

STRONG KIDS NEWS



Miracle Weekend a Celebration of Children

TWO YEARS AGO, CORY MILBURN'S PARENTS HELD THEIR SON FOR THE FIRST TIME. THEY THOUGHT IT WOULD BE THEIR LAST.

The doctors had done everything they could do for the extremely premature baby and everyone held their breath waiting to see if he would fight his way back.

The next morning, friends and family walked in his honor in the Stroll for Strong Kids. And Cory fought back. This year, on May 30, Cory will join hundreds of others to walk in the annual fundraiser. For the first time, he will walk on his own two feet.

Every year, Miracle Weekend – a combination of the fundraising walk and the annual Children's Miracle Network Telethon on News10 NBC – is a time for the Rochester and Finger Lakes community to pause to celebrate the miracles in our midst. A baby born much too early who survives, even thrives. A boy whose heart is beating more than four years after some thought there might not be any hope left. A girl who might've gone blind without the expertise of doctors in her own backyard. A pre-teen freed from the shackles of a severe and chronic digestive disease. And a baby who has fought off cancer and four bouts of meningitis.

These miraculous and strong children are only representatives of hundreds of other Golisano Children's Hospital kids who have been through so much in their young lives. See page 3 for more information about Stroll, Telethon and to meet our 2009 Miracle Kids.



Photo by: Amanda Padgham



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Dear Friends —

Politics and economics. They pervade everything we do.

How many hospitals and hospital beds does upstate New York need? In what kind of institutions?

How many healthcare professionals should upstate train and how far should we go to lure them to or retain them?

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Should we do all of this as multiple separate institutions or banded together as one?

These are important questions for the future of our region. But they are largely questions of relevance to adult medicine. Why? Because here in Rochester, all pediatricians and pediatric subspecialists are members of the Department of Pediatrics of the University of Rochester Medical Center. Because URMCPediatrics' physicians are medical directors and consultants to all of the region's neonatal care facilities. Because URMCPediatrics' weekly Grand Rounds lectures for healthcare professionals are seen "live" at Golisano Children's Hospital at Strong and Rochester General Hospital and electronically in realtime at Arnett-Ogden and Cayuga Medical Center.

Because the Region-wide Asthma Initiative for children and families involves URMCP, Unity Health System, Rochester General Hospital, Regional Community Asthma Network, Rochester City School District, and Monroe Plan for Medical Care. Because our Ruth A. Lawrence Poison Center and our continuing medical education courses for professionals and our pediatric surgery programs serve all of the counties around and beyond Monroe.

Because, while politics and economics have their place, children can't wait for either one. They must have the very best safety and quality healthcare the field has to offer. Their families must have privacy, information, compassion, comfort – the very best it is possible to provide. We cannot do this in our current facility. In fact, it is nothing short of a testament to the support of you – our wonderful

community – and the outstanding efforts of our faculty and staff that we manage to provide the kind of care we provide every day to the thousands of children who come through our doors each year.

If you have any doubt of the need for and impact of what we have always worked to our fullest to provide – outstanding healthcare for all of the children in all of our region – read about our very special 2009 Miracle Children. Each one of them and the families and communities who love and support them has a lesson for us all. Bravery, dignity, humor in the face of adversity, perseverance against the toughest of obstacles, and the power of a family's love – how could we let politics and economics interfere with giving our best to all of Rochester's children?

Private patient rooms, enough space for a family member to stay with each child overnight, the ability to get X-rays and MRIs and CTs without leaving the child-friendly inpatient building, enough space around each isolette for family members to visit comfortably with a premature newborn, and the kind of facility, training, treatment and illness prevention programs, and equipment that will lure the very, very best healthcare professionals to Upstate NY and allow us to continue to work "miracles" for generations of children!

In tribute to and hopes for the continued good health of all of our Miracle Children and their families,

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

MIRACLE WEEKEND '09



26th Children's Miracle Network Telethon on News 10NBC

presented by Perkins Restaurants

Every year, children and families touched by Golisano Children's Hospital come together to share their remarkable stories at the annual Children's Miracle Network telethon, hosted by News10 NBC. This year's five special Miracle Kids will appear on this live broadcast with their families, as will numerous other local families with extraordinary stories to tell about their experiences with Golisano Children's Hospital at URM.

The telethon will broadcast live from the Strong Memorial Hospital lobby from 10 a.m. to 1 p.m., and 7 to 11 p.m., Sunday, May 31. To make a pledge during the event, please dial (585) 241-KIDS, or log on to www.gchas.org to make a gift online.



13th annual Stroll for Strong Kids (and 5K Run)

Presented by:  M&T Bank

This year's Stroll and new 5K Run will be held Saturday, May 30, and take place at Wilson Quad on the University of Rochester campus. The Stroll will culminate with a carnival, brimming over with rides, games, treats and eats for all ages. This new twist on an old family favorite is sure to be a hit.

Registration for certified 5K Run will be from 8:00 to 9:00 a.m., with the Run beginning at 9:00 a.m.. Registration for the Stroll will be from 8:00 a.m. to 1:00 p.m., with the Stroll starting at 9:30 a.m.. Rides and entertainment will follow the walk and continue until 1 p.m. Register online today at www.gchas.org or call Golisano Children's Hospital's Office of Advancement at (585) 273-5948.

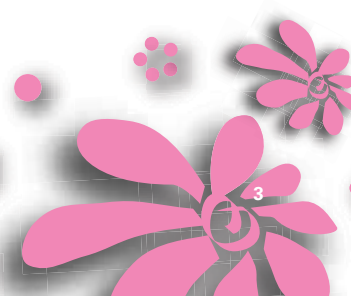




Photo by: Amanda Padgham

Dying baby gains strength in his parent's loving arms

Patti and Mike Milburn's first miracle was Kyle, conceived with the help of the Strong Fertility Center at the University of Rochester Medical Center. He was just 6 months old when the family's second miracle journey began. Mike and Patti and their children from previous marriages, Carlyn, age 8, and Mike Jr., now 16, were enjoying bonding with Kyle, when Patti began to show some symptoms of pregnancy. With previous fertility problems, how could this be?

Patti and Mike went to the doctor and were stunned to learn that she was already 17 weeks along. Still adjusting to the idea of another child on the way, Patti's water broke when she was only 25 weeks along. The doctors hoped to prolong the pregnancy for another 10 weeks to improve the baby's chances, five days later, on April 29, the baby

came anyway. Cory was 15 weeks premature and only 1 pound 8 ounces, a micropreemie. Golisano Children's Hospital neonatologists whisked him down the hall to the neonatal intensive care unit (NICU). Patti didn't get to hold her baby boy and her husband didn't even get to see him.

Cory had what NICU staffers call a "honeymoon period." Although dangerously early, he was hanging in there. But on May 15, Mike and Patti's anniversary, the honeymoon was over.

Cory was struggling with the ventilator, and his central line, through which he got a cocktail of life-saving medications, began failing. Timothy Stevens, M.D., M.P.H., medical director of the NICU, told the family they were running out of options. They needed to prepare themselves for the possibility that Cory wouldn't make it.

Stevens gave Cory steroids to help his lungs, and he and a team of specialists worked to get a new central line into Cory. It took five hours and Cory was exhausted and barely holding on.

"I sat in the NICU next to Cory's bed until midnight, saying, 'Not today, Cory. Today is not the day to go.' Cory kept fighting for his life," Patti said.

The next two weeks were a blur of medical interventions and endless hours in the NICU. Then came June 1. The hospital called at 6 p.m. to tell the Milburns they should come in and say goodbye. It didn't look like Cory would make it.

"When we walked in, Cory was a purplish-blue color and had a team of doctors and nurses working on him," Patti said. "I won't forget Heather (Goetzman, P.N.P.) said, 'Get right in there and you can talk to him.' It was

the first time we had been able to get that close to him,” Patti said.

Patti leaned in to her baby boy and told him, “You fought hard enough for us, so if you have to go, it’s OK.” She looked around at the nurses and doctors trying to save her son and saw tears in their eyes. The nurses and Sanjiv Amin, M.D., F.A.A.P., a neonatologist in the NICU, suggested Patti and Mike hold their son while still connected to the ventilator. It was the first time they’d been able to do so. He was so tiny and fragile yet so beautiful.

Amin had given Cory additional doses of steroids to see if the medication would help, but he was clear that Cory’s prognosis was grim. Patti and Mike wanted to have Cory baptized, so a hospital chaplain performed the baptism with the nurses and doctors gathered around them. Mike held him and Carlyn caressed his tiny head, saying she didn’t want to let her baby brother go. Kyle was brought in so, one day, he could be told he saw his baby brother. The nursing staff closed their section of the NICU and let the family have a few parting moments with baby Cory.

Amin warned them that, if he survived, Cory would be at risk for significant developmental problems as a result of the aggressive steroid treatment.

“I was thinking it would be like a miracle for him to survive because we exhausted routine treatment options,” Amin said. “He was gradually going down hill. The NICU staff was questioning whether we should prolong the inevitable. But the family wanted to see if a second dose of steroids would help, so we kept him going until we could see the effect of steroids a few hours after administration.”

The Milburns were told they could hold Cory until he passed. Around 11 p.m., the Milburns’ extended family started to leave. They planned to walk in the hospital’s annual Stroll for Strong Kids the next morning no matter what.

Patti and Amin kept an eye on Cory’s vitals the whole time they held



Photo by: Amanda Padgham

him, expecting his oxygenation to start to drop off. But miraculously, his vital signs improved. They placed Cory back in his incubator, and his oxygenation gradually improved over the next hour.

From that day on Cory took baby steps to improvement. He endured 21 days of the steroid treatment that the family knew could cause developmental

disabilities. Eventually, he was able to breath on his own and the family could hold him. His older sister, Carlyn, and big brother, Mike, visited. And on Aug. 10, 2007, two days before what would have been his due date, Cory finally got to go home. He was on 11 different medications, but he was home.

At the suggestion of the medical team, Patti and Mike kept Cory isolated from public places and visitors for the rest of his first year of life. Some friends joked that they didn’t believe he existed because they’d never seen him. But on his first birthday, Patti and Mike threw an enormous party in their Spencerport neighborhood, inviting 100 friends and family members to meet precious Cory. He was the star, the Miracle Kid.

A year later, he is an outgoing and healthy child. He has very few developmental effects of the lifesaving steroid treatment he received. He has some trouble with his eyesight from retinopathy of prematurity (ROP), a common problem among preemies. But he’s a walking, talking, gregarious toddler.



Photo by: Amanda Padgham

Taylor Randall Miracle Kid



Photo by: Amanda Padgham

High-spirited girl gains a new shot at life

Imagine spending ten years in and out of hospitals with life-threatening conditions. At 12 years old, Taylor Randall has spent more time in hospitals than most people spend in a lifetime.

“I’ve learned a lot after 10 years of Taylor’s illness. For most of her life, she’s really been sick all year long with only a few months of good health,” explained Regina Randall, Taylor’s mom.

When Taylor was 3 and living in Florida, she was diagnosed with Crohn’s disease – a genetic autoimmune disease in which the immune system attacks the gastrointestinal tract, causing it to swell – and ulcerative colitis, a form of a long-term digestive disease that also inflames the colon. Crohn’s disease can manifest as colitis.

Taylor was prescribed steroids to deal with Crohn’s and colitis. While the steroids reduced inflammation and suppressed Taylor’s immune system, they also had many negative side effects, including weight gain and frequent memory loss. Regina recalls that at

3-years-old, Taylor needed a daily reminder of where her toothbrush was.

Despite a lifetime of unexpected hospitalizations due to flare-ups – spikes



in Taylor’s symptoms that often sent her to a hospital – and prescription drugs that seriously impinged on Taylor’s life, Taylor and her mom maintained a rosy outlook as she grew.

“Parents don’t realize that when you’re stuck, you have to make the best of everything. The more upbeat and positive you are, the better,” Regina said. “It’s just common sense.”

Regina brought Taylor’s bedroom to her when Taylor was in any one of the

various hospitals she grew to know over the years (including a hospital in Florida, Texas Children’s Hospital, Children’s Hospital of Philadelphia and Golisano Children’s Hospital at the University of Rochester Medical Center). Regina would draw smiley faces on the board and bring in familiar items like Taylor’s bedside lamp.

Even though Taylor and her mom tried to keep their spirits high, Taylor’s condition worsened over time. The Randalls eventually left Texas, where they had initially resided and sought care at Texas Children’s Hospital, and moved to Painted Post, near Corning, N.Y., so they could be closer to family and close to another highly regarded children’s hospital – Golisano Children’s Hospital.

When Taylor’s ankle shattered in day care after kicking a soccer ball in April 2007, questions were raised as to whether being steroid-dependent was helping Taylor or hurting her. Doctors at Golisano Children’s Hospital, including Natalie Sikka, M.D., a pediatric

gastroenterologist, decided to use a new technology that has only recently become available: a capsule endoscopy, which involves swallowing a small pill that moves down the intestinal tract and captures images along the way.

This technology was pivotal in Taylor's ultimate diagnoses, since neither an endoscopy, in which a long tube is inserted through the mouth and can go down as far as the top part of the small intestine, nor a colonoscopy, which goes up the other way and can only reach up where the small and large intestine meet, could provide doctors with a clear view of Taylor's small intestine, Sikka explained.

Prior to this surgery, Taylor's symptoms had waffled between being indicative of Crohn's disease, which can occur anywhere between the mouth and the anus in the intestinal tract, and ulcerative colitis, which is confined to the colon, said Sikka. Once doctors could see that Taylor's small intestine was normal through images from the capsule endoscopy, the doctors knew that Taylor's colon was the only diseased part of her body. They determined that Taylor did not have Crohn's disease; she only had ulcerative colitis.

Since ulcerative colitis is an isolated disease that only affects the colon, the doctors determined that Taylor a colectomy was the best option for Taylor. The surgery would remove Taylor's colon – the section of her intestines that was causing her so much trouble.

Taylor was referred to Walter Pegoli, M.D., professor and chief of Pediatric Surgery at Golisano Children's Hospital. In Oct. 2007, Pegoli performed a total colectomy to remove Taylor's colon and a J-pouch ileoproctostomy – a surgical construction of an opening between the lowest part of the intestine and the rectum. After about three months of healing and using a colostomy bag, in Jan. 2008, Taylor went in for a second surgery to take down the opening in the body and hook the two ends of Taylor's small bowel back together.

Taylor did very well for awhile. Her bowel function had returned and she was recovering just fine, according to Pegoli. Taylor wrote an essay for a writing contest at the Corning Library about her experiences, which she humorously titled "The Day I Gave My Colon to the Dudes in Blue": "We tried to have fun," Taylor wrote, "like the time my mom made a tree out of construction paper and glued it to the ceiling over my bed. It was cool because it was fall outside, so as time went on the leaves fell on top of me just like they fall off the trees outside. My mom said I shouldn't miss the leaves falling."

Despite missing an average of 50 days of school a year for her medical complications, Taylor was named one of the six finalists out of 164 entrants in the writing contest. Later in the piece, Taylor adds that her mom and the nurses at Golisano Children's Hospital loved to make things for Taylor to make her room feel more comfortable.

Just as Taylor was closing the book on her life as a frequent patient and was adapting to being a kid, in May 2008, something started going horribly wrong. Taylor began vomiting violently.



Regina was adamant about traveling 1 1/2 hours to Golisano Children's Hospital. Having had so many close calls with Taylor, she knew something was seriously wrong and she wanted Taylor cared for by top-notch pediatric specialists. Scar tissue has twisted around Taylor's small bowel, making the top part look like a balloon and the bottom part look like a dime, as Regina describes it. Nothing could get through Taylor's intestine.



Photo by: Amanda Padgham

If Regina had waited much longer, Taylor's small bowel could have perforated and split and Taylor may have had to have her bowel cut out. This could have caused serious complications, since Taylor's body was still healing from her earlier operations. Regina recalls the fear she felt, but she found some comfort in seeing that the operating room was crowded with health care professionals, all working hard to help Taylor, much like how Taylor's earlier surgeries had been.

Miraculously, the small bowel had not perforated and Pegoli was able to cut the scar tissue that was twisted around the small bowel, leaving the bowel intact. Pegoli said the operation was very delicate and serious. Regina recalls that despite the severity of this operation, Taylor was up and walking around just a day later. Taylor was eager to recover and get back to the normal life she was on her way to having.

Taylor felt very safe when she was recovering: she and her mother had come to see Golisano Children's Hospital as a second home. The nurses at Golisano Children's Hospital have always gone "above and beyond," according to Regina. "The nursing staff

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Boy born with half a heart survives and thrives

Rhonda Ellison was six months pregnant when she and her husband, James Gaines, got the kind of news all parents dread going into an ultrasound: something was wrong with their baby. They needed to go to the Children's Heart Center at Golisano Children's Hospital.

The couple consulted with a cardiologist and were devastated to learn that Jason had hypoplastic left heart

syndrome, a condition that meant the whole left side of his heart – aorta, aortic valve, left ventricle and mitral valve – was underdeveloped.

The left side of the heart does the critical job of pumping oxygenated blood to the rest of the body. Hypoplastic left heart syndrome is the leading cause of death from cardiovascular disease during the first two weeks of life

and is responsible for about 2 percent of all congenital heart defects. Without surgical intervention within days of birth, babies with the syndrome die.

Initially fearing the worst, Rhonda and James were relieved when Dr. (George) Alfieris (chief of pediatric cardiac heart surgery) assured them that there was a medical procedure that could increase Jason's chance for survival.

On Sept. 12, 2004, Rhonda went into labor and she delivered almost without incident.

"I got to hold him, and he cried, just like my other babies. He was actually breathing on his own," Rhonda said.

Alfieris and his specialized team had three goals going into the first surgery: to open the wall between the top chambers of the heart so that both the oxygenated and blue (or unoxygenated) blood in the heart could mix; to rebuild a very small aorta and allow it to receive blood from the right ventricle; and to place a shunt or tube from the aorta to the lungs so that blood could get to Jason's lungs.

"His first of three planned surgeries went very well, however, his breast bone was not put back together immediately because we were concerned about swelling. His chest remained open for about five days after surgery," Alfieris said. "He's a really strong little boy."

Caring for Jason was not the same as it was for the couple's older children (Jason was one of 11; he now has a little sister, too). Rhonda and James were nervous about keeping him safe, but his cardiologist, Cecilia Meagher, M.D., reassured them Jason was doing well.

Six months later it was time for Jason's next surgery. The second surgery connected the blue blood usually returning to the heart directly to the lungs. Jason pulled through the surgery well but he developed a chylothorax or a building up of lymphatic fluid in the chest

Photo by: Amanda Padgham



cavity, a serious complication if not caught early. Jason's team, which included Regina Cable, N.P., caught the condition early. A chylothorax can develop in children after open heart surgery due to high vein pressure in the lungs. To treat it, the fluid is drained from the lung cavity and then the child is placed on a low-fat diet.

"Reducing fat consumption is important because fat is absorbed into the lymphatic system and – in this situation – then leaks into the lung cavity making it difficult for the infant to breathe," Cable said. "Jason was on a low-fat diet for about three months."

Until Jason's lungs were mature enough to handle the final procedure, Meagher kept an eye on his heart's development, making sure he would be ready. Other than some routine childhood illnesses, Jason was doing well.

On Nov. 3, 2008, Jason had his third open-heart surgery. During a seven-hour surgery, Alfieris finished routing Jason's blue blood past his heart and to his lungs and allowed the right side of his heart to just pump oxygenated blood to the rest of Jason's body. The surgery took seven hours, but it felt like an eternity to Rhonda and James.

"The surgery went well. It was only a few days before we were able to unhook the ventilator," Alfieris said.

Unfortunately, Jason was unable to keep his oxygen level high enough, so he was reattached to a ventilator. But his blood oxygen levels remained very low.

"Then he had some changes in his lungs that scared all of us and required an emergency procedure in the pediatric cardiac intensive care unit (PCICU)," Meagher said.

An ultrasound of Jason's heart revealed a clot in the tube that was taking Jason's blue blood directly to the lungs. Jason was given a clot-dissolving medicine and that decreased the size of the clot.

Daniel Miga, M.D., a pediatric cardiologist, took Jason to the cardiac catheterization lab to determine the cause of his low oxygen levels and discovered that his left lung was not picking up oxygen. Jason's heart was functioning well, but his left lung had completely collapsed.

"They kept trying things, but they didn't know a magic fix. That's when they decided to open up his chest again," Rhonda said. "His dad called the family to come to the hospital, fearing Jason, who was clinging to life, would not survive. I remember Dr. Meagher hugged me. The fear was paralyzing."

Jason's breast bone was reopened to give his lungs more room to expand. When Rhonda came out of the PCICU, Jason's extended family was there.

It was reassuring for Rhonda to have them there, but the reason for their presence was unnerving.

"It was very scary, but I didn't give up on him. I never do," Rhonda said. "I knew in my heart that my son would pull through. I knew he wasn't going anywhere."

Jason stayed in the hospital for more than seven more weeks and his chest was left open for the majority of that time. A special wound healing machine was placed on his chest to help him heal and allow him to breathe off the ventilator despite his breast bone being separated.

"Dressing changes in this situation can be very frightening especially to a 5 year old but Jason handled it like a trooper," Cable said. "When Jason's wound was close to being healed he was discharged home."

Rhonda still had to change his incision bandage once a day and bring him back to the hospital weekly. Today, his parents say the whole experience hasn't really fazed him, even if his mom and dad continue to worry about him.

"When I check the area, Jason will often ask, 'How does it look? Am I OK? Does it look good? Or, are we going back to the hospital?'" Rhonda said. "He isn't scared by any of it. He's our miracle child."

Photo by: Amanda Padgham



Photo by: Amanda Padgham



Toddler's mysterious meningitis trumps cancer threat

Brooklynn Spencer's mother Samantha knew something wasn't right. The 8 month old had the flu recently, but it had been four weeks. She should have been better. The Elmira mother of four pushed for blood tests in early October 2007. A few hours later, there was a knock at the door.

A physician – not even Brooklynn's own pediatrician – came to the house

as soon as her blood tests came back. Brooklynn's white cell count, which should have been about 5,000, was 56,000, her hematocrit, which should have been 35 to 40 percent, was 13 percent and her platelet count, which should have been more than 150,000, was 13,000. Those levels were so concerning, she needed to get specialized care immediately.

Photo by: Amanda Padgham



Sam and her husband Bill rushed with Brooklynn to Golisano Children's Hospital at the University of Rochester Medical Center, not knowing how long they'd be gone or whether they'd be bringing their baby girl back with them. Acute Lymphoblastic Leukemia (ALL) had taken over Brooklynn's bone marrow, so she wasn't making any normal blood cells. But it was the most common pre-B cell type, enough for the Spencers to hold on to a lot of hope.

"It's one of the better ones to have," Sam said. "You don't want any, but if you have to have it, it's one that's more curable than most."

Still, treatment has not been easy on Brooklynn. In fact, she's had one of the most difficult to treat cases of ALL Golisano Children's Hospital has ever seen. But it wasn't the cancer that she struggled with; it was bacteria many of us carry in our intestines with no symptoms: Vancomycin-Resistant Enterococcus (VRE).

Brooklynn was three weeks into the induction phase of treatment with her pediatric oncologist Laurie Milner, M.D., the first time she got sick with VRE.

"She went to sleep and she just didn't wake up," Sam said. "The nurse came in and changed her, did vitals and she didn't move. Usually, the cuff would make her scream."

The nurse knew something was very wrong, so she called the doctors, who decided to do a spinal tap to check Brooklynn for meningitis in addition to the VRE sepsis she had already developed. It was positive and it was bad. It was resistant to pretty much every antibiotic.

Brooklynn was moved to the pediatric intensive care unit (PICU), and the Spencers were told to expect the worst. Mary Caserta, M.D., a pediatric infectious disease specialist, knew there had to be a way to fight the infection,

so she delved into old case studies and called colleagues across the country. She came across a case of a premature infant with VRE meningitis who successfully fought it off with an old antibiotic that isn't often used anymore. Caserta added it to a cocktail of four antibiotics and started treatment.

"It was hard because one of the most effective antibiotics for that type of meningitis required Brooklynn's immune system to fight the infection, but her immune system was completely knocked out by her cancer treatments," Caserta said. "We threw everything we had at her."

Brooklynn started getting better. Her blood and spinal fluid were free of the bacteria, but it wasn't the last time the family thought it was the end for Brooklynn. She had seven bouts of VRE and four bouts of meningitis. And each time, Sam played a large part in saving her.

"She knows Brooklynn inside and out. If she says something isn't right, we know we have to do something," Milner said.

Because of all the infections, Brooklynn missed 12 weeks of chemotherapy, which Milner called "nerve-racking." The induction phase of chemotherapy treatment is very important to fighting leukemia. But the cancer hasn't come back.

"It's amazing that she hasn't relapsed, given all the delays in her chemotherapy and reductions in her chemotherapy doses," Milner said. "I still worry. Because of the meningitis, we couldn't give much of the chemotherapy directly into the spinal fluid the way we usually do."

Brooklynn finally went home June 9, 2008, nine months after she was admitted for what is usually a month-long induction phase of chemotherapy. She didn't remember her house, her crib or her dog, but it didn't take her long to readjust. Her siblings, 3-year-old Iain, 5-year-old Abigail and 8-year-old Hunter, were so excited to have her home, they

had to be constantly reminded to take a step back or they'd smother her with their affection.

Brooklynn wasn't home long when she landed back in the hospital again. Once, it was for pancreatitis. Another time, it was a blood clot in a neck vein. And once, it was kidney stones. However, Brooklynn's most complicated problem after she finally went home was getting the medications she needed to save her life. Her central line kept getting infected and scar tissue from previous lines made it difficult to put in new ones. She had seven central lines in just eight months.

She's also had three peripherally inserted central catheter (PICC) lines, the first one in her foot because they couldn't get anything else in anywhere. She had that one for 15 weeks, until October, when she was scheduled to get another central line placed through surgery. After two hours of trying, Walter Pegoli, M.D., chief of Pediatric Surgery, came out and told the Spencers the scar tissue from other placements made it impossible for him to put in a new one and suggested they try interventional radiology. Interventional radiology successfully got a line into the right side of her neck, and she went home a day later. A week later, another complication – a blood clot – forced the removal of that one, and a PICU team had to work hard to get a new PICC line in the left side of her neck.

A month later, while staying at the Ronald McDonald House, practically a second home to the Spencers, Brooklynn pulled the PICC line out herself. "It's one of those things where



you had to laugh. It's just been so much trouble," Sam said. Once again, after much effort, the PICU team came through with a PICC line in her foot.

Brooklynn still has a long road ahead of her. Because she was so sick for so long, she missed important developmental milestones, like eating solid food. She now has a severe aversion to anything being put in her mouth, so she gets most of her nutrition from a tube in her stomach. But she's growing and getting stronger and more curious every day.

Brooklynn's chemotherapy treatment doesn't end until November, but she is already a miracle for everything she's been through.

"I'm so thankful that we live so close to Golisano Children's Hospital because they're so good. Two hours doesn't seem close, but look at all the families who have to leave their state," Sam said.

Photo by: Amanda Padgham



Victor girl undergoes major cranio-facial surgery to save her sight

Today Tea Papke is a sixth grader at Victor Intermediate with three years of experience in all-star cheerleading under her belt and a heart of gold. However, if her father hadn't happened to bend down as Tea stood up six years ago, Tea's life could have taken a completely different turn: she could have gone blind.

When Tea was 5 she banged into her father's glasses and he noticed an unusual bump and grew concerned. The Papkes took Tea to a dermatologist, who opted to leave the bump alone, since it wasn't hurting Tea. A year later, she complained of an aching pain around her eyes during a first-grade eye test.

The Papkes went back to the dermatologist, who recommended Tea's pediatrician, Kevin Klossner, M.D., of the Penn-Fair Pediatric Group perform a CAT scan, which combines special x-ray equipment with sophisticated computers to get clearer images of internal parts of the body. A few days later, Klossner called Amy and revealed Tea's diagnoses: fibrous dysplasia.

Fibrous dysplasia is a genetic disease in which bone is progressively replaced with a softer expandable bone. This condition is extremely rare and there is no known cure. The tumor-like growth is generally benign, but locally aggressive, which means it would grow

significantly if not removed. Klossner recommended the Papkes go to John Giroto, M.D., a pediatric plastic surgeon who specializes in craniofacial anomalies and Howard Silberstein, M.D., a pediatric neurosurgeon, both at Golisano Children's Hospital at the University of Rochester Medical Center.

"We figured we'd have to go out of town for a plastic surgeon and a neurosurgeon," said Amy. "Most people don't think of Golisano Children's Hospital until their child has been there."

Giroto found Tea's tumor was growing inward, toward her optic nerve. Because Tea's monostotic fibrous dysplasia was only in one bone, if the surgeons removed enough around the area of the tumor, Tea would be in the clear. If it wasn't removed, however, the tumor would compress Tea's optic nerve and blind her. Giroto explained that the tumor would also continue to grow as a deformity that eventually covered Tea's entire face and that it could potentially cause brain damage. Leaving the tumor alone was no longer an option – it had to be removed.

Giroto and Silberstein told the Papkes about the procedure and what to expect. Tea and her family are "delightful folks," said Giroto, but he also sympathized with what they were going through. Giroto expressed that naturally, any parents would be upset if a neurosurgeon and a plastic surgeon said their little girl had to undergo massive reconstructive surgery to remove a tumor moving toward her brain. Tea's parents did not want to worry Tea with scary details about the operation, but the first-grader was insistent. "Going through a situation like this made her grow up faster," said Amy.

On April 8, 2004, the day of Tea's operation, Tea, her parents and her brother were joined by Tea's grandparents and other local family members. Tea's aunt from South Carolina also made the trip up to offer her support. Tea was given a sedative and Amy carried her daughter into the operating

room. As Tea sat on the operating table with a mask over her nose, she held her mother's hand until she fell into a deep sleep.

Tea underwent the day-long procedure and Giroto and Silberstein proceeded with the huge coordinated team effort while the Papkes anxiously waited with other families for their children, who were all undergoing equally nerve-racking operations. "We all comforted one another," Amy explained. Silberstein was careful to get the brain and skull out of the way while Giroto removed the tumor and reconstructed the eye socket and part of the forehead. Once the operation was over, Tea was taken to the pediatric intensive care unit, where she rested for about a week. She

recovered at home for a week and then returned to school a few hours a week until she was ready to go back to full days of school.

Now fully recovered, Tea has grown into a compassionate young lady. "We gave her some money for Christmas. She figured out how much money she had to give and decided to donate all of it. I explained, 'Well, you really don't have to give away all of your money,'" Amy chuckled. Tea has also donated her hair to "Locks of Love" twice and assists with a special needs cheerleading team at Premier Cheer, where she is a cheerleader.

Tea still visits Giroto about once a year for a CAT scan to make sure there is no leftover soft tissue that could grow

into a larger problem. "It's been five years and I haven't seen anything yet, so I guess we did a pretty good job," Giroto said.

Amy finds a lot of comfort in having a hospital with such highly-qualified health care professionals so close to home. She explained that the Papkes often run into Silberstein at their local ice cream store in Victor and see Giroto out as well. Amy finds it amazing that with so many patients, both doctors still remember Tea by name. Tea is doing great and the Papkes have found solace in knowing that such a rich resource lies right at their door steps.

Photo by: Amanda Padgham



MIRACLE MAKER AWARDS

Golisano Children's Hospital couldn't provide the top-notch care it does without the community's support. Community groups, companies, individuals and families routinely rally together for the region's children, and the hospital is eternally grateful. Every donation has a story behind it and every fundraiser started for a special reason.

This year, the hospital has chosen five truly exceptional people and groups to present with Miracle Makers Awards for their efforts on behalf of children and families in need. The award-winners are our neighbors and our friends, our family members and our colleagues. Yet with a remarkably strong commitment to helping children and an

immense amount of work, they've chosen to become real, live heroes. Our hope is that in reading these stories, you draw inspiration and comfort in the power and drive our community holds to improve the lives of our future citizens.

Outstanding Commitment by Grateful Parents

Team Taylor wins by a landslide

There are no champions for children quite like parents. Parents are an essential part of the Golisano Children's Hospital community. They rally friends and families together, share stories from the heart and tirelessly work as advocates for our future generation. This year, a special category has been created to celebrate the remarkable efforts that parents have made to help Golisano Children's Hospital at the University of Rochester Medical Center. There isn't a more worthy recipient of the first-ever grateful parents Miracle Maker Award

than Jennifer and Tim Brush.

Jennifer and her husband, Tim, have turned what started out as a small gathering to remember their daughter Taylor into one of the most anticipated and well-attended fundraisers of the year for Golisano Children's Hospital: the Taylor Brush Dinner Dance. Team Taylor, which Brush affectionately calls the group of friends and family that support Jen and Tim's efforts, has raised more than \$115,000 for Golisano Children's Hospital.

Now in its seventh year, the Taylor Brush Dinner Dance is attended by hundreds of people annually. "It's been kind of a snowball effect. I invited my friends, then they invited theirs, and the next thing you know, we had 335 people who were braving a snowstorm to come," said Jennifer Brush, referring to the 2008 event.

The event has a dinner and is followed by music from dedicated DJ David E., who has provided music for the event for years. The raffle boasts a variety of items, all donated by the community. This year's event auctioned off a diamond necklace, worth \$2,000 and donated by Jerry's Jewelers, a Nintendo Wii donated by Bob Jacobson of B&L Wholesale Supply, and a garage

door and opener donated by Brush's family's company, Tracey Door.

"We try to make the event a fun night out. We show a movie every year to share local stories. Even though Taylor's not here, we want to showcase a few of the many success stories out there," said Brush. Brush, a third grade teacher, reaches out to other teachers and students to find stories about kids who have been helped by Golisano Children's Hospital and to encourage them to get involved.

A little bit of encouragement goes a long way. Brush started attending children's hospital events when a friend got a letter about the Stroll for Strong Kids and suggested starting a team. Brush invited ten family members and friends to join the walk, ironed "Team Taylor" on some t-shirts, and a dynamic fundraising team was born.

Brush emphasizes that it is actually "Team Taylor" that has earned the Miracle Maker Award, not just Brush. Ever a team player, Brush recognizes that by working together, miracles can happen.

"I know that we're the ones getting this award but it's really not just us," insisted Brush. "It's our friends, our family: we're just a very small part of it. It's really the team. 'Team Taylor' has been incredible, and it's a small testament to the impact Taylor has had on everyone in this community."



Fairport Music and Food Fest

Spirited community group is on a roll with giving



After four years of exponential growth, the Fairport Music and Food Fest (FMFF) has become one of the most anticipated community fundraisers of the year. With dozens of bands, food vendors galore and numerous activities for kids culminating at the end of the summer along the Erie Canal, who wouldn't want to attend this annual knock-out fundraiser?

The event, which has raised more than \$150,000 for the University of Rochester Medical Center's Golisano Children's Hospital in just four years, is an outgrowth of what started and still continues to be the Ed Kaufman Golf Tournament, also a benefit for Golisano Children's Hospital. "The event is great, but we wanted to find another vehicle to generate more revenue," said Andy McDermott, co-organizer of FMFF.

"We tried to figure out a good way to throw a party without ruining our collective lawns," joked Rob Burch, who shares the responsibility of organizing the event with McDermott.

The Village of Fairport extended their support for a music festival fundraiser along the Erie Canal, offering



to close off a section of Lift Bridge Lane from noon to dark to make space for the bands, vendors, kids' activities and all of the attendees. The village and organizers also provide three stages and sound for area bands, who perform at the event for free. By the time August rolls around, the event garners roughly 170 participants, including vendors, bands, girl scouts and cub scouts, Fairport sports teams and many other dedicated supporters.

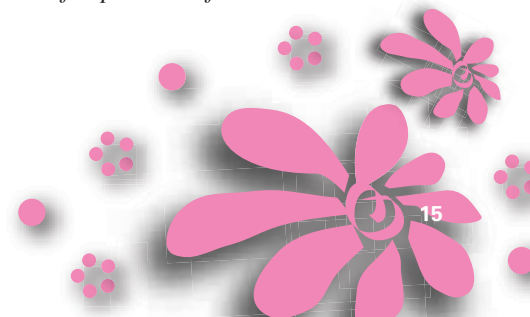
The community's support for the fundraiser has helped make it wildly

successful. The first year, FMFF raised \$13,700 for the hospital and each following year, the event has broken its previous record. Last year, the event quadrupled the first year's total, netting \$57,500.

The growth of this event is no fluke. McDermott and Burch spend about ten months a year planning for Fairport Music and Food Fest. The two are joined by about ten committee members, who help plan from the beginning of January until the day of the festival, which will begin this year at 12 p.m., Saturday, Aug. 29.

"It's a hobby for us, so it really doesn't seem like work," explained Burch. One would be hard-pressed to find a more worthwhile hobby than helping the children in our community.

For their hard work, ambition and enthusiasm, Golisano Children's Hospital is proud to honor the community group that organizes Fairport Music and Food Fest with a Miracle Maker Award. For more information on this year's 5th annual festival, visit www.fairportmusicfest.com.





Tops never stops giving kids more

Tops Friendly Markets sticks to a clear and straightforward belief: keep the giving local. Through its fundraising and volunteering, hosting and sponsoring events, and an ever-strong desire to help our region's children, Tops has been awarded this year's Outstanding Commitment by a Children's Miracle Network (CMN) Sponsor.

Since Tops became a CMN sponsor in 2005, the company has raised nearly \$200,000 for Golisano Children's Hospital at the University of Rochester Medical Center. More important than the money Tops has raised, though, is the vigorous commitment Tops has made to help children in the Rochester area.

"We have a simple philosophy: 'Living here, giving here,'" said Andy Brocato, senior manager of community relations and special events at Tops Markets.

The lucid motto sets the tone for understanding the relationship that has developed over the years between Golisano Children's Hospital and Tops.

Tops goes above and beyond to support the children's hospital, providing volunteers and food for events, holding promotions and shopping sprees at its stores, sponsoring the annual Drive for Miracles Radiothon and Children's Miracle Network Telethon and hosting its own fundraising events like Monte Carlo Night.

"I know when I ask, 'Can you help us out?'" their answer is always an enthusiastic "Yes," said Betsy Findlay, associate director of the Office of Advancement for Golisano Children's Hospital.

Tops associates recognize the importance of giving back to the communities they live and work in, especially when they see what a difference Golisano Children's Hospital makes to this community. It was natural for Tops to join the Children's Miracle Network for just that reason. The network, which includes 170 children's hospitals nationwide, is wonderfully wide-spanning institution that forges bonds between children's hospitals and the corporations, like Tops, who want to help them. The special connection between Tops and the hospital goes even deeper because one of Tops' associates, Eric Czekanski, has a personal connec-

tion with the hospital. Eric is not only a manager at Tops, but he is also a grateful parent.

Eric's son Bryce has a rare genetic disorder, called Hurler-Scheie syndrome, which consequently brings Bryce and Eric to Golisano Children's Hospital every week for synthetic enzyme-replacement therapy. Bryce has gotten to know the hospital very well over the past six years he's been receiving his weekly IV-therapy, which lasts six-hours each session.

Bryce has created artwork for the Monte Carlo Night invitations and for Kards for Kids, a special set of holiday cards that Tops sells to raise money for the children's hospital. Bryce and his dad have shared their story at children's hospital events like Radiothon and the opening of the Pediatric Outpatient Treatment Center in 2008. The Czekanskis' dedication has inspired employees at the 19 Tops stores that support Golisano Children's Hospital to be enthusiastic advocates for the hospital.

"We're extremely honored and extremely humbled to join the wonderful sponsors who have been named Miracle Makers in past years," said Brocato, "Of course, the award is secondary. We don't support Golisano Children's Hospital for recognition, we do it for the right reasons – for the good of the community."

William Levine: Giving back to his community with spirit



William Levine has been a generous donor to Golisano Children's Hospital at Strong for the past 14 years. His name is revered throughout the University of Rochester for the generous spirit with which he gives back to his community. We are proud to celebrate Levine's continuous generosity in the name of our community's children by presenting him with the Miracle Maker Award for Outstanding Commitment by an Individual.

"Bill has always put our community first. His generosity with the University of Rochester Medical Center reflects a broader understanding of the importance of investing in our region's future," said Bradford C. Berk, M.D., Ph.D., CEO of the Medical Center.

Over the years, Levine has been an incredible contributor to our region's children, including sponsoring many of the children's hospital's galas and serving as honorary chair of the gala in 2004. But Levine's most transformative and generous gift to Golisano Children's Hospital was helping to fund one of the children's hospital's crowning achievements: the William and Mildred Levine Pediatric Surgical Suite.

The suite, which opened in June

2006, helps the more than 6,600 children each year who undergo surgery at Golisano Children's Hospital, by providing pre- and post-operative care that is specifically catered to meet a child's needs.

The William and Mildred Levine Pediatric Surgical Suite is recognizably a space for children and their families, providing a seaside background in the halls and the waiting room to create a calming ambiance for kids. A pre-operative room in the suite offers families a space to be with their children minutes before surgery. After surgery, parents can speak with their surgeon and then go to a Post Anesthesia Recovery Unit, where their child is being monitored. Before the suite, this space was shared with adults and didn't allow for parents to visit their children immediately after surgery.

With 21 great-grandchildren, 16 girls and five boys, Levine strongly believes in helping children at Golisano Children's Hospital at Strong. "They're our future citizens," said Levine.

Levine's grandson, Todd Levine, is on the Board of Directors for Golisano Children's Hospital. "He's

"Bill has always put our community first. His generosity...reflects a broader understanding of the importance of investing in our region's future." Bradford C. Berk, MD, PhD

a very charitable person," explains Levine. Todd is clearly taking after his grandfather, who has contributed to other projects for the University of Rochester as well, including the William and Mildred Levine Pavilion.

With a lifetime of charitable giving under his belt, Levine remains an active member in the community. "I'm 93 now and I'm still going to work every day, still active, and still giving," explained Levine.



LeChase Construction: Building a path to our children's future care



Improving the care of our area's youngest patients requires a lot of hard work on many different levels. To provide the best care for our pediatric patients, who come from 17 counties in the Finger Lakes Region, we need up-to-date facilities to offer advanced care. LeChase Construction Services has helped Golisano Children's Hospital at the University of Rochester Medical Center (URMC) lay the foundation for the highest quality of health care for our patients.

"LeChase Construction has been a wonderful resource to our community. The company has insightful leaders, stellar services and an enthusiastic interest in strengthening establishments in the Rochester-area," said University of Rochester President Joel Seligman.

For the past 13 years, LeChase Construction's support has helped fund important projects that pave the way to



better patient care at Golisano Children's Hospital. The construction company has generously donated to the children's hospital at URMC through corporate sponsorships and participation at many of the hospital's fundraising events.

In addition to building the pediatric

intensive care unit, LeChase Construction also helped fund the unit, which has dramatically improved facilities for pediatric patients in need of almost any medical service or treatment imaginable. The company has also supported the neonatal intensive care unit, where our tiniest patients receive care.

Over the years, LeChase Construction has been a corporate sponsor and eager participant in many annual fundraising events, including the Golisano Children's Hospital Golf Classic and the annual Gala, the hospital's biggest annual fundraising events, and the Ski Invitational and Radiothon.

"I love these events because they show the true spirit of our community. There is such a need to protect and care for our next generation and I appreciate being able to be involved first hand and to witness the generosity of all of those who participate in supporting these important efforts," said Wayne LeChase, chairman and managing partner at LeChase Construction Services.

The company is also very generous with the Medical Center as a whole, having donated half-a-million dollars to date. Wayne LeChase is an exemplary donor himself, both to the children's hospital and to the medical center. LeChase recently joined the Eastman Dental Foundation Board and also serves on the University of Rochester's Board of Trustees.

"Giving back to the community is important – I have always felt that to be a part of something truly you need to be involved and committed to the cause. Building partnerships, building community and building legacy is vital to long-term success," said LeChase.

Pediatric allergist endows professorship

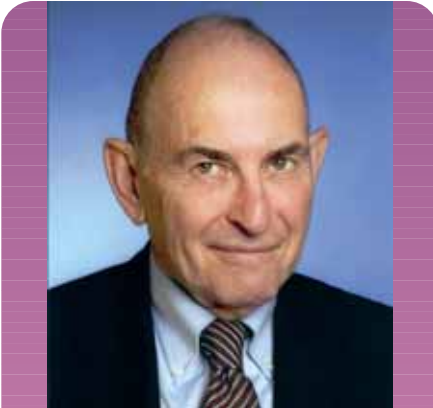
Medical professionals devote their lives to helping people heal. On top of the countless children he has treated in his nearly 50 years of practice, Eric M. Dreyfuss, M.D., clinical assistant professor at Golisano Children's Hospital at the University of Rochester Medical Center (URMC), has ensured that the next generation of children who require services in his field, pediatric allergy, get the best possible quality of care.

Dreyfuss, who has worked in pediatric allergy since 1962, has donated \$2 million to establish the Founders Fund, which will support pediatric allergy training programs and endow a new professorship for pediatric allergy at URMC's Golisano Children's Hospital.

Endowed professorships are given to faculty who are viewed as exceptional in their fields and institutions. In times when the economy is faltering and its future remains uncertain, funding through endowments is extremely valuable. Through this type of donation, Dreyfuss can provide the means for investigating new ideas in pediatric allergy when traditional National Institutes of Health resources are especially tight.

As a donor to an endowed professorship at Golisano Children's Hospital, Dreyfuss will be in on the ground-floor of important research, teaching and clinical care in pediatric allergy. "Rochester has been very important in establishing the fields of allergy and pediatric allergy in the United States," Dreyfuss emphasized.

Dreyfuss is passionate about the



"Rochester has been very important in establishing the fields of allergy and pediatric allergy in the United States." Dreyfuss

significant role Rochester has had in the establishment of the subspecialties of allergy and pediatric allergy and wishes to sustain its remarkable reputation in the field. Dreyfuss's devotedness to his practice can be well-explained by the fact that he was trained under Jerome Glaser, M.D., who initiated a pediatric allergy clinic in the 1940s.

In a piece Dreyfuss wrote titled "The Rochester, New York Tradition: Allergy and Allergists," the pediatric allergist highlighted the many successes of allergists at URMC. In 1946, for

instance, Glaser was granted one of the first certificates in the new subspecialty and became one of the initial members of the subspecialty board of pediatric allergy for the American Board of Pediatrics. In addition, Glaser and Douglas E. Johnstone, M.D., Glaser's successor and director of the pediatric allergy clinic at URMC, were both charter members of the section of allergy of the American Academy of Pediatrics. Johnstone was also past president of the International Association of Asthmology and also of the American Association of Certified Allergists.

"We are so very grateful to our friend and colleague, Dr. Eric Dreyfuss, for giving us the opportunity to establish novel research and education programs, expand our clinical services, and lure the best and the brightest physician-scientists and trainees in pediatric allergy to upstate New York. 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, NY," said Schor.

In addition to funding the endowment for a professorship at Golisano Children's Hospital, Dreyfuss has also established a donor-advised fund, a charitable giving vehicle created so Dreyfuss can more easily manage his gifts to URMC and other qualified charities. It functions much like a family foundation at a fraction of the cost. Dreyfuss has also been very generous in donations to the Wilmot Cancer Center at URMC.

Through his medical career and his charitable gifts to URMC, Dreyfuss has proven himself to be a remarkable individual, who is fully dedicated to the Rochester-area community and solidly invested in the future of our children. To learn more about establishing an endowed professorship, please contact Scott Rasmussen at (585) 273-5932 or srasmussen@admin.rochester.edu.

"We are so very grateful to Dr. Eric Dreyfuss, for giving us the opportunity to establish novel research and education programs, expand our clinical services, and lure the best and the brightest physician-scientists and trainees in pediatric allergy to upstate New York." Nina Schor

CMN Partners Fundraisers Flourish



1 Tim Hortons' Week of Treats Brings Sweet Rewards

Tim Hortons' Smile Week gave folks an opportunity to share smile cookies with their loved ones around Valentine's Day with an added gift of kindness to our region's children. For the past four years, Rochester-area Tim Horton's stores have spent a week selling Smile Cookies for \$1 each to support Golisano Children's Hospital at URM. This year's special promotion raised more than \$8,400 for the children's hospital, adding up to \$28,400 in total over the years.

2 IHOP Pancake Day Whips Up Fantastic Funds

The IHOP restaurants in Irondequoit and Henrietta held their 3rd annual National Pancake Day on Tuesday, Feb. 24. All day, IHOP doled out free pancakes, asking that customers make a donation to Golisano Children's Hospital at URM. The two Rochester-area IHOP restaurants raised more than \$1,100 this year, bringing their total to \$5,000 in donations for the children's hospital over the four years they've participated in this fundraiser.



3 Wal-Mart Fundraisers Work Wonders

With an annual golf tournament, employee cook-outs, red and yellow balloon sales and compassionate employees, Wal-Mart has been one of Golisano Children's Hospital's most dedicated fundraising partners. Last year alone, our 12 local Wal-Mart and two local Sam's Club stores raised more than \$275,000. Wal-Mart also surpassed their \$1 million gift to the Pediatric Cardiac Intensive Care Unit that they began to collect in 2002.

This year, Wal-Mart reached yet another special occasion, and it is all thanks to one extraordinary employee. Wally Straight, a part-time greeter at the Wal-Mart in Canandaigua, who has been collecting donations for Golisano Children's Hospital since 2002, surpassed the \$250,000 mark in fundraising. Straight started gathering donations from customers at his Wal-Mart entrance post after losing one of his 13 grandchildren just before the child's fifth birthday. We'd like to offer a heartfelt thank you to Wally for his remarkable efforts.

Wal-Mart and Sam's Club will be continuing their quest to help Golisano Children's Hospital during our "Miracle Month" this May. Between May 1 and June 14, they'll be collecting donations for the hospital, a dollar-by-dollar endeavor that proves to have extremely successful outcomes. Last year, Wal-Mart raised \$64,000 during Miracle Month.

Golfing for Kids, the Wal-Mart Golf Tournament in which Golisano Children's Hospital is one of the two beneficiaries, will take place Wednesday, May 20, at The Links at Ivy Ridge Golf Club in Akron, NY. For more information on this fundraiser, please contact Betsy Findlay at (585) 273-5933.



Additional CMN Balloon Sales

Kinney Drugs (Lyons): Sunday, March 15 — Sunday, May 24

A Plus/Sunoco: Wednesday, April 1 — Monday, May 18

upcoming events

All of May, Amanda Padgham Fundraising Month. Capture magic moments of your own while making a memorable donation to our region's children. During May, schedule a session with Amanda Padgham Photography and 10 percent of the proceeds from the prints you order will benefit Golisano Children's Hospital at the University of Rochester Medical Center. Mention this promotion and you'll also receive a complimentary 8x10" photo. Sessions fill up quickly, so call soon to make a reservation at (585) 764-2341. To view Amanda's work, visit www.amandapadghamphotography.com.

May 23 & 24, 2nd annual Roc City Rib Fest, Ontario Beach Park. Enjoy the best assortment of ribs in Rochester or join in on the competition at this family-friendly event during Memorial Day weekend. This year, the event has a new location on the beautiful shoreline of Ontario Lake. The festival is open to the public 10 a.m. – 10 p.m., Saturday, May 23, and 10 a.m. – 7 p.m., Sunday, May 24. Tickets are \$5 for adults and free for children under 12-years-old. For info., email info@roccityribfest.com or visit www.roccityribfest.com.

July 25, 20th annual Ten Ugly Men, Genesee Valley Park. Celebrate the 20th anniversary of this favorite summer event, hosted by the legendary Ugliers, to benefit the Bright Eyes Fund for pediatric brain tumor treatment at Golisano Children's Hospital. Tickets are \$30 for adults, \$10 for kids between 13 and 20 years old and are free for children 12-years-old and under. To purchase tickets or to learn more about this year's event, visit www.tenuglymen.com.

Oct. 11–17, 13th annual Cruise for a Cause, Norway. Take a trip on the Norwegian Pearl and raise money to kids right here in the Finger Lakes region. Last year, this benefit raised more than \$2,000 for Golisano Children's Hospital. For more information on this, which starts with rates as low as \$579 per person, please call 1-888-461-2628 ext. 276.

Golf Events

For more information on the following golf events, call Golisano Children's Hospital's Office of Advancement at (585) 273-5948 or visit www.gchas.org.

May 20, Golfing for Kids Tournament sponsored by Wal-Mart and Sam's Club

June 22, 21st annual Kiwanis Charity Golf Tournament

June 24, 14th annual B&L Wholesale Golf Tournament

July 16, 9th annual WNY Optics Golf Tournament

Aug. 3, 10th annual Tim Milgate Golf Tournament

Aug. 3, 7th annual Kittelberger Charity Golf Tournament

Aug. 24, Ed Kaufmann Children's Hospital Classic

Sept. 14, 13th annual Golisano Children's Hospital Classic



DAVID YURMAN CABLE FOR A CAUSE TRUNK SHOW

Choose from an extensive selection of David Yurman jewelry assembled for this special event.

**SATURDAY, MAY 2ND
10:00 - 5:30**

A percentage of all proceeds from this event will be donated to the Golisano Children's Hospital.

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SAVE THE DATE and JOIN US FOR THE

3rd Annual

"Evening of Wine & Wishes"

A wine and beer tasting event to benefit the Neonatal Intensive Care Unit at Golisano Children's Hospital at Strong

Friday, May 15, 2009

6-10 PM

Rochester Museum & Science Center
657 East Avenue

A formal invitation will be mailed soon. We hope to see you on May 15th!
Sponsorship opportunities available.
For more information call 585-273-5948.

Community Fundraising

1 ABVI: Using all of our community resources to help local families

ABVI-Goodwill has reached out to families at Golisano Children's Hospital at the University of Rochester Medical Center, along with other nonprofits and offered a valuable gift to our most needy families year-round— gift cards to Goodwill.

In August 2008, ABVI-Goodwill, a nonprofit organization that provides programs, services and jobs to the blind and visually-impaired in our community, launched the Good Neighbor Program. Thanks to this program, 200 gift cards, or \$5,000 worth of merchandise, have been issued to families served at Golisano Children's Hospital.

Golisano Children's Hospital's reach extends great distances, so some families have to rush here from relatively far away to get emergency care for their children. Thanks to the Good Neighbor program, social workers can offer ABVI's gift cards to families like these, so mothers and fathers can get a change of clothes or books and toys for their children. ABVI-Goodwill's products are very inexpensive, so families can get a lot of important items with their \$25 gift cards.

ABVI-Goodwill is a nonprofit that has set out to help other nonprofits. Recognizing the importance of using all of the community's resources to improve the lives of families in need, ABVI will continue to offer these much-needed gifts indefinitely as demands arise. For more information on ABVI and store locations, go to www.abvi-goodwill.org.

2 Panera Doubles Fundraising for Children's Hospital

Panera Bread stores have whipped up a huge sum of money to benefit kids at Golisano Children's Hospital. Over the past year, they have doubled the money they raised in the previous year for the hospital, raising more than \$20,000 through their Panera coffee promotion and Operation Dough-Nation collection boxes.

Setting up Panera's Dough-Nation boxes in all seven Rochester-area stores was paramount to doubling donations, since 2008 marked the first full year customers could donate spare change at Panera Bread stores to Golisano Children's Hospital.



Panera's annual coffee promotion also contributed to Panera's successful year of fundraising. Each November and December, Panera stores sell coffee mugs, which entitle customers to unlimited coffee refills for the duration of the year. Panera donates a portion of these sales to Golisano Children's Hospital.

On top of Panera's winter promotion and donation boxes, the local stores help Golisano Children's Hospital by handing out the more than 2,800 cookies during the annual fundraising event Stroll for Strong Kids.

3 Sports Teams Get Extra Points for Kindness

Teammate camaraderie has extended from the field out to kids most in need of someone fighting by their sides. For years, teams of all kinds have stepped up to hold fundraising games, welcome patients in as special guests, and visit kids at Golisano Children's Hospital. From junior varsity to professional, from horse-racers to basketball players, our area teams have fought the good fight for kids in our community.

We'd like to offer a spirited shout-out for sports teams who have helped our region's children over the past year: Chris



Schiller and the Knighthawks lacrosse players, the Finger Lakes Racetrack jockeys, Brian Mormon and the Buffalo Bills, the Nazareth Flyers and the St. John Fisher Cardinals basketball teams for "Battle of the Beaks," Pittsford Mendon and Pittsford Sutherland basketball teams for "Rainbow Classic," the Pittsford crew team for "Row for Strong Kids," the Eddie Meath All-Star Football Game players and cheerleaders and "Buckets" Blakes from the Harlem Globetrotters.

special thanks

- The New York Apple Association barreled \$4,000 for Golisano Children's Hospital during their fall apple sale at the area Wal-Mart locations.
- Cruise for a Cause amassed \$2,050 for Golisano Children's Hospital during their October 2008 cruise.
- Special thanks to Ida Wheeler for holding the 2nd annual Holiday Showcase on Dec. 6. This all-star local youth talent show raised a record \$2,895 for our region's only children's hospital.
- Many thanks to ESL Sports Centre for coordinating and holding the 3rd annual Nutcracker on Ice to benefit Golisano Children's Hospital! The great cast of youth performers skated to a tune of \$690.
- The 8th annual Rainbow Classic proved again that kids really do make a difference! The girls and boys basketball teams and the cheerleaders at Pittsford Sutherland and Mendon raised \$24,950 to complete their pledge to name a patient room in the PICU in memory of their classmates, Katelyn Pasley and Ryan McCluski.
- Jan. 31 marked the 5th annual Cycle for Hope. This spinning fundraiser held at a dozen health clubs around the Rochester area raised \$23,241 for the children's hospital and Camp Good Days.
- The 2nd annual Battle of the Beaks, basketball games played by rivals Nazareth and St. John Fisher, raised \$15,000 for Golisano Children's Hospital admission tickets, raffles, t-shirt sales, concessions and a student athlete dance at Nazareth. Proud parents Becky and Mike Fahy spearheaded this last year with the help of Board Member Kim McCluski in honor of their NICU miracle baby, Kelsey.
- The 2nd annual "Keeping Hope Strong" fundraiser event at JB Quimby's raised \$10,700 for Pediatric Surgery. The fun event was organized by grateful parents Despina and Scott Mitchell, whose son Mason underwent numerous surgeries at Golisano Children's Hospital. Thank you.
- Many thanks to Paul Tessonni and Mark Schwartz for organizing the infamous ski outing. The 7th annual Ski Invitational at Bristol Mountain raised \$48,250 for Golisano Children's Hospital. Nearly 100 people hit the slopes on February 9th and enjoyed a beautiful sunny day, all for the kids.
- The Iron Butterfly Health Club in Victor held their annual "Be Strong for Others" family fun night in March on Friday the 13th and brought good luck to Golisano Children's Hospital, raising \$2,350. That combined with Cycle for Hope the Iron Butterfly raised nearly \$6,000 this year for Golisano Children's Hospital.
- Many thanks to these and all generous supporters and event organizers that benefit Golisano Children's Hospital. We recognize that economic times are tough and we appreciate every bit of support. Thank you.

Special thanks to these and all generous groups that support Golisano Children's Hospital. If you are interested in hosting a fundraiser please go to www.gchas.org and complete the Community Fundraising Application Form or call 585-273-5948.

Taylor Randall

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gave us constant encouragement," she said.

Regina remembers a special occasion in which Taylor's nurses made an exception when Taylor was on NPO – a Latin abbreviation for "nothing by mouth" – and had been fed through a line for 17 days. On Taylor's birthday the nurses came in with a big Jello cake that spelled out Taylor's name.

Taylor's doctors at the children's hospital were equally supportive in advisory roles. When Taylor's fourth grade teacher was insensitive about her frequent medical absences, which Taylor had no control over, Regina turned to her doctors at Golisano Children's Hospital for help. Together, they decided that Taylor should be homeschooled for the year so she had more flexibility to recover.

Taylor has since switched schools and loves her new teacher and class-

mates. She is even active enough to have joined the lacrosse team, which Regina jokes that she reluctantly allowed after Pegoli and her doctors encouraged the physical activity. (Like any mother would be in Regina's situation, she was excited Taylor was eager to get involved but a little bit nervous.) Taylor has since also gained a love of art, singing, is dabbling in theater, and aspires to be a fashion designer or a "large vet doc," according to her mom.

After all Taylor has been through, she's quite a "tough kid, who doesn't like to complain," said Pegoli, "When I first met her, she was demure, laid back, quiet and withdrawn. Now, she's become an outgoing, interactive, normal adolescent." Taylor's optimistic attitude, supportive family, dedicated health care professionals and devoted mother have helped lead to Taylor's miraculous and dramatic improvement. At 12 years old, Taylor finally gets the chance to be a kid.

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