best protocols for treating pediatric cancers. The new chemotherapy regimen she was given had been developed specifically to decrease side effects in children under age 4, with both Down Syndrome and AML. Arie met all of the criteria.

Children with Down Syndrome are about 15 times more likely to develop AML, but while they also have a better long-term AML survival rate than those who do not have Down Syndrome – about 80 percent compared to roughly 50 percent – they tend to be more sensitive to chemotherapy's side effects. Besides nausea, Arie experienced several serious fever episodes that kept her hospitalized an additional two to three weeks at a time.

"She didn't let any of it bother her," Sandra said. "Every day, she handled it."

More than that, on her best days, she was often seen running down the hospital halls, hugging the nurses, and rubbing Dr. Andolina's head. Her exuberant personality earned her a nickname: "Mayor of the Fourth Floor." In her more subdued moments, she repeatedly watched *Shrek* movies and perfected the art of sleeping in until noon.



Just as she was finishing up her treatments, Arie, who had a weakened immune system, contracted a very severe abdominal infection that caused high fevers, abdominal cramping and diarrhea, and required an extra week of hospitalization.

All in all, Arie was hospitalized five of the seven months she received care at Golisano Children's Hospital – a highly unusual length of time and one that caused some anxiety once

she returned home to a place that wasn't nearly as familiar as her hospital room.

"Do you know where you are?" Sandra asked one early evening after the toddler awoke.

Arie shook her head.

"This is your house. You're home."

Arie stood still.

"Are you scared? Do you want to come in the living room with me?"

All Arie could do was shake her head and cry, until she saw her older sister, Zyiona, playing with some of her toys. She slowly walked over to join in.

These days, Arie is more full of life than ever, a high-energy toddler with gold-rimmed glasses that match her trademark hoop earrings.

After her last chemotherapy session, two of the nurses she'd developed a particularly close relationship with hosted a *Shrek*-themed birthday party – a thoughtful substitute for a missed summer trip to Disney World.

"We got so attached to everyone there," Sandra said. "If you needed a shoulder to cry on, they were right there. If you needed to talk to them, they kept things confidential. They all went above and beyond for us."

Charlie Levin

Continued from page 9

three months later is that the heart changes so much once babies are breathing outside the uterus, and by that time it has been working very hard just to keep up some basic, minimal requirements," said L. Eugene Daugherty, M.D., chief of the Division of Pediatric Critical Care at Golisano Children's Hospital. "So his heart was really strained and stressed by the time he came here."

As family members rushed to the hospital to lend support, the pediatric cardiac team led by George M. Alfieri, M.D., a nationally recognized pediatric cardiac surgeon, worked hard to stabilize Charlie, an effort that lasted a full 10 days before the first surgery.

In the meantime, Ken sought medical opinions from children's hospitals in Washington, D.C., where his close friend from childhood is a pediatric cardiologist, and Philadelphia. Both opinions were the same – moving Charlie anywhere else would be too risky, and he was in the best hands possible, given that Golisano Children's Hospital is the leader in pediatric cardiac surgery throughout western New York.

During the eight-hour surgery, Meredith went upstairs to the Ronald McDonald House

within the Hospital, hoping to find something to do to keep her hands busy. She and Ken were staying there, while Parker stayed with her grandparents. Meredith scrubbed the bathroom floor in her room, then offered to help with the laundry, a request the volunteers granted. "Everybody tried to give us our space and be there for us at the same time," she said. "They were wonderful."

Charlie was in the hospital for six weeks after the surgery, which reduced the blood flow to Charlie's lungs, re-routed the right ventricle to pump blood to his body, and repaired the aorta. At 13 months, now healthy and strong, he went through a second surgery that re-routed the blood flowing back from the top third of his body so that it rushed directly to his lungs. This time, he only needed six days of recovery, and received physical therapy and occupational therapy to help him catch up to where he should be. He will have two more surgeries before kindergarten – one to repair a leaky valve and another to redirect the blood flow from his lower body directly to his lungs.

Despite some complications, Charlie has recovered faster than anyone had predicted. Now down from eight medications to two, Charlie, with his sideways smirk and single dimple, is pretty much a normal 3-year-old boy.

There's still a long road ahead, and he will

need lifelong therapies, but his parents feel that the medical team at Golisano Children's Hospital has fully prepared them for what's to come.

"Technically, they answered every question we had, and on a social level, there was a lot of hand-holding," Ken said. "To set us at ease without being disingenuous, while being honest about the situation at the same time, is an amazing skill."

Inspired by their son's care, Ken and Meredith started the group Heart Works, aimed at extending and improving the lives of other children with congenital heart disease. The Levins were hoping to raise \$20,000 in proceeds, split evenly between the American Heart Association (AHA) and Golisano Children's Hospital, at their first fundraiser, but they doubled that amount. Their mission is to help the AHA fund local pediatric cardiac research and Golisano Children's Hospital purchase new equipment for the Children's Heart Center.

"The team at Golisano Children's Hospital is world-class, from the people cleaning the rooms to the surgeons and everyone in between," Meredith said. "It's an organization we'll continue to support forever."

Gavin Steel

Continued from page 10

"You don't want to let him go because you don't know if you're holding him for the last time," Jason said. "It was the scariest thing I've ever been through in my entire life."

When Gavin came out of surgery four hours later, his parents were able to catch a glimpse of him – "looking like a little baby doll, all tiny and swollen," recalled Christie – as he was quickly wheeled to his room. He'd done remarkably well, needing minimal blood transfusions and oxygen.

Unfortunately, there would be more hurdles to overcome. When Gavin stopped breathing in Jason's arms, he had to be rushed to Golisano Children's Hospital's Pediatric Intensive Care Unit for intubation, blood transfusions and additional tests. That's when he was diagnosed with 22q11.2 deletion syndrome, more routinely known as DiGeorge syndrome and caused by the absence of a small piece of chromosome 22. Normally, when the body is fighting off such a serious condition, it tends to shrink while the size of the head remains the same. In Gavin's case, his head was proportionate to his body, his fingers and toes were elongated, and he had a dual uvula and other characteristics of the syndrome.



Gavin stayed in the hospital for three months after the emergency visit. Just two days after going home, he wound up back at Golisano Children's Hospital with a life-threatening respiratory illness known as MRSA pneumonia. After a nearly two-month stay, Gavin had only a week's reprieve at home before returning yet again for cystic fibrosis-related dehydration, which required another seven days in the hospital. Other hospital visits followed for a strong course of antibiotics and ear tube placements.

"We had some really scary moments and felt completely lost, but the communication, coordination and response from everyone at the hospital was great," said Jason, who has since become a stay-at-home dad to Gavin and his older siblings, Evan, Natalie, and Mercedes. He and Christie, who had both been employees of BonaDent Dental Laboratories in Seneca Falls during Gavin's

ordeal, say the company was tremendously supportive, continually raised money for the family, and allowed time off whenever it was requested. Jason plans to return to work once Gavin starts kindergarten.

Now age 2, Gavin has gained weight and breathes well. Golisano Children's Hospital is one of the few places in the country that can do lung function testing in infants, and Gavin's lung functioning, monitored regularly since his cystic fibrosis diagnosis, has improved.

"It took him a long time to catch up, and he's still not totally there, but he's probably one of the happiest kids we've ever known," said Christie.

Gavin still has multiple medical needs, though. He takes enzymes every time he eats, is on several inhalers, and has nebulizer and airway clearance vest treatments three times a day (the vest treatment is done up to five times daily when he's sick). And Golisano Children's Hospital is still very much a part of Gavin's life; he was hospitalized for three days recently for severe bronchiolitis.

"We tell everybody that Golisano is the best hospital there is," said Jason. "We can't talk highly enough about everybody there. They didn't just take care of Gavin, they treated the whole family. And they treated us like family."

A promotional graphic for Miracle Jeans Day. The background is a blue denim texture. On the left, the text "Go casual for kids!" is in red, followed by "miracle JEANS day" in large, stylized blue letters. Below this is a blue shield with a white question mark. On the right, a photograph shows the legs of several children sitting on a bench, wearing various styles of blue jeans. Below the photo, the text "save the date" is written in a large, white, sans-serif font. At the bottom left, the text "Miracle Jeans Day" is in large blue letters, followed by "Wednesday, September 12, 2012" in smaller blue letters. Below that, it says "Wear your favorite jeans in support of your local Children's Miracle Network Hospital." in blue. On the bottom right, there is a circular logo for "miracle JEANS day" and a rectangular box with the text "Don't forget to add Miracle Jeans Day to your calendar! For more info visit MiracleJeansDay.com".

Go casual for kids!
miracle JEANS day

save the date

Miracle Jeans Day
Wednesday, September 12, 2012

Wear your favorite jeans in support of your local Children's Miracle Network Hospital.

Don't forget to add **Miracle Jeans Day** to your calendar!
For more info visit **MiracleJeansDay.com**

CAMPAIGN CORNER

The Meliora Challenge: The Campaign for the University of Rochester

The \$100 million Golisano Children's Hospital campaign is part of the University of Rochester Medical Center's \$650 million campaign and the overall \$1.2 billion goal of *The Meliora Challenge: The Campaign for the University of Rochester*.

A Letter from the Co-Chairs of the Golisano Children's Hospital Campaign

Building a state-of-the-art medical facility to match the extraordinary care that is given within the walls of Golisano Children's Hospital at the University of Rochester Medical Center is absolutely essential. Families turn to us for compassionate, experienced medical care that is close to their home and in an environment they can trust. Golisano Children's Hospital is determined to continue meeting the needs of our community.

We all have a responsibility to ensure that our region's only children's hospital is equipped to provide the best care possible – for the kids

of today and for generations to come. With your help, we will construct a brand new children's hospital, built by the community, for the community.

The Golisano Children's Hospital campaign has two components – exciting plans for a new building and the growth and enhancement of seven key pediatric programs. Last July, our generous namesake, Tom Golisano, pledged \$20 million to support the children of our region. This incredible gift set plans in motion for a brand new children's hospital. We are very excited to share that late this summer or early this fall, just a little more than one year after Tom's pledge commitment, we will break ground for the new hospital.

The hospital will house an expansion to our Neonatal Intensive Care Unit, which serves more than one in 11 babies born in the 17-county Finger Lakes region, and is desperately in need of more space. The new building's 56 inpatient rooms will give parents the privacy and space they need to be close to their child when they're needed most. Parents are crucial members of their child's care team. The extra inpatient space will help ensure that parents are very much a part of the conversations and decisions pertaining to their child's medical care.

With a focus on enhancing some of our already stellar programs, including pediatric cancer, cardiology, neonatology, surgery, autism, palliative care and adolescent eating disorders, we position ourselves to become national leaders in pediatric care. We will be better poised to retain the talented, compassionate residents we train, and better equipped to recruit the best and brightest pediatricians and specialists from across the nation. We'll be contributing to the economic growth for our great city of Rochester and can delight in securing our status as the flagship institution for pediatric care in upstate New York.

We share the University of Rochester's promise for "Meliora" – aspiring to be "ever better" for the community for which we care so deeply. Your support will help us transform the care we provide for the tens of thousands of children and families who rely on us each and every year. Please join us in our quest to provide a brighter future for our community's children.



Sincerely,
Lissa McAnarney, M.D., and Mike Smith
Co-Chairs for the Golisano Children's Hospital
Campaign

COUPLE DEVOTED TO CHILDREN'S HOSPITAL ESTABLISH PROFESSORSHIP POSITION NAMED IN HONOR OF DR. ELIZABETH R. MCANARNEY, PROFESSOR AND CHAIR EMERITA

ROGER AND CAROLYN FRIEDLANDER'S NAMES MAY BE FOUND AT LOCATIONS THROUGHOUT THE UNIVERSITY OF ROCHESTER, BUT FOR THE FIRST TIME THEIR GENEROSITY WILL ACCOMPANY A PROFESSORSHIP: THE DR. ELIZABETH R. MCANARNEY PROFESSORSHIP IN PEDIATRICS FUNDED BY ROGER AND CAROLYN FRIEDLANDER.

The Friedlanders chose to recognize McAnarney, professor and chair emerita of Pediatrics at the University of Rochester Medical Center (URMC), for her lifetime of work benefitting children locally and internationally.

"Roger and Carolyn's gift is significant because it honors scholarship and faculty excellence," said University President Joel Seligman. "Lissa McAnarney embodies the very best of academic medicine; she's a truly respected scientist, teacher, and clinician, who is richly deserving of this honor."

"As longtime friends of the University and the Medical Center, we are deeply grateful to the Friedlanders for their decades of generosity and for establishing a professorship to honor one of our most esteemed and accomplished faculty members," said URMC CEO Bradford C. Berk, M.D., Ph.D.

The Friedlanders' generous commitment will go toward Golisano Children's Hospital's \$100 million campaign, which will support both a new children's hospital and major enhancements to pediatric programs. The effort is part of the University of Rochester Medical Center's \$650 million campaign and the overall \$1.2 billion goal of *The Meliora Challenge: The Campaign for the University of Rochester*.

Roger Friedlander was the chair of the children's hospital fundraising board in 1993 when McAnarney was named the sixth chair of the Department of Pediatrics and pediatrician-in-chief of what is now Golisano Children's Hospital.

"We are so fascinated and intrigued by what she has done for children all over the world. She was the perfect person to recognize in this way," Roger said. "This is not just



Roger and Carolyn Friedlander

financial involvement; it's heart to heart."

McAnarney knew the Friedlanders before Roger's participation on the board, through Carolyn's work as a dedicated pediatric nurse practitioner at Elmwood Pediatric Group. McAnarney was delighted to have Roger lead the board as she took the helm of the children's hospital.

"He brought a deep intellectual acumen, business acuity and a love for children to the children's hospital board, and Carolyn has always been a great friend of the hospital," McAnarney said.

Pending approval by the University's Board of Trustees, the professorship will be held by Richard E. Kreipe, M.D., professor of Pediatrics and a protégé of McAnarney's. Kreipe is the founding director of the Child and Adolescent Eating Disorder Program at the hospital and is a board-certified pediatrician and adolescent

medicine specialist, as well as a Fellow of the Academy for Eating Disorders. His professional focus for the last 30 years has been on pediatric eating disorders, and he has published numerous research studies, articles, book chapters, position papers and reviews on the topic.

"Dr. Kreipe is not only one of the most knowledgeable eating-disorder specialists in the country, but also one of the country's most dedicated advocates for children, and Rochester is fortunate to have him," said Nina F. Schor, M.D., Ph.D., pediatrician-in-chief of Golisano Children's Hospital and the William H. Eilinger Chair of Pediatrics at the University of Rochester Medical Center.

"We're delighted the Friedlanders have given us the opportunity to honor both him and Dr. McAnarney through this professorship."

Kreipe is a consultant to the American Psychiatric Association regarding diagnostic criteria for eating disorders in young people, and is a past-president of the Society for Adolescent Health and Medicine (SAHM). He is the founding medical director of the Western New York Comprehensive Care

Continued on page 26



Elizabeth R.
McAnarney, M.D.

Golisano Children's Hospital at the University of Rochester Medical Center could not be the hospital it is today, or the hospital our region needs us to be tomorrow, without the generous support from members of our community. It is an honor and a privilege to recognize this year's Miracle Maker Award recipients. Each supporter has his or her own unique reason for getting involved with the hospital – whether it was

a personal experience that spurred the need to give back, pride for our local community or the hope of building a healthier tomorrow for our children. We hope you'll enjoy reading these stories of how our Miracle Makers came to be involved with our region's only children's hospital and how their relationship has grown and evolved over the years.



Miracle Maker Award for Outstanding Commitment by an Individual Tom Golisano, the quintessential Miracle Maker

There is no question that our community's children will have a better, brighter future because of Tom Golisano. Our hospital namesake has done much to ensure that Golisano Children's Hospital at the University of Rochester Medical Center (URMC), the region's only children's hospital, can continue to blossom and grow for generations to come.

Thanks to Golisano's first major gift of \$14 million in 2002, Golisano Children's Hospital was able to recruit outstanding faculty to build the Pediatric Intensive Care Unit, Pediatric Surgical Suite, and the Pediatric Treatment Center and to expand programs in cardiac care, general surgery, neuromedicine and more. Last July, Golisano surprised the community by generously pledging to contribute \$20 million to help build a brand new state-of-the-art children's hospital. For all that Golisano has done and the exciting future he has made possible, it is an honor and a privilege to

recognize him as this year's Miracle Maker Award recipient for Outstanding Commitment by an Individual.

"It has been a dream of ours to build a new hospital for many years. Tom's generosity has enabled us to put the plans in motion, so we can create one of the best children's hospitals in the country," said Nina F. Schor, M.D., Ph.D, pediatrician-in-chief at Golisano Children's Hospital and the William H. Eilinger Chair of Pediatrics at URMC. "Tom's support, commitment and passion for helping children made for an easy decision to choose him for this award. We are pleased to recognize Tom for his many contributions."

Golisano's latest pledge brings his total giving to the children's hospital to \$34 million, making him the University of Rochester's most generous living donor. In addition, the Golisano Foundation has given \$1.6 million to the University of Rochester's Strong Center for

Developmental Disabilities to establish the Institute for Innovative Transition.

The legacy Golisano is creating is built upon both in his commitments to the hospital and in the generosity he has inspired among others, including Paychex, which donated \$100,000 last September, and Mike and Alice Smith, who have pledged to give \$1.3 million toward Golisano Children's Hospital's campaign. The Golisano Children's Hospital campaign is part of the University of Rochester Medical Center's \$650 million campaign and the overall \$1.2 billion goal of *The Meliora Challenge: The Campaign for the University of Rochester*.

"Tom stands by what he believes in and what's more, he ignites a spark of passion in those around him," said Scott Rasmussen, director of advancement at Golisano Children's Hospital. "To Golisano Children's Hospital and the Finger Lakes Region, Tom Golisano is and always will be the quintessential 'Miracle Maker.'"



Miracle Maker Award for Outstanding Commitment by a Volunteer

Sheets family shows love and strength after loss

When Jim and Stephanie Sheets lost their baby boy, James Kempton, just 11 days before the Stroll for Strong Kids, they had a very tough decision to make. Should they cancel the plans they had made with family and friends to walk in honor of James? Or were they ready to push forward, even though he was no longer with them, knowing that the funds they were raising could help others? Their answer gets to the heart of who this incredible family is and why they've earned the Miracle Maker award this year, for Outstanding Commitment by a Volunteer.

Jim and Stephanie did walk on June 3, 2000. And, while the dedicated effort they've put forth in volunteering for many hospital events over the past 12 years has helped others like their son, that's not the reason they walked. They did it for the nurses and hospital staff, who had cared for their son during the many months he was in and out of Golisano Children's Hospital at the University of Rochester Medical Center.

"We really just believed that the nurses and hospital staff had done so much for our family that we didn't want to miss our chance to support them," said Stephanie. "A lot of times,

when you think about the Stroll and the kids there, you think of kids who had been in the hospital but went home. Here we were, walking for our son, yet we didn't have him any longer. But at the same time, seeing all his nurses was great. They had really become like family to us."

James' stay in the hospital was a formative experience for everyone in the family, including Stephanie's daughter Laura, who was only 5-years-old when her brother was ill. Now a mature young lady, 17-year-old Laura aspires to be a pediatric nurse. She is enrolled in New Visions at BOCES, an impressive program that trains high school students planning on careers in health care. It seems almost serendipitous that Laura is right back where she was as a little girl – training on the hospital's 4-1600 unit with the same nurse manager, Jeanne Kirby, who cared for her baby brother all those years ago.

"It's amazing that, at such a young age and given the circumstances, Laura walked out of the hospital with a positive experience. It says a lot about the nurses and staff and doctors at Golisano Children's Hospital," Stephanie said. The Sheets offer to help Golisano Children's

Hospital whenever and wherever they can. Jim and Stephanie joined the Stroll committee the year after their first walk, and they've been helping run the show ever since. Jim is really "the co-director on the day of the Stroll. He's our guy," said Michael Fahy, assistant director of Advancement at Golisano Children's Hospital.

They also volunteer at the Gala, help with the Fairport Music and Food Festival, lend their support to the Ten Ugly Men Festival when they can, have assisted at the Genesee Valley Hunt Races, sit on the Community Fundraising Committee, share their story at community fundraising events, and the list goes on.

"We cannot thank the hospital enough, so Jim and I have always taken the approach that wherever the hospital needs some elbow grease, we'll be there," said Stephanie. As appreciative as they are, it's really the hospital that has gained the most from the contributions that this warm, gracious and enthusiastic set of supporters has offered. It's both an honor and a privilege to honor this wonderful family with this year's Miracle Maker award.



Miracle Maker Award for Outstanding Commitment by Grateful Parents Czekanski family refuses to leave hospital's success to chance

For the past nine years, Bryce Czekanski has spent his Tuesdays at Golisano Children's Hospital at the University of Rochester Medical Center for synthetic enzyme-replacement therapy. Bryce was born with a rare genetic disorder called Hurler-Scheie syndrome, for which there is no cure. With much time spent at the children's hospital, Bryce and his parents, Eric and Sheryl Czekanski, and sister Shana have met many people and have befriended other treatment center families and hospital staff members.

"We're in the hospital so much," Eric said. "We wanted to find a way to give back to all of the people we have met and who have helped us."

Eric and Sheryl have found a number of ways to get involved, with help from their family, friends and colleagues at Tops Markets and Providium/Gallagher. The Czekanskis continuously support the annual Drives for Miracles Radiothon and Children's Miracle Network Telethon, and with the help of a close personal friend and Tops Markets, started the Monte Carlo Night fundraiser six years ago. Their involvement has earned them the Miracle Maker Award for Outstanding



Commitment by Grateful Parents this year.

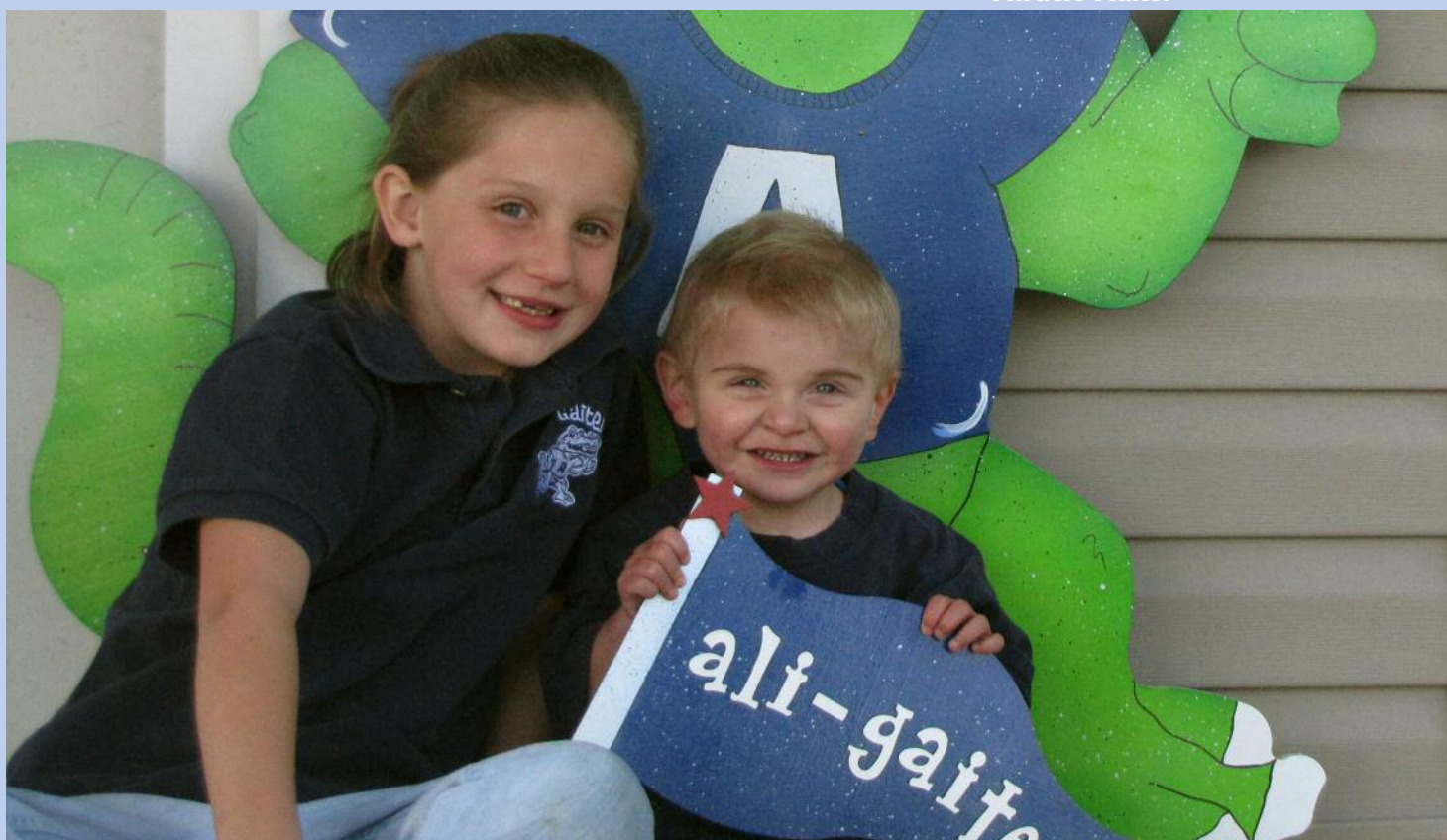
"When people found out about Bryce's condition, everyone asked how they could help," Eric said. "The fundraisers are a great way to get everyone involved and make a positive impact."

The Monte Carlo Night fundraiser is a casino night event, which takes place every March, and usually attracts 300 guests. There is a silent auction with donated items, autographed sports items, art work and a weekend getaway. The 2011 event raised \$11,500 for Golisano's Children's Hospital. The event has raised close to \$50,000 for Golisano's Children's Hospital over the years.

The fundraiser is designed to make the guests really feel like they are at a casino, which makes the event something everyone can have fun with. Bryce's involvement makes the event even more special. Bryce uses his wonderful artistic ability to draw pictures on all of the tickets, which is something he enjoys doing every year.

"We are grateful to the Czekanski family for their dedication," said Betsy Findlay, director of advancement at Golisano Children's Hospital. "They have inspired their co-workers and friends to really create a group effort with the Monte Carlo Night fundraiser and are always eager to help in any way possible with the various events we hold throughout the year."

The Czekanski family is honored to receive the Miracle Maker award, but still attributes the success from their fundraising to their family, friends, hospital staff and co-workers that have supported them from the very beginning.



Miracle Maker Award for Outstanding Commitment by a Community Group

Team Ali-Gaiters strides toward a decade of successful fundraisers

After Ali Klube's successful treatment in 2002 for a serious heart condition, her parents were inspired to give back to Golisano Children's Hospital in appreciation for the phenomenal care they received. As a result, they have been dedicated supporters of the annual Stroll for Strong Kids raising more than \$2,000 in 2003, their first year of participation.

The crew took on the name "Team Ali-Gaiters," using a clever play on the word "gait," which is a way of walking. Their enthusiasm blossomed as they discovered how much they could help and how many ways there were to get involved. The team has grown from less than 10 members to 45. Just as the team's numbers have grown, so too has their involvement. In 2003, they launched the Team Ali-Gaiters Clam Bake to raise additional funds.

But their story doesn't end there. Five years into Team Ali-Gaiters' fundraising efforts, Ali's cousin Nathan was born with a serious heart condition.

"At the time we got involved in 2003, we had no idea that we'd been raising money to give back to another member of our family," said Jackie Klube, Ali's mother

and an aunt to Nathan.

Nathan received the same exceptional care as Ali, and has had two of three surgeries he needs to repair his heart. Nathan's experience has inspired the Team Ali Gaiters to deepen their commitment, raising more than \$115,000 in the past nine years and ultimately earning them the Miracle Maker Award for "Outstanding Commitment by a Community Group" for 2012.

Spending so much time at Golisano Children's Hospital made the Klubes intimately aware of the number of families in need of the support that community groups like Team Ali-Gaiters provides. Each year at their Clam Bake, Team Ali-Gaiters honors other children who have been treated at Golisano Children's Hospital. Connecting these families at their own event provides motivation for all members of Team Ali-Gaiters.

The Clam Bake event has grown exponentially. Starting with about 100 people in the Klubes' backyard, last year's Clam Bake attracted 600 people. The ninth annual Clam Bake, scheduled for June 9 at the Honeoye Falls Fire Department Training Grounds,

is a family-friendly event that features music, food and beverages, clowns, a bouncy house and more.

Music for Miracles, another event sponsored by the Klubes, came to fruition two years ago as an additional way to raise money for Golisano Children's Hospital. This year's date has not been set yet, but the event will follow its traditional format of "five bands for five dollars," Klube said.

"Team Ali-Gaiters is always looking for ways to get involved with supporting families, both through their fundraising efforts and by developing strong relationships with other families who know what it's like to have a loved one in the hospital," said Michael Fahy, assistant director of Community Affairs at Golisano Children's Hospital. "It's really inspiring to see what a tightly knit group Team Ali-Gaiters continues to be as more families jump on board. They are all such a pleasure to work with and it's been an honor to get to know the Klube family and everyone on Team Ali-Gaiters over the years."



Miracle Maker Award for Outstanding Commitment by a Corporation

Advantage Federal Credit Union still finds new ways to help hospital after 20 years of caring

For the past 20 years, Advantage Federal Credit Union has shown how committed they are to giving back to their community by whole-heartedly supporting Golisano Children's Hospital at the University of Rochester Medical Center. Advantage sponsors many of the hospital's annual fundraising events, encourages employees to volunteer and continues to come up with exciting, new fundraising initiatives to support our region's only children's hospital. This dedication and involvement has earned Advantage Federal Credit Union the Miracle Maker Award for Outstanding Commitment by a Corporation for 2012.

Recognizing the value in providing hands-on support, Advantage employees are always quick to jump on volunteering opportunities, such as answering phones at the hospital's annual Radiothon. Advantage CEO Jeff Bocach shows his loyalty year after year by sponsoring and attending the Golisano Children's Hospital Gala and Golf Classic.

"As the credit union for the University of Rochester, it is really important for us to find ways to support those that we serve," said Bocach. "Many of us have had kids at

Golisano Children's Hospital for various reasons, and we truly appreciate the type of care that is found there."

Advantage's investment in helping our community's children has led them to create some successful fundraising initiatives, like their grand-slam promotion with the Rochester Red Wings. Four years ago, Advantage came up with a way to celebrate the success of our city's baseball team while also giving back to the hospital that does so much to serve our community. Advantage donates \$25 to Golisano Children's Hospital for every double hit at a Rochester Red Wings home game. Thanks to the players' many successful hits, this usually amounts to \$3,000 to \$4,000 each season.

Currently in the works is a Golisano Children's Hospital debit card. Every time the debit card is used for a purchase, the merchant pays a small fee to the credit union. Advantage will set aside a portion of what they earn on each purchase, and at the end of the year, that grand total will be presented to Golisano Children's Hospital as a donation.

"The team at Advantage has been a passionate, long-standing supporter of the

Children's Hospital," said Betsy Findlay, director of advancement at Golisano Children's Hospital. "They go out of their way to find ways to support us, both financially and with their own service and volunteering. They are truly enthusiastic about helping kids and the community that they serve."

To date, Advantage Federal Credit Union's giving has exceeded \$66,000, and the joy that their generosity brings to the Advantage team warrants that they will continue to be supporters of Golisano Children's Hospital for many years to come. Golisano Children's Hospital is grateful for the service and support from the Advantage team, and is proud to honor Advantage Federal Credit Union this year with a Miracle Maker Award.

AUTISM ON THE RISE

GOLISANO PEDIATRICIAN EXPLAINS NEW RATE TO COUNTRY

JUST BEFORE WORLD AUTISM DAY, THE CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC) RELEASED STARTLING NEW RATES FOR AUTISM IN THE UNITED STATES – 1 IN 88 CHILDREN, 1 IN 54 BOYS AND A MARKED INCREASE AMONG HISPANIC AND AFRICAN AMERICAN CHILDREN. THE CDC INVITED GOLISANO CHILDREN'S HOSPITAL'S SUSAN HYMAN, M.D., TO ATLANTA FOR THE ANNOUNCEMENT TO HELP EXPLAIN THE INCREASE AND WHAT COMMUNITIES NEED TO DO TO HELP THESE CHILDREN AND FAMILIES.

Hyman said there are many reasons for the increase. Pediatricians have been very actively screening for autism at younger ages and on an ongoing basis. Plus, families and educators are much more aware of autism and have made a more accurate diagnosis possible.

"There's also the very real possibility that there is an increased prevalence of autism. We know there is a genetic predisposition to autism. We also know now, through increasing research in the area, that there are environmental factors," Hyman said.

She added that although more research needs to be done to determine what those environmental factors are, none of the studies show an association with vaccines. She said the increase in identification among minority children shows that pediatricians and



educators are doing a better job of providing services to that traditionally underserved population.

Golisano Children's Hospital at the University of Rochester Medical Center is actively involved in treating and diagnosing the community's children with autism, and in researching the most effective ways to screen and treat children with autism. The hospital is also a national leader in

researching the diet and nutrition of children with autism, which is often a big concern for parents.

"Parents will tell you that their child will only eat crunchy food or will only eat white food, and they're right," Hyman said. "With typical toddlers, a family may say their child won't eat any vegetables, but that's not really the case. Once a week, broccoli will make it into their mouths. But for families with children with autism, if they say their child only eats green food – their child really only eats green food."

Because of that, Hyman said, nutrition studies are incredibly important to ensuring children with autism get everything they need in their diet. This is especially true because toddlers outgrow their food aversions, but children with autism grow to be adults with autism, carrying those potential nutritional issues with them throughout a lifetime.

Despite recent progress in research like the nutrition studies Hyman and her team are performing and successes in diagnosing children younger and getting them more effective treatment earlier, Hyman said research into autism and its causes is far from over.

"No matter how much we've done, there's more to do."

To learn more about how you can help, visit <http://bit.ly/GCHautism> or call Marc Misiurewicz at (585) 276-3595.

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Spotlight on CMN Hospitals Sponsors



Local IHOP Restaurants Flip to Help Kids

IHOP restaurants know that the only thing better than delicious pancakes are free delicious pancakes for a good cause. On Jan. 25, the Rochester IHOP restaurants held a special promotion to provide free kids' meals when a \$5 donation per kid was made to Golisano Children's Hospital at the University of Rochester Medical Center. Then, on Feb. 28, IHOP restaurants nationwide celebrated National Pancake Day with the Children's Miracle Network (CMN) Hospitals. The two Rochester-area IHOP restaurants raised more than \$10,104 for the hospital this year, nearly tripling the funds raised last year. Golisano Children's Hospital is grateful to these wonderfully ambitious supporters who go above and beyond to help our community's children year after year.

Walmart and Sam's Club Celebrating a Quarter Century of Caring

Walmart and Sam's Club stores have been supporting CMN Hospitals for 25 years – raising more than \$600 million for CMN Hospitals in the process. Over the years, our 13 local Walmart stores and two Sam's Club stores have continued to amaze us with their tremendous support. Since 2011, these stores have raised an incredible \$2.6 million for Golisano Children's Hospital. Local Walmart and Sam's Club stores are well into another great season of giving. Keep an eye out for an opportunity to purchase CMN Hospitals balloon icons in stores from May 1 to June 11.



Many thanks to Our CMN Hospitals sponsors:

- Special thanks to the 13 Rochester-area Brueggers Bagel Bakeries for their support during the second annual Bottomless Mug campaign and Free Coffee Day on Nov. 9.
- In 2011, area RE/MAX locations raised more than \$22,000 to support Golisano Children's Hospital as a CMN Hospitals sponsor. The associates at the RE/MAX offices contribute through the Miracle Home Program where they give a specified donation for every transaction they make. Support also comes through various sponsorships of our annual events including our Stroll for Strong Kids and Gala. Our thanks to all of our RE/MAX offices for their generosity and commitment to helping kids.
- The area Valvoline Instant Oil Change locations raised more than \$2,376 during their 2011 campaign. The nine area locations sold miracle balloons to help children in our region.
- The three area Great Clips locations raised more than \$1,300 last year during the CMN Hospitals campaign for Golisano Children's Hospital.

Community Spotlight

Harrowing start to son's life empowers Milburn family to help hospital in many ways

A deep passion to give back to the hospital that saved their son's life serves as continuous motivation for Mike and Patti Milburn. The Milburns are deeply involved in supporting the Neonatal Intensive Care Unit (NICU) at Golisano Children's Hospital, where their son, Cory, spent the early months of his life. Born 15 weeks premature, at just 1 pound, 8 ounces, Cory was featured as a Golisano Children's Hospital Miracle Kid in 2009. (To read his incredible story, visit <http://bit.ly/CoryMilburn>.)

The Milburns are committed to the hospital in many ways, making a point of sharing their inspiring tale with the hope of comforting and encouraging others to believe that miracles really can happen. Mike and Patti have taken leadership roles on the NICU's Parent-to-Parent Committee, to help other families whose babies are being treated in the NICU. As parent advocates, they've been part of the Hospital Building Planning Committee from its onset, to ensure that the new Golisano Children's Hospital meets families' needs.

On top of all of this, Mike and Patti are active volunteers when it comes to hospital fundraising events. Since they began participating in the Stroll for Strong Kids in 2009, the Milburns have ranked within the top three Golisano Children's Hospital fundraisers for the most funds raised every year. They also donate their time to volunteer at the Children's Hospital Gala, the Ten Ugly Men Festival and other community fundraising events. In addition, the Milburn family hosts two fundraisers of their own – a casino bus-trip fundraiser in March and a euchre tournament in April.

Golisano Children's Hospital is deeply appreciative of all the support and generosity from the Milburn family over the years. Mike and Patti's appreciation of and continuous dedication to the hospital help more babies like Cory receive the best possible care.



Kittelberger Florist grows good deeds on the green to give back

The impact that Golisano Children's Hospital has on our community's children may be overlooked, unless you realize how many families have benefitted from the hospital's wide range of services. In addition to caring for children with chronic illnesses, our health care providers also tend to acute injuries and diseases and perform a full complement of surgical procedures. Because of its extensive reach into our community's families, it's not uncommon to find someone with a personal connection to Golisano Children's Hospital – perhaps even by stopping at the local florist's shop.

Four years ago, the daughter of Billy Horeth, of Kittelberger Florist, was admitted and treated for a cleft palate. Having experienced the extraordinary services and care that the hospital offers its patients and families, the Horeths were motivated to give back to help the hospital that does so much good for so many people.

As a result, the Horeth family – along with everyone at Kittelberger Florist – hosts the annual Kittelberger Golf Tournament to support

Golisano Children's Hospital. At noon on Monday, Aug. 6, golf lovers will gather at Sodus Bay Heights Golf Course to tee off for kids' health. Participants will enjoy an afternoon of golf and a complimentary dinner to celebrate the day's success. To register for this year's event, please call (585) 737-4008 or email bill@kittelbergerflorist.com.

The appreciation and dedication the folks at Kittelberger Florist have shown for the hospital is helping children in our community receive the best quality of care that they not only need, but that they deserve. Golisano Children's Hospital extends its immense gratitude to everyone at Kittelberger Florist for their continuous support and generosity.

Remembering artist John Kuchera



John Kuchera, Pittsford resident and creator of the iconic Sandy Strong mascot for Golisano Children's Hospital at the University of Rochester Medical Center, passed away peacefully on Jan. 25 at 80 years old.

A native of West Aliquippa, Pa., Kuchera lived a life filled with art. He began his career when he was just 10 years old, winning an Aliquippa newspaper contest for creating a villainous character called Frogman for *Dick Tracy*, a popular detective comic strip at the time.

Over the decades, Kuchera had a colorful career, which included painting balloons for the Macy's Thanksgiving Day parade, serving as a journalist in the Navy and illustrating more than 75 books. Rochester residents might be familiar with Kuchera's old comic strip, "Spadder," which he once did for the *Democrat and Chronicle*.

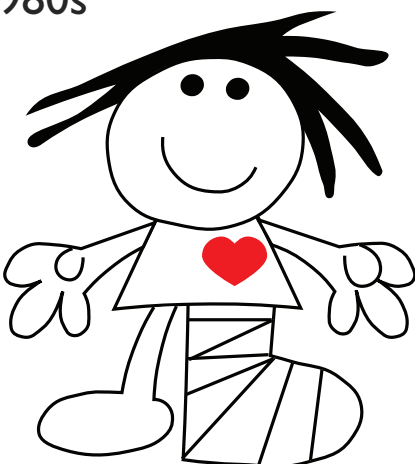
Despite Kuchera's long list of artistic contributions over the course of his lifetime, the creation that resonates most with the Golisano Children's Hospital community is the beloved character and mascot Sandy Strong, which Kuchera created in the 1980s. Much like Mickey Mouse, Sandy Strong – the memorable "child on the mend" – is still very recognizable, though she's evolved quite a bit over the years.

In 2002, Sandy got a splash of color, with a new bright red dress and six new friends – three girls and three boys, collectively known as Sandy's Friends. In 2009, Sandy and her friends were revised further. They gained dimension with extra shading and more life, with sparkles in their eyes. Today, Sandy can be seen wearing all sorts of fun costumes like a golf outfit for the Golf Classic and a cape for the superhero-themed Stroll for Strong Kids.

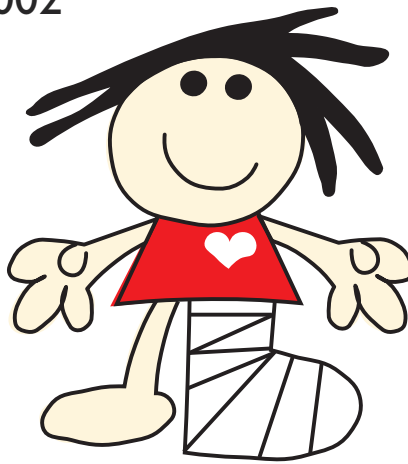
Golisano Children's Hospital would like to salute the life of John Kuchera and thank him for having left an indelible mark on our institution's identity with the gift of his art and imagination

Sandy Strong's evolution since her creation by John Kuchera.

1980s



2002



2009



Upcoming Community Events

May 23, Iced Coffee Day, Rochester-area Dunkin' Donuts. Stores will donate \$1 from the sale of each iced coffee to the hospital. Enjoy a delicious, cool drink while making a difference for kids.

May 25–28, Roc City Rib Fest, Ontario Beach Park. Enjoy some of the best barbeque in the Northeast during this beloved Memorial Day weekend festival, which benefits Golisano Children's Hospital. Tickets are \$5 and are free for children younger than 12-years-old. For more information, visit www.roccityribfest.com. To volunteer, please call (585) 273-5948.

July 21, Ten Ugly Men Festival, Genesee Valley Park. Join in on this much-anticipated summer festival to help local charities. General admission tickets are \$30 in advance, \$40 at the door and are free for children 12-years-old and younger. Please visit www.tenuglymen.com for more information or call (585) 273-5948 if you'd like to volunteer at this year's event.

Aug. 25, Fairport Music & Food Festival, Lift Bridge Lane in Fairport. Don't miss out on this family-friendly celebration of music and food, which will run from noon to 10 p.m. to benefit Golisano Children's Hospital. Tickets are \$10 in advance, \$15 at the door and free for children 12-years-old and younger. For further details, please visit www.fairportmusicfest.com. Please contact Rob Burch (585) 703-0957 or Andy McDermott at (585) 370-3831 to find out about sponsorship opportunities. To volunteer, please email kclark04@rochester.rr.com.

Children's Miracle Network (CMN) Hospitals Balloon Icon Promotion
Visit these area CMN Hospitals sponsors during their spring fundraising promotions, during which they'll sell \$1 balloons to benefit Golisano Children's Hospital:

- Kinney Drugs, March 16–May 19
- Rite Aid, April 1–May 19
- Walmart and Sam's Club, May 1–June 11
- Tops Friendly Markets, June 19–July 2

Golf Events

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

May 22, Golfing for Kids Tournament, sponsored by Walmart and Sam's Club

June 25, 5th annual Cheshire A/V Golf Classic. Visit www.egolfevent.com/cheshireclassic.

June 20, B&L Wholesale Supply Golf Tournament

Aug. 6, 10th annual Kittelberger Charity Golf Tournament

Aug. 13, RE/MAX Plus Golf Tournament. Contact Jaci Cannan at (585) 279-8040.

Aug. 27, 15th annual Ed Kaufmann Golf Tournament



SAVE THE DATE!

Join us for the
16th Annual

Golisano Children's Hospital
Golf Classic

Monday, August 27, 2012

Featuring three PRIVATE courses again this year!
Monroe Golf Club, Country Club of Rochester, and Oak Hill West

More information will be sent in the coming weeks! Any questions or to register early, please call (585) 273-5948 or visit www.gchas.org

A rich history of outstanding achievement continues

Dr. Richard E. Kreipe Receives Award from Society for Adolescent Health and Medicine

Adolescent Medicine physicians are especially attuned to the pivotal stage in life, during which children make the big and often difficult transition into adulthood. Richard E. Kreipe, M.D., professor of Pediatrics, at Golisano Children's Hospital at the University of Rochester Medical Center (URMC), has been recognized for his more than 30 year-career in advancing research, education, clinical care and community outreach to better address the health care needs of adolescents.

Kreipe has been awarded with Outstanding Achievement in Adolescent Medicine from the Society for Adolescent Health and Medicine (SAHM). Kreipe is past-president of SAHM, the only international organization dedicated exclusively to advancing the health and well-being of adolescents.

Kreipe has dedicated his career to shining light on the private and very serious issue of eating disorders for patients, families and colleagues. He is founding director of Golisano Children's Hospital's Child and Adolescent Eating Disorder Program and the founding medical director of the Eating Disorders Recovery Center of Western New York – a regional network of care that provides evaluation, treatment and prevention services for young people affected by eating



Richard E. Kreipe, M.D.

disorders and their loved ones. In addition to continuing to conduct research, serve patients and work with colleagues to improve health care services for adolescents, Kreipe recently co-edited the *Textbook of Adolescent Health Care*, published by the American Academy of Pediatrics in June 2011.

"It is humbling to receive this honor for the work that I care so passionately about –

helping young people and their families," said Kreipe. "I consider myself fortunate to be part of the rich history of pediatricians in Rochester committed to caring for adolescents."

Kreipe is the fifth physician with ties to URM to receive this prestigious award. Adele Hoffman, M.D., a graduate of the University of Rochester's School of Medicine and Dentistry, received the inaugural award for Outstanding Achievement from SAHM in 1981. Elizabeth "Lissa" McAnarney, M.D., professor and chair emerita of Pediatrics at URM, was awarded this honor in 1989, followed by Stanford B. Friedman, M.D., who was the first chief of Adolescent Medicine at URM. Donald P. Orr, M.D., trained as a fellow at URM and was recognized for his work by SAHM in 2009.

"Our faculty members have made a substantial footprint in the field of Adolescent Medicine," said Nina F. Schor, M.D., Ph.D., pediatrician-in-chief at Golisano Children's Hospital and chair of URM's Department of Pediatrics. "We are proud to serve our local community and through the work we've done here and shared with our colleagues around the world, we've established ourselves as key players in this continually growing and increasingly important field of medicine."

Friedlander professorship

Continued from page 15

Center for Eating Disorders, which forms a coordinated, integrated network of care across its full range of services.

"This professorship is a fitting honor for Dr. McAnarney, who has always been responsive to whatever the University needs," said Mark B. Taubman, M.D., dean of the University of Rochester School of Medicine and Dentistry. "The choice of Dr. Kreipe as the first faculty member to hold the professorship doubly honors her because he was one of her former fellows."

Roger's involvement with and support of the children's hospital has remained strong in his roles as member of the URM Board and

the University of Rochester Board of Trustees. The Friedlanders have supported programs and projects throughout the University, but felt compelled to endow a professorship in McAnarney's name.

The professorship complements McAnarney's extensive list of achievements. She was elected to the Institute of Medicine of the National Academies in 2000 and chaired the Interest Group on Maternal and Child Health and Human Development. She was named a fellow of the American Association for the Advancement of Science in 1998. She served as president of the American Pediatric Society (2004–2005), the first woman president of the Association of Medical School Pediatric Department Chairs (1999–2001), and a member of its Executive Board from 1994–2003. She was also president of the Society for Adolescent Medicine and served for three years on its Executive Council.

The first woman to chair the Department of Pediatrics at URM, McAnarney earned the Albert Kaiser Medal from the Rochester Academy of Medicine (2003), the 18th annual Athena Award from the Women's Council of the Rochester Business Alliance, Inc., and the Crystal Heart Award from the Ronald McDonald House. She also serves on the Board of Trustees of Nazareth College.

"It is a singular honor to be acknowledged by one's University and by cherished friends with the creation of a professorship in one's name. There is no other acknowledgement in academics that resonates so deeply," McAnarney said.

Special Thanks

Many thanks to these and
all generous supporters and
event organizers that benefit
Golisano Children's Hospital!

- The 10th annual Ski Invitational at Bristol Mountain enjoyed a record breaking year by raising nearly \$70,000 in February. We extend a special thank you to Paul Tessori and Mark Schwartz for organizing the event and appreciate all of the continued support.
- Thank you to Patrick Booher and Graham Lodge for organizing the Cruise for a Cause event and generating a donation of \$1,175 for Golisano Children's Hospital.
- The Walworth Lions Club contributed \$100 to support the hospital, special thanks to Bill Boyd and everyone involved.
- Thank you to Debbie Henderson for all of her help with the Photo Finish 5K run and helping raise a \$195 donation.
- Kohl's Associates in Action Grant generated \$500 for the kids at Golisano Children's Hospital, special thanks to Joelle Cain and everyone at the Webster Kohl's location.
- We appreciate all of the support offered to us through the various donors who participated in the ROC the Day event – the hospital earned \$1,340 in donations.
- The in-store promotional efforts of Spirit Halloween successfully raised \$12,395 for Golisano Children's Hospital. Our gratitude goes out to Kristen St. John and everyone at Spirit Halloween for all of their help and support.
- The Pittsburgh Steelers Fan Club generated a donation of \$4,000 – thank you to Kathleen Buckwell and all club members for the support.
- We extend our thanks to all of our friends at the Panera Bread Foundation for contributing \$10,000 and for all of their support.
- Thank you to Tyler Bischooping for donating the profits from his Lemonade Stand – Tyler raised \$36 for Golisano Children's Hospital.
- We appreciate all of the support given to us from the RIT Management Information Systems & Women in Business, a special thank you to Andrew Bacigalupo for all of his help generating the \$435 donation.
- Thanks very much to the organizers of the 9th annual Ugly Disco for raising funds to support the Bright Eyes Pediatric Brain Tumor Research Fund and the Pediatric Supportive Care Program at our region's only children's hospital.
- We sincerely thank the organizers student athletes and wonderful members of the Nazareth College and St. John Fisher College community for another wildly successful year with the 5th annual Battle of the Beaks fundraising events and the 3rd annual Winter Walk for Strong Kids. The events raised more than \$15,000 for the hospital.

If you are interested in hosting a fundraiser
please contact Michael Fahy at:
michael.fahy@rochester.edu or 585-276-5176.

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