Spring 2010

University of Rochester Medical Center

Golisano Children's Hospital

STRONG KIDS NEWS

Miracle Kid Bridgette Merriman strolls through the walk-in kalidascope at the Strong Museum of Play. The museum kindly opened its doors to Golisano Childern's Hospital for this issue's Miracle Kids' photo shoot.

Photo courtesy: Ken Huth

Miracle Weekend celebrates 30 years

MIRACLES ARE AMAZING FEATS OF TRIUMPH AGAINST ADVERSITY. THEY ARE AWE-INSPIRING EXAMPLES THAT GIVE US HOPE, INSPIRATION AND THE DRIVE TO KEEP MOVING FORWARD WHEN TIMES ARE TOUGH. BUT WHAT DOES IT TAKE FOR A MIRACLE TO HAPPEN?

The formula is actually quite simple: It takes strength, commitment, trust, and, perhaps most importantly, teamwork. Our 2010 Miracle Kids have survived and thrived amidst life-threatening diagnoses and sudden health scares because families and their providers have come together as a team to help them gain strength and persevere.

During Miracle Weekend June 4 and 5, which is made up of the Stroll for Strong Kids fundraising walk and the Children's Miracle Network Telethon on News 10NBC, thousands will come together with the same spirit of collaboration that helped save the five courageous Miracle Kids. Families will join forces to celebrate these miracles, and to help support the future generation of children who will rely on Golisano Children's Hospital at the University of Rochester Medical Center for their care.

For more information about Stroll, Telethon and to meet our 2010 Miracle Kids, see page 4.

in this issue

Dear Friends—

The word "miracle" often conjures up the image of things that happen inexplicably, things beyond the comprehension and capabilities of mere mortals.

From where I sit, the miracles you will read about in this issue of our Newsletter, divine assistance notwithstanding, are all the result of the hard work and perseverance of dedicated interdisciplinary teams focused on one all-important population: our children. Parents, children, community volunteers, physicians, nurses, social workers, therapists, clergy, trainees make wonderful things happen for the children and families of western NY, the US, even the world. And they do it so selflessly, so invisibly, so naturally that in the end, it looks like a miracle! But to call it solely that would be to greatly downplay the mission-critical importance of our greatest resource, the passionate individual.

Golisano Children's Hospital recently had the honor and pleasure of sending welcome letters to the medical students around the world who, come July 1, will become our next generation of interns. This group is, the most diverse, most broadly national and international, most experienced in professional areas other than medicine, and most involved in social service advocacy and research of any we have ever welcomed to Rochester. They are, collectively, Caucasian, African-American, Asian and Hispanic; they come from North America, Central America, South America, Europe and Asia; they have worked in the Peace Corps and Americorps, at the National Institutes of Health and in a vineyard in central NY. I know we and our patients and families will teach them a great deal. But I am equally confident that we will learn and benefit so much from them. I am so looking forward to this!

Many of my colleagues have told me it is a "miracle" that we got so many people from warmer, sunnier climates to want to come to Rochester, NY, to train. But this is no miracle. A remarkable team of current trainees, faculty, staff and, indirectly, our welcoming and appreciative community worked in collaboration to make this happen and win over all of these outstandingly accomplished individuals. And given the fact that the cost of training vastly outweighs the clinical reimbursement and graduate medical educational funds these trainees can garner, we depend completely on our community partners – our "miracle makers" – understanding the value of this extraordinary talent to help us recruit and retain these individuals. Education is not a directly billable expense; but our ability to provide care to our patients into the future and our ability to do the research that moves the frontiers of our capabilities depend critically upon it. Our trainees today are our healthcare providers, child health advocates, and biomedical researchers of tomorrow. Miracle or not, we are honored to partner with you all to make this happen!

Best regards,

Nina F. Schor

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

Peter Formicola: a true champion for children

Peter Formicola devoted his life to helping others and giving back to the community he loved. Formicola was a man of action. He embraced his civic responsibility, leading community groups, sitting on many local government committees and supporting non-profit organizations to improve the lives of the people of our region.

Peter passed away Dec. 20 after a battle with cancer. "Peter was one of those rare selfless consensus-builders," said Nina F. Schor, M.D., Ph.D., chair of the Department of Pediatrics at University of Rochester Medical Center (URMC) and pediatrician- in-chief of Golisano Children's Hospital at URMC. "He could work with anyone and make everyone realize that the common good and the synergies of community must be the first priority."

Ever the good Samaritan and a dutiful citizen, Formicola was a Monroe County legislator for nine years, Gates's GOP leader, chairman of the Board of the Monroe County Water Authority, president-elect for the Rochester Rotary Club, past president of the Italian Heritage Foundation, a founding board member of Camp Good Days and Special Times and a board member of Monroe County Sheriffs' Foundation and of Golisano Children's Hospital.

"Peter filled a big spot on the Golisano Children's Hospital Board," said Howie Jacobson, the board's chair.

Even before he joined Golisano Children's Hospital's board in 2008, Formicola was a major sponsor for several of Golisano Children's Hospital's annual gala events. Formicola's love for this event made him the perfect choice to be honorary chair of the 2009 gala.

> "Peter and his wife Allison were thrilled to be a part of this event, especially because they knew the event would have such a tremendous and positive impact on children – something [Peter] cared so deeply about." Betsy Findlay

"Peter and his wife Allison were thrilled to be a part of this event, especially because they knew the event would have such a tremendous and positive impact on children – something [Peter] cared so deeply about," said Betsy Findlay, director of Golisano Children's Hospital's Office of Advancement.

Formicola was determined to make the 22nd annual gala the best ever and true to his word, he succeeded in doing so. The event raised close to $700,000 for Golisano Children's Hospital – nearly $200,000 more than it had in the previous year. The success of the record-breaking event was no fluke. Formicola spent many hours helping plan the Tuscan-style event and was instrumental in securing many sponsors and live auction items.

In recognition of the instrumental role he played in gala events of the past, the 2010 gala will be dedicated to Formicola on Oct. 30.

"Peter and his wonderful wife, Allison, gave so much of the time and energy to ignite one of the most successful galas ever in 2009," said Jacobson. "As a close friend to the children of our region, he will be missed, yet his memory and spirit will carry on."

Stars align to bring boy back from the brink

It wasn't unusual for Addison Koons to climb into bed with his mother, Lisa Ashman, in the middle of the night. It happened so often that she would barely wake up. But when he climbed into bed with her at 3 a.m. September 9, 2009, the day he was going to start kindergarten, he didn't snuggle in like usual.

Addison started making a weird noise and his body went rigid. He wouldn't wake up. Lisa knew something was terribly wrong. Was he having a seizure? She ran to get the phone and called 911. Addison stopped breathing. The dispatcher talked Lisa through CPR (cardiopulmonary resuscitation) while she waited for the first responders.

Within minutes, the Henrietta Fire District, Station 5, arrived and took over CPR. An officer told Lisa to pack a bag while the crew worked on her little boy in an ambulance.

"I ran outside with all my stuff. I was afraid to even look in the ambulance," Lisa said, recalling that horrific night. "I didn't know if he was even alive."

Lt. Mike Kreuzer, and firefighters Kevin Erickson and Joseph Backer Jr. recognized that Addison was in cardiac arrest and used an automated external defibrillator (AED) to shock his heart. A short time later a Henrietta Volunteer Ambulance arrived with paramedics Herbert Dixon and Brian Bartolick and EMTs Alexander Malec and Matthew Jarrett. They intubated Addison and shocked his heart back into a regular rhythm by the time he arrived at Golisano Children's Hospital at the University of Rochester Medical Center.

The trauma room was packed. Lisa couldn't see her boy past all the people working on him. They kept asking her questions. Did he bump his head? Could he have swallowed any medications? Has he been sick? Lisa couldn't think of anything that would make Addison go into cardiac arrest. She couldn't make sense of what was happening.

Then Lisa heard someone in the room say, "Wow, this kid is really strong," and a little relief and hope washed over her.

"I figured that if he was responding to them even a little bit..."

Then Lisa Ashman heard someone in the room say, "Wow, this kid is really strong," and a little relief and hope washed over her. Maybe Addison was going to make it.

Addison was taken to the pediatric cardiac intensive care unit (PCICU) where he was stabilized, put into a medically induced coma and where they started the hypothermia protocol, in which Addison's body was cooled to 91.5 degrees Fahrenheit. Adult studies have shown that people who have a witnessed cardiac arrest have better neurological outcomes when they are cooled shortly after arrest. Hypothermia slows down the body's metabolism and lessens potential damage to the brain and vital organs caused by the lack of oxygen during cardiac arrest.

Karen Powers, M.D., chief of the PCICU, came to Lisa who was anxiously awaiting word on how her boy was doing. Powers told her that Addison was stable and sedated and was on a ventilator.

"He looked so still," Lisa said. "They were still doing some things, an echocardiogram, and trying to explain to me some things but I wasn't processing at that point."

The echocardiogram showed that Addison's heart was structurally normal, and since the screening tests showing that he hadn't ingested anything dangerous, all signs pointed to a sudden arrhythmic death syndrome, perhaps Long QT syndrome. Arrhythmias can occur spontaneously or with a stimulus, such as exercise or an adrenaline surge.

"This is what AEDs out in the community are meant for," said Cecilia Meagher, M.D., a pediatric cardiologist at Golisano Children's Hospital. "Before AEDs were available, many young people with sudden arrhythmias like Addison could die before help arrived."

Even though Addison's heart was no longer in an abnormal rhythm, he wasn't out of the woods yet. Cardiac arrest, in his case, due to a very rapid abnormal heart rhythm, can starve the body of oxygen causing damage to vital organs, such as the brain.

A day after he was cooled all the way down to 91.5 degrees, doctors and nurses started to warm him back up. His organ functions looked good, but they needed to wake him to see if his brain was functioning properly. Before he could even fully wake up, his heart went into an arrhythmia. PCICU staff was ready to shock his heart again, but an increase in beta blocker anti-arrhythmia medication got his heart back into a normal rhythm.

The episode told Meagher and the PCICU team that Addison's arrhythmia was behaving more like a rare arrhythmia, Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT). Many pediatric cardiologists might see only one or two cases of CPVT in their entire careers, if at all. Treatment for the arrhythmia includes beta blockers and an internal defibrillator.

The next few days were spent helping Addison's body fight off a minor infection. On Sept. 18, nine days after Addison's cardiac arrest, he was well enough to undergo surgery to implant a device into his abdomen with electrical leads going into his heart. George Alfieris, M.D., chief of pediatric cardiac surgery, worked with Spencer Rosero, M.D., a URMC cardiologist who specializes in electrophysiology, to implant the defibrillator. If Addison's arrhythmia recurs, the device will shock his heart back into

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Photos courtesy: Ken Huth

Optimism and teamwork keep toddler's rare cancer at bay

Toddlers don't usually come out of the operating room (OR) with an idea for a Halloween costume, but Hailey Coniber is no typical toddler. Over the past year, the 3-year-old has been through half a dozen surgeries and many more hospital visits, and yet her optimism and curiosity have prevailed over what might have otherwise seemed like a dire situation.

> *"I've only seen two of these cases in my 20-year career."* Pegoli, M.D.

At the beginning of February 2009, Hailey's mom, Melissa, noticed a very subtle anomaly on her 2-year-old. A few tiny hairs had cropped up around Hailey's pubic area. Melissa took Hailey to see their local pediatrician in Leroy, who recommended they visit Nicholas Jospe, M.D., chief of Pediatric Endocrinology at Golisano Children's Hospital at the University of Rochester Medical Center.

Jospe found that Hailey had an overactive adrenal gland, which was causing precocious puberty, and a CT scan later revealed that Hailey had an apple-sized tumor on her left adrenal gland. Jospe referred the Conibers to Walter Pegoli, M.D., chief of Pediatric Surgery at Golisano Children's Hospital. Two days later, the family met with Pegoli to talk with him about removing Hailey's tumor.

"It was all very overwhelming. We kept trying to reassure ourselves," said Hailey's mom.

The surgery, which took place April 8, was expected to last four hours, but took only 45 minutes. Pegoli met with the family afterwards and told them that he had excised, or taken out, the entire tumor and the affected adrenal gland. Although the likelihood that the tumor was cancerous was less than 1 percent, Pegoli wanted to run it through pathology to be sure.

Unfortunately, the test was positive for cancer.

"It's extremely rare that an adrenal gland has a cortical tumor, which is cancerous, as opposed to a neurogenic tumor, which tends to be benign," said Pegoli. "I've only seen two of these cases in my 20-year career."

Hailey went home the day before Easter but ended up back that same day to be treated for ileus – an intestinal blockage that can occur after abdominal sur-

Photos courtesy: Ken Huth

gery. A CT scan picked up two spots on Hailey's right lung. Since it was difficult to tell at that point whether the spots were cancerous, Melissa and Jason were advised to monitor Hailey and to come back three weeks later to see if the spots had grown.

When the family returned for the next CT scan, it appeared that Hailey's spots might be cancerous lesions. Hailey had her second surgery on May 29, and Pegoli performed a thoracotomy – an incision into the pleural part of the chest to get access to the lungs. He resected, or removed, three lesions from Hailey's right lung. Later, results from pathology showed that the cancer had spread to her lungs.

The Conibers tried to maintain a sense of normalcy for Hailey. They kept two Curious George stuffed animals on hand to take turns being with Hailey during her procedures. On June 5, Hailey returned to the operating room yet again, this time to place a central venous line so Hailey could begin her vigorous cancer treatment. A central line is a catheter tube passed through a vein to the chest portion of the large vein that returns blood to the heart.

A few days later, the Conibers began meeting with Lauren Bruckner, M.D., Ph.D., assistant professor of Pediatrics and Oncology at Golisano Children's Hospital, for Hailey's chemotherapy treatment. It was important to both the family and pediatric oncologist that they develop a strong working relationship.

"We talk about how the care of a child with cancer is truly a partnership between the family and the child's health care providers," said Bruckner. "There isn't a better example of this than the way in which Melissa and Jason have advocated for their daughter."

Bruckner was struck by how thoroughly the Conibers prepared for appointments with questions and a list of Hailey's medications and reactions to treatment. "Dr. Bruckner was very good about listening to us and looking through our notes with us," said Melissa. "We felt almost bad bombarding her with questions."

Melissa and Jason took notes daily, and even hourly. Note-taking, as it turns out, was instrumental to Hailey's treatment. Hailey was taking 24 medications to fight cancer and replace hormones that her body was no longer able to produce since her left adrenal gland had been removed. Hailey's medications came with just as many side effects, all of which were carefully observed by her parents. Melissa and Jason got to the point where they could predict the timing of the drugs' side effects.

Despite their diligence, Hailey began to run the other way when she saw her parents coming because she knew another dose of medication was coming with them. Her nausea, a side effect of the chemotherapy, also made it difficult for Melissa and Jason to persuade Hailey to eat.

The Conibers asked Bruckner and Pegoli about inserting a gastrostomy feeding tube that could supply Hailey with the medications and nourishment she needed. The tube, which looked like a button on the belly and would be surgically placed

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Photos courtesy: Ken Huth

a gift from his sister

and fast response save teen from brain disease

When Connor Tillapaugh was 9, his teacher at Lima Christian School, Beth Long, told his parents she was concerned about him.

Connor was having some staring episodes and trouble paying attention in school. Long encouraged Connor's parents to take him to see his pediatrician, Janet Casey, M.D., clinical associate professor of Pediatrics at the University of Rochester Medical Center (URMC). After an abnormal EEG test in the fall of 2005, Casey referred Connor to Jonathan Mink, M.D, chief of Child Neurology at Golisano Children's Hospital at URMC, for further testing.

During a routine neurology exam, Lisa Augostini, P.N.P., conducted a simple neurological test called the Bebinski sign, which involves scratching the sole of the foot and noting the big toe's reflex reaction, she noticed something was wrong. Typically, the central nervous system responds with the big toe pointing down, but Connor's toe pointed up.

Mink suspected he knew what Connor had, but wanted to run a few additional tests to confirm the diagnosis. The

results from Connor's MRI showed a white matter abnormality and a blood test confirmed Mink's suspicion: Connor had a rare brain disorder called X-linked adrenoleukodystrophy (X-ALD).

Because of a defective gene on the X-chromosome, patients with X-ALD lack a specific enzyme that is important for breaking down very long-chain fatty acids. Without this enzyme, the very long-chain fatty acids will build up and progressively damage the brain and adrenal gland, causing debilitation and eventual death, in just a few short years.

Mink knew that a bone marrow transplant was the best option for Connor, but just to be sure, he reached out to ALD experts, who agreed that a bone marrow transplant was Connor's best chance at halting the rapid progression of this life-threatening disorder.

Since enzymes in the white blood cells were failing to break down the long-chain fatty acids, a bone marrow transplant would give Connor new cells from a donor in place of the defective cells. If his body accepted the new cells, those cells could provide the needed enzyme to break down long-chain fatty acids and prevent them from damaging the brain.

A popular 1992 movie Lorenzo's Oil highlighted a special type of oil, which was developed to reduce the levels of very long-chain fatty acids, but since Connor was already showing disease symptoms and the diet lacks substantial long-term results, Mink knew it wasn't the best option for Connor.

Mink wanted the family to consider all of Conner's options, so he suggested the Tillapaughs get a consult from ALD experts at the University of Minnesota. Mink also invited them to consider having Connor's bone marrow transplant there. He told them that Golisano Children's Hospital was an excellent center for performing pediatric bone marrow transplants, should they choose to stay in Rochester for treatment.

"We decided we trusted the people at Strong because while they may not have been experts in this disease, we knew they were more than capable of doing the transplant," said Michelle.

Michelle and her husband David had five young children, which was another big consideration when they were deciding where Connor should have his transplant. They didn't want to split up the family, potentially for several months, while sending one parent to stay with Connor out of town and leaving the other parent with the family's four other children – Rebecca, Rachel, Jessica and Amanda – whose ages ranged from 2 to 10. In Rochester, however, the family had each other for support, a familiar environment to heal in and providers they already knew.

Mink referred the family to Craig Mullen, M.D., chief of Pediatric Hematology and Oncology at Golisano Children's Hospital, to discuss the transplant.

"Dr. Mullen went through process of transplant, let us know what to expect, gave us a general timeline and outlined the risks and benefits," said Michelle. "Everyone was great about being timely. It's really the reason Connor is doing so well now."

The Tillapaughs and their providers were indeed racing against the clock. The very long-chain fatty acids in Connor's body were building up quickly and they couldn't afford to wait too long for the transplant, or the acids would take an irreparable toll on Connor's brain function.

Connor's sisters were the most likely to be good donor matches for his bone marrow transplant. There was a 25 percent chance that each of Connor's four sisters would be a good match, Mullen said.

"Without a match within Connor's immediate family, there was a high probability the transplant wouldn't work or that there would be severe immunological problems afterwards," said Mullen.

Connor's oldest sister Amanda, who was 10 at the time, and Connor's youngest sister, Rebecca, who was 2, turned out to be the best donor matches. The family decided that it made the most sense for Amanda to be Connor's donor. "Amanda was a little scared, but she also wanted to help her brother," said Michelle.

Just about a month after Connor had first come to see Mink, on Nov. 14, Amanda donated a sample of bone marrow to try to save her brother's life. David stayed with Amanda as Mullen performed a minor surgery to extract a sample of

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Girl diagnosed with cancer is an inspiration to family and friends

Mike and Tracey Merriman had always believed that Golisano Children's Hospital at the University of Rochester Medical Center was a vital resource for children in the Rochester-area community, but they never imagined how grateful they would come to be for the compassionate health care staff and expert medical care their daughter would one day receive.

Photos courtesy: Ken Huth

"Bridgette grew up with an incredible sense of self and aura of confidence about her. She takes everything that life throws at her in stride," Tracey explained. "We believe now that she was born with that incredible strength to prepare her for the obstacles that she was destined to face further down the road."

Mike and Tracey started noticing signs that something was amiss on Martin Luther King Day in January 2009. Eleven-year-old Bridgette had a bad cough, so they took her in to her doctor's office to be treated for congestion. Two weeks later, they noticed a lump on her neck, but were told it was a backed up gland, so they didn't think much of it. Tracey noted that Bridgette had lost some weight too, but she was an avid swimmer and it was the peak of swim season, so the weight loss didn't seem unusual.

When Mike and Tracey returned from a family trip to Florida with their children, Bridgette, Natalie and Sean, they decided to set up an appointment with Bridgette's pediatrician, Elliot Kaplan, M.D., just to be sure everything was okay. Bridgette had been coughing terribly and unusually tired during their stay in Florida. Kaplan found that Bridgette had lost another six pounds and that there were more swollen glands not only on her neck, but on other parts of Bridgette's body as well.

Kaplan promised to call that evening with the results from some blood work tests and a chest x-ray. Mike and Tracey thought this was a bit peculiar, but they figured she had mono, pneumonia or something else relatively benign.

The phone rang at about 6:30 p.m. that evening. Kaplan told them Bridgette had spots on her lungs. He had spoken with David Korones, M.D., pediatric oncologist at Golisano Children's Hospital, who wanted to see Bridgette that very night. Within two hours, Korones and a team of other doctors sat down to talk with Mike and Tracey, ordered more blood work, did a chest x-ray and a CAT scan and told Bridgette and her family that she probably had Hodgkin's lymphoma. Korones explained that Bridgette would need to go into surgery the very next morning, so that Walter Pegoli, M.D., Golisano Children's Hospital's chief of pediatric surgery, could remove the large swollen gland on her neck and confirm the diagnosis.

Bridgette was very brave, but her eyes began welling up with tears when she heard the news. Mike and Tracey told their daughter it was okay to cry. "I'm more worried about my mom," she said, looking over at Tracey, "Is she going to be okay?" Bridgette asked Korones.

By the next afternoon, the surgery was completed. Results from the surgery, along with a number of other tests conducted over the next few days, indicated that Bridgette's cancer was at an alarming stage four, which meant it had spread throughout her lungs, chest and lower abdomen. Four days later, Bridgette started her first round of chemotherapy. Eleven days after the family first met Korones, they were sent home to Penfield to continue Bridgette's journey toward healing.

While in the hospital and over the past year Bridgette, who turned 12 in January, surprised the adults around her in many ways. Korones, who offers pedi-

atric palliative care for patients and their families in addition to cancer treatment, explained that the most important thing in terms of dealing with a child with a new diagnosis of a potentially life-threatening disease is to gauge from the doctor's impression and the parents how much they want to know.

"It was very quickly apparent Bridgette was a child who could handle the information and in fact, she seemed to do better from knowing what was going on," said Korones. "Bridgette's parents were extremely supportive of this."

Bridgette used a journaling Web site, Caring Bridge, to educate, inspire and comfort many friends and family members. Through her Web page, she taught her many supporters about peripherally inserted central catheter lines, different needle sizes and much more. She wrote with a sense of experience but with the tranquility of a child.

> *"It was very quickly apparent Bridgette was a child who could handle the information and in fact, she seemed to do better from knowing what was going on."*

During the first month she was receiving treatment, Bridgette took great interest in a doctor who had come from Ethiopia to shadow Korones named Kalid Asrat, M.D. One day, the Merrimans approached Korones with a suggestion Bridgette had made that completely blew him away.

Bridgette had learned from Asrat that many children with cancer in Ethiopia had no access to chemotherapy. The 11-year-old wanted to harness the support her good-natured family and friends were offering her to help children on the other side of the world. The family started a fund called Chemo for Kids and they encouraged friends and family members to

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With specialized care

a little fighter gets a strong future

April and Nick Harford didn't think too much about the newborn screening tests they did at the start of their pregnancy during the summer of 2008. It was just a matter of routine. But when their Ithaca obstetrician told them the test showed their baby had a chance of having spina bifida, it no longer felt routine.

The Harfords, who live in Brooktondale near Ithaca, made an appointment with a perinatologist in Elmira. The week-long wait for the appointment was excruciating for April so she begged her obstetrician to do an ultrasound in the meantime. Thankfully, the spine looked normal. Unfortunately, the abdomen did not.

The specialist in Elmira confirmed that the Harfords' baby had gastroschisis, a congenital defect of the abdominal wall in which the belly doesn't close all the way, allowing the intestines and, sometimes, other organs to form outside the body. The defect occurs in about 1 in 5,000 to 1 in 10,000 babies.

"I was devastated. It was our first baby," April said. "Defects are something you think about but you never think it's going to happen to your baby."

The defect was very apparent even to April's and Nick's untrained eyes - big loops of intestines floating around inside the amniotic fluid. The specialist said the baby, which they now knew was a boy, seemed to also have a dilated bowel. They were worried about obstructions developing somewhere in those loops, so the Harfords would need to come back every other week for monitoring.

After a few visits, the three-dimensional ultrasounds started to feel routine. April even went by herself, but at her 32-week check, she brought her sister so she could see her nephew's face.

"They put the monitor on me and started looking. Then the nurse stopped and said she needed to get the doctor," April said. "I knew something was wrong."

The baby had developed a new complication – a large, unidentifiable bubble on his bowel. They weren't sure if it was his bladder, another organ or something else entirely. They wanted to deliver the baby immediately, but Nick wasn't there and April didn't feel ready. She was worried the baby wasn't far enough along.

The specialist called Golisano Children's Hospital at the University of Rochester Medical Center (URMC) for a second opinion. Walter Pegoli, M.D., chief of pediatric surgery, said April should see a perinatologist at URMC before making any decisions.

April and Nick drove to Rochester that afternoon, petrified they were going to deliver their baby boy the next morning. Daniel Grace, M.D., the high-risk obstetrician who saw them when they arrived, reassured them. The baby just needed some additional monitoring to make sure he was doing OK and growing larger. The planned caesarean section in December needed to be at URMC, where all the right specialists were available.

April thought she might've just been a little dehydrated when she started feeling sick at about 7:30 p.m. Nov. 25. She was almost 36 weeks along. They had an appointment to meet Pegoli the next morning and she hadn't yet toured the neonatal intensive care unit (NICU). She called her obstetrician who told her to lay down and see how she felt. When the crampy feeling didn't go away by 12:30 a.m., she and Nick started driving to Rochester.

An hour or so into the drive, a police officer pulled them over for speeding. Nick barely got the story out of his mouth

Photos courtesy: Ken Huth

when the officer told them to get on their way.

"Just drive as safe as you possibly can," April remembered him saying. She said he must have known how nervous they were.

The couple arrived at URMC at about 2 a.m., and it didn't take long for the obstetrical team to see that April was in labor and already 5 centimeters dilated. The baby was OK but he was coming. They tried to slow down her labor while they called Pegoli in to prepare to perform surgery on the soon-to-be-born baby boy.

Owen Harford arrived at 5:21 a.m. by caesarean section and he was immediately whisked off to surgery. Nick caught a glimpse of Owen in the hallway, but April didn't get to see or hold her new baby. The Harfords waited nervously for news about their son. April's cell phone rang. It was Pegoli's office, calling to cancel their consultation with the pediatric surgeon that morning because he had an emergency surgery. "That was me! We're here!" April told the scheduler. It was a brief moment of levity for the Harfords.

Meanwhile, Pegoli was in the operating room marveling at the sheer amount of bowel outside Owen's tiny belly.

"There was more bowel than baby," Pegoli said.

Usually, when faced with gastroschisis, Pegoli uses a manufactured plastic device called a silo to hold the bowels over the baby's belly until there is room enough for them in the abdomen.

"His defect was so big that we had no off-the-shelf silo to use," Pegoli said. "So I built one."

When Pegoli came to see the Harfords after the initial surgery, April asked what the bubble was on Owen's bowel. Pegoli said it was just a cyst and wasn't anything serious, but what was more concerning was the sheer amount of bowel Owen had outside his body. He said he wasn't sure it would all fit into his tiny abdomen. But Owen was ready to meet his parents.

April was worried about her baby and still groggy from the anesthesia when Nick wheeled her into the NICU to see

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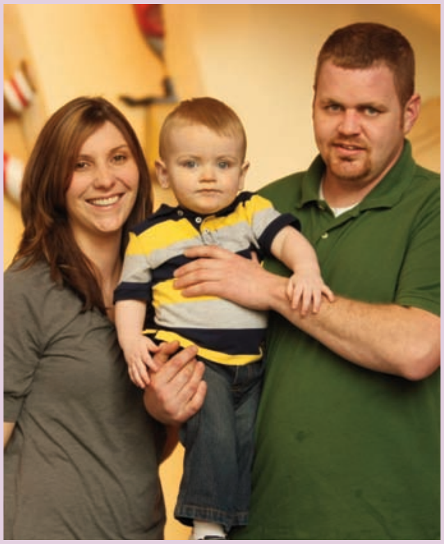
> *"His defect was so big that we had no off-the-shelf silo to use. So I built one."* Walter Pegoli, M.D.



Miracle Maker Awards

This year's Miracle Makers have certainly earned their stripes as champions for kids at Golisano Children's Hospital at the University of Rochester Medical Center. Many of our Miracle Makers have been reliable supporters for years and even decades, including Howie Jacobson, faithful leader of the children's hospital's board, who has been involved for nearly 14 years.

This year marks the 30th anniversary for Martha Brown Middle School's support of children's hospitals and Walmart and Sam's Clubs have been a part of the Children's Miracle Network for nearly two decades.

Another set of award recipients has grown their support as their child continues to grow and strengthen. Mike and Becky Fahy's dedication to the hospital began the moment their daughter was born five years ago. The Cabot Group is the devoted presenting sponsor of the annual Golisano Children's Hospital's Gala and has pledged to continue that tradition for years to come.

All of our Miracle Maker Award recipients have unique reasons for supporting the hospital and yet all are bound by the common tie of being engaged with, passionate about and dedicated to Golisano Children's Hospital.

Outstanding Commitment by a Corporation

The Cabot Group

THE CABOT GROUP

> "Golisano Children's Hospital is our region's greatest asset. I truly believe that. Nothing is more important than our children and Golisano Children's Hospital addresses their needs in such a warm, personal and professional manner." Mike Smith

Golisano Children's Hospital at the University of Rochester Medical Center (URMC) relies on generosity from our community to assist us in providing exceptional care for the tens of thousands of patients treated here. The Cabot Group has stepped up to the plate not only by recognizing the hospital's needs, but by resolving to invest in the future care of our community's children.

"Golisano Children's Hospital is our region's greatest asset," said Mike Smith, owner of the Cabot Group. "I truly believe that. Nothing is more important than our children and Golisano Children's Hospital addresses their needs in such a warm, personal and professional manner."

As presenting sponsor of the annual Gala in 2008 and 2009, The Cabot Group laid down a platform of support upon which two incredibly successful events were built – the latter of which brought in record-breaking donations. When The Cabot Group offered to be the presenting sponsor of the 2008 Gala, the company made a commitment to act as the leading sponsor for the next 10 years. This very generous long-term pledge will ensure the future success of the children's hospital's biggest fundraising event for years to come.

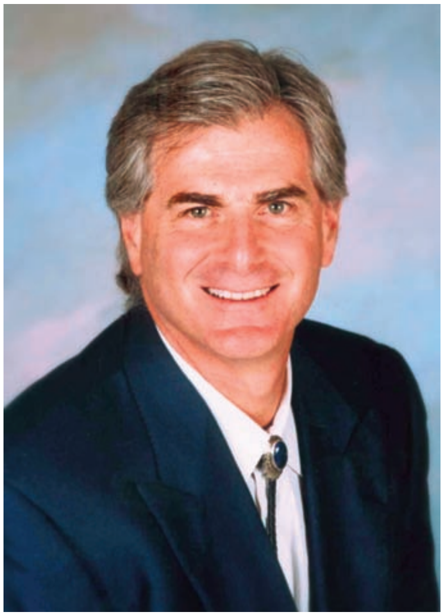
"The Cabot Group has made an investment in children's health that will have a very positive impact on the lives of thousands of children," said Bradford C. Berk, M.D., Ph.D., chief executive officer of URMC.

In addition to its Gala sponsorship, The Cabot Group has given its support as a sponsor to the annual Golf Classic and Smith has recently accepted an invitation to join Golisano Children's Hospital's board. Smith and his wife, Alice, also acted as honorary chairs at the 2008 Gala.

Golisano Children's Hospital would like to thank The Cabot Group for its long-term commitment to help the children in our community receive the best medical care possible. We would like to congratulate them on their 2010 Miracle Maker award for Outstanding Commitment by a Corporation and look forward to our future partnership with such a wonderfully warmhearted local company.

Outstanding Commitment by an Individual

Howie Jacobson



Jacobson's charisma and ingenuity have opened the doors to all sorts of possibilities for encouraging the community to get involved including corporate promotions, community-wide events and donations.

Howie Jacobson is hard to miss with his iconic bolo tie and incredibly warm personality. For more than 14 years, Jacobson has acted as an outstanding ambassador for improving children's health in our community through his work as the board chair at Golisano Children's Hospital at the University of Rochester Medical Center (URMC). Jacobson's creativity and strong connection with members of the community have helped elevate awareness of and recruit supporters for our region's only children's hospital.

Jacobson is passionate about the care Golisano Children's Hospital provides for children in our community. In 1995, Jacobson's son was injured in a terrible bicycle accident and was airlifted to Golisano Children's Hospital, where he was treated by Walter Pegoli, M.D., chief of pediatric surgery. Jacobson had been involved with the hospital before that, but seeing his own son receive the quality care Jacobson had heard so much about was a pivotal juncture in the relationship he would take on with Golisano Children's Hospital. Jacobson joined the children's hospital's board shortly afterwards and accepted a leadership role as chair of the board in 2004.

"To many in the Greater Rochester region, Howie Jacobson is the recognizable face of Golisano Children's Hospital," said Nina F. Schor, M.D., Ph.D., pediatrician-in-chief of Golisano Children's Hospital and chair of Pediatrics at URMC. "He has selflessly devoted his time and considerable energies to the children and families we serve."

The creativity Jacobson has exercised throughout his work with Golisano Children's Hospital has been undeniable. For example, in 2001, Jacobson organized the Horses on Parade project, a community project that brought beautifully designed horses from local artists into the community and raised more than $100,000 for Golisano Children's Hospital. In 2003, Jacobson helped coordinate the Animal Scramble, another animal-centric art project, which generated funds for local charities, including nearly $30,000 for Golisano Children's Hospital. Those two local art initiatives are just two of the many nuanced projects Jacobson orchestrated to benefit Golisano Children's Hospital.

Jacobson is and always has been a connector. "He knows everyone in town and can get them energized and motivated," said a fellow board member, Mark Siewert. "As board chair, Howie's leadership, compassion and enthusiasm have really moved us forward."

Jacobson's charisma and ingenuity have opened the doors to all sorts of possibilities for encouraging the community to get involved including corporate promotions, community-wide events and donations. Jacobson's auctioneering style has also brought an enormous amount of energy to the annual gala's live auction, which Jacobson has chaired for the past several years.

"I have been humbled by the fact that I work with an amazing board and get to be a cheerleader throughout the community for the doctors, the nurses and the staff that work at the hospital 24/7," said Jacobson.

Golisano Children's Hospital is extremely grateful for the unique and powerful impact Jacobson has brought to his work with the children's hospital's board and the community as a whole. We are honored to award him with the Miracle Maker Award for Outstanding Commitment from an Individual.

Outstanding Commitment by Grateful Parents

Mike and Becky Fahy

Kelsey Fahy was born at 2 lbs., 9 ½ oz., to Mike and Becky Fahy. Kelsey was born at 30 weeks gestation and spent 46 days fighting for her life in the neonatal intensive care unit (NICU) at Golisano Children's Hospital at the University of Rochester Medical Center.

Now 5-years-old, Kelsey is healthy, adorable and the apple of her parents' eyes. The Fahys, who also have a little boy named Garrett, have never forgotten the experience they had at Golisano Children's Hospital.

"We're constantly looking for more ways to give back," said Mike. "We're just ecstatic about the care that Kelsey received and we'll never be able to repay the NICU for that, but the events offer a great way to help give back."

Three years ago, Mike and Becky, who both work at Nazareth College decided to tap into the rivalry games between "beaked" college basketball teams, the Nazareth Golden Flyers and the St. John Fisher Cardinals.

Since then, the Battle of the Beaks has been extended to include a set of basketball games at St. John Fisher and Nazareth, student-athlete semi-formals at the two colleges and a student-run Winter Walk for Strong Kids. The family-friendly Winter Walk, which debuted this past February, attracted more than 150 participants and raised $3,100 for Golisano Children's Hospital.

"The students do a great deal of the work under Mike and Becky's strong leadership," said Kim McCluski, Golisano Children's Hospital board member. "It has been exciting and fun to watch the Battle of the Beaks take on a life of its own."

The set of events has brought in nearly $50,000 over the years, and perhaps more importantly, the enthusiasm that started with the Fahys has rubbed off onto student athletes and continues to grow.

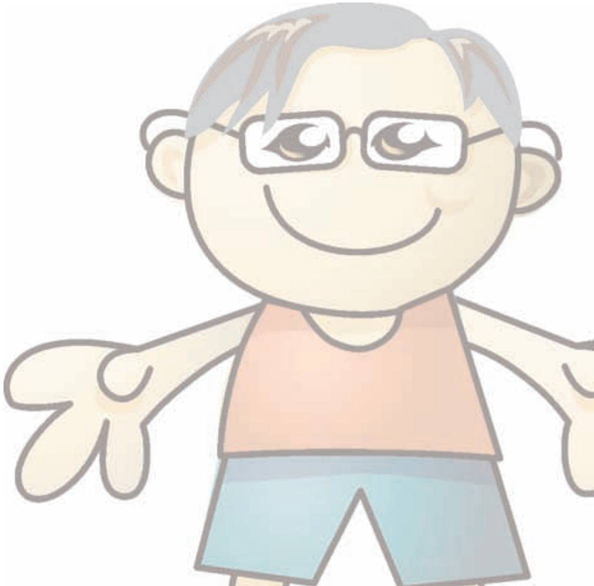
"Almost all of Nazareth's student athletes have been involved in the children's hospital's fundraising events in some way or another," said Becky.

Many student athletes have been empowered to start their own fundraising initiatives to help pediatric patients. For example, one of the men's basketball players that Becky advises decided to get the team to ask for sponsorships to donate to Golisano Children's Hospital for every 3-pointer the team makes each game. The team donated nearly $300 last season alone.

"When you meet the Fahys, you can't help but like them," said Bob Jacobson, Golisano Children's Hospital board member. "They're great. We are truly fortunate to have this sincere and dedicated couple using their talents to help us at Golisano Children's Hospital."

Mike and Becky are grateful for the Miracle Maker Award, but insist that it really belongs to the larger community of student athletes and administrative staff from Nazareth and St. John Fisher Colleges. "The students have put so much time and effort into these events," said Mike. "We couldn't have done it without them."

> "We're just ecstatic about the care that Kelsey received and we'll never be able to repay the NICU for that, but the events offer a great way to help give back."



Outstanding Commitment by a CMN Sponsor

Walmart & Sam's Club

For nearly two decades, Walmart and Sam's Club stores have partnered with children's hospitals to help improve comfort and care for patients and their families across the nation. The local stores have raised more than $2.6 million for Golisano Children's Hospital at the University of Rochester Medical Center.

In recent years, local Walmart and Sam's Club stores have gone above and beyond to help our hospital, reaching or exceeding a gift of $200,000 each year. Their successful fundraising ventures have made Walmart and Sam's Club stores the largest fundraising group for Golisano Children's Hospital by leaps and bounds.

Excitement for children's hospital fundraisers permeates Walmart and Sam's Club stores, especially during May's Miracle Month, which the hospital's avid supporters have extended into a six-week period. Managers and employees do a variety of in-store fundraising including hot dog sales, raffles, walks and CMN balloon sales.

Wally Straight has been emblematic of this energy and enthusiasm among Walmart employees. Straight, a Walmart greeter in Canandaigua and Newark and grandfather of 13, collected donations for Golisano Children's Hospital and raised $266,058 in just seven years.

"The great thing about this group is that the associates get so excited to help out," said Betsy Findlay, director of Golisano Children's Hospital's Office of Advancement. "Whether it is answering phones at the Drive for Miracles Radiothon and CMN Telethon or raising funds in the store, they are committed and enthusiastic." Many of the associates' children or grandchildren have been treated by Golisano Children's Hospital, which heightens their eagerness to help support the hospital.

Golisano Children's Hospital is delighted to honor such a devoted partner for this year's CMN Miracle Maker Award. Local Walmart and Sam's Club stores give to Golisano Children's Hospital through CMN, a non-profit organization that raises funds for more than 170 children's hospitals across the nation.

"We are honored to receive this award," said Tim Bernard, regional market manager for Walmart. "We are proud to support Golisano Children's Hospital, which plays an essential role in providing world-class quality care for the community's children."

Their successful fundraising ventures have made the group of Walmart and Sam's Club stores the largest fundraising group for Golisano Children's Hospital by leaps and bounds.

Outstanding Commitment by a Community Group

Martha Brown Middle School

One simple phrase has been the driving force behind a massively successful endeavor students at Martha Brown Middle School have taken on to help their peers: Kids helping kids.

This spring, Martha Brown Middle School will celebrate its 30th year of holding fundraising events for children's hospitals and its fifth year giving to Golisano Children's Hospital at the University of Rochester Medical Center. David Dunn, principal of Martha Brown Middle School, is a strong advocate for the fundraising events.

> "We love seeing the students take on leadership roles and really embrace the phrase, 'Kids helping kids,' when they rally around their friends who have been treated here."

"Anytime you do community service, you're modeling giving back," said Dunn. "This is something the school and community can embrace...Golisano Children's Hospital affects everyone in some form – family, neighbors, friends – everyone has been touched."

The event started as a math-a-thon for St. Jude Children's Research Hospital in Memphis, TN. The math-a-thon, which encouraged students to ask for sponsors to do math problems, began taking off in 1997, when students started raising between $16,000 and $20,000 a year.

Five years ago, teachers and students decided to throw their support behind Golisano Children's Hospital, since many students had received care there and wanted to give back to the place that was helping so many children in their community. The group worked with Karen Eisenberg, associate director of Golisano Children's Hospital's Office of Advancement, to tailor the fundraising event to work locally.

"Students and staff at Martha Brown Middle School have been fantastic to work with," said Eisenberg. "We love seeing the students take on leadership roles and really embrace the phrase, 'Kids helping kids,' when they rally around their friends who have been treated here."

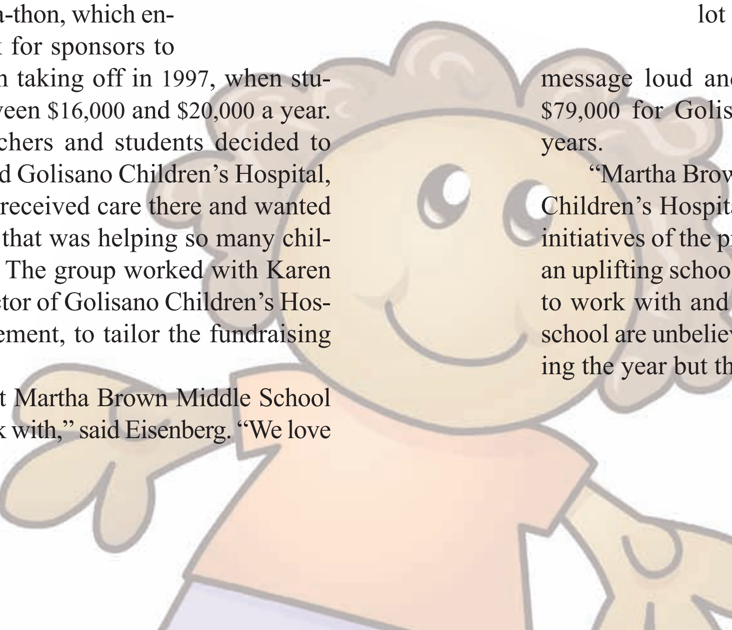
The event has moved from a quiet, studious activity to an outdoor event that encourages students to walk in teams and wear group-themed costumes.

The school starts promoting the event about a month ahead of time with morning announcements, fun promotional music and an assembly to introduce and entice sixth-graders to get involved. Maura Kerkezis, a health teacher at Martha Brown, and Maureen Aguglia, a math teacher at the school, show a video that includes footage in the hospital and students participating in past events. Kerkezis and her colleagues show the video to all seventh- and eighth- graders during their health periods.

"We tell students we want them to help raise money for other kids because it feels good and they're making a difference in a lot of lives," said Aguglia.

Students certainly hear their teachers' message loud and clear. The event has raised nearly $79,000 for Golisano Children's Hospital in just four years.

"Martha Brown rocks," said Bob Jacobson, Golisano Children's Hospital board member. "The leadership and initiatives of the principal and teachers manifests itself in an uplifting school spirit that you can feel. They are a joy to work with and their fundraising results for a middle school are unbelievable. They have many fundraisers during the year but their enthusiasm never wanes."



Winter Radiothon Rounds Out a Great Year in Giving

This past winter's 100.5 The Drive for Miracles Radiothon certainly didn't feel chilly, despite the cold weather outside. Thanks to Clear Channel, staff at 100.5 FM The Drive, the event's sponsors, and the many community members who participated by sharing stories and making donations to show their support, the radiothon raised more than $80,000 for Golisano Children's Hospital at the University of Rochester Medical Center.

Radiothon hosts JP Hastings and Julie DePasquale didn't miss a beat during the 40-hour, 10th annual event. The Radiothon ran from early morning hours Thursday and Friday and into the evening in Strong Memorial Hospital's lobby and all day Saturday at Eastview Mall, Dec. 10 through 12.

We would like to extend a very heartfelt thank you to the many people who invested an incredible amount of time and energy into helping make the 2009 Drive for Miracles Radiothon a resounding success, including our presenting sponsor for the second year in a row, Advantage Federal Credit Union, and Hyundai, T-Mobile/Blackberry and Monroe Oxygen and Medical Equipment.

14th annual Golisano Children's Hospital Golf Classic

The 14th annual Golisano Children's Hospital Golf Classic will begin with lunch and registration at 11 a.m. Monday, Sept. 13, across three golf courses, including Monroe Golf Club, Country Club of Rochester and Ravenwood Golf Club. The day of golf will wrap up with a dinner at Monroe Golf Club. Last year's tournament raised a gross total of $350,000 and drew in more than 450 golfers. To register for this year's event, please call (585) 273-5948.

Photo courtesy: Messenger Post News

Remembering Noah

A community carries on a young boy's legacy

In his 100 months of life, Noah Passero touched the lives of more people than anyone could have possibly imagined. The memory of Noah has brought together an incredibly compassionate and powerful community of families and friends determined to make a difference in the lives of others on behalf of one brave little boy.

Noah passed away in April 2008 from complications with a heart disease known as cardiomyopathy. In less than two years, his family and friends have raised more than $29,700 for the Pediatric Cardiology Division at Golisano Children's Hospital at the University of Rochester Medical Center through various fundraisers, including a jazz band benefit concert at Spry Middle School, a Webster Thomas High School car wash, a penny wars competition held by Webster Thomas High School and perhaps most well known of all, 100 Innings for Noah.

Noah's grandfather, City of Rochester Softball Commissioner Andy Yazwinski, and his parents, Dan and Wendy Passero, decided to start the 100-inning slow-pitch softball fundraiser in honor of Noah in fall 2008. They wanted to bring family and friends together both to commemorate the 100 months of Noah's life and to rally support to positively impact the lives of others.

Last year, despite the chilly, rainy October weather, 100 Innings for Noah grew immensely, nearly doubling the amount donated to the Pediatric Cardiology Division at Golisano Children's Hospital (from $9,000 to $14,056) and nearly quadrupling the number of people who signed up to be organ donors (from 16 to 62).

When asked about the incredible outpouring of support on behalf of her son, Noah's mother explained that from the

Photo courtesy: Wendy Passero

Photo courtesy: Messenger Post News

time he was little, it seems as if Noah was destined to bring people together. “You just had to know Noah,” said Wendy. “There was something special that just drew people to him … It’s like he knew what he was destined to do, he was compassionate and kind towards everyone.”

Noah’s peers continue to strive to emulate the kindhearted spirit their friend was known for. Every year, two fifth-graders from Webster Schlegel Road School who possess the same qualities as Noah are honored with the Noah Passero Golden Heart Award. Noah’s older brother Nick and his middle school classmates continue to write the name “Noah” as the reason they participate in Jump Rope for Heart. A set of baseball games and a Webster memorial garden have been dedicated to Noah. Noah’s memory is still very much alive in the hearts of the people he touched and will continue to live on through the good deeds done by the community that loved him.

For more information about organ donations, visit *www.donorrecovery.org.* To find out more about next year’s 100 Innings for Noah event, which will take place Oct. 2, contact Andy at (585) 323-2635.

Pediatric Cardiac Surgery Adds Surgeon

Francisco J. Gensini, M.D., recently joined the University of Rochester Medical Center (URMC) as an assistant professor of surgery. He is the newest member of the pediatric cardiac surgery team at Golisano Children’s Hospital lead by George Alfieris, M.D. A native of Cali, Colombia, Gensini came to URMC from Seattle Children’s Hospital in Seattle where he was one of the first ACGME approved fellows in congenital cardiac surgery in the United States.

“We’re excited to add Dr. Gensini to our team. His addition bolsters our already strong surgical program for children with congenital heart defects and makes it possible for us to help more children from upstate New York and northern Pennsylvania,” said Alfieris.

Gensini earned his degree in medicine and surgery from Universidad del Valle, Cali, followed by a general surgery residency. Gensini received a degree in cardiovascular surgery from Fundación—Clínica Cardiovascular Santa María, College of Medicine of the Universidad Pontificia Bolivariana in Medellín, Colombia.

In addition to filling the role of attending physician in cardiothoracic surgery at the Fundación—Clínica Valle del Lili in Cali, Gensini completed a two-year fellowship in pediatric cardiothoracic surgery at Great Ormond Street Hospital for Children in London, United Kingdom, followed by a fellowship in extracorporeal membrane oxygenation (ECMO) in the Department of Pediatric Cardiac Intensive Care. Gensini has also held the positions of resident physician and chief resident physician in general surgery as well as fellow in cardiothoracic surgery at the University of Washington in Seattle.

Better Day Buddies partnership brings cheer to Pediatric Treatment Center

Sometimes, it's the little things that make a difference. The gift of an unexpected hot meal or a new craft project can significantly improve the hospital experience for a child who frequents the hospital for outpatient treatment.

For the past two years, the Better Day Buddies Program has brought smiles to the faces of children and families in the B&L Wholesale Pediatric Treatment Center at Golisano Children's Hospital at the University of Rochester Medical Center (URMC). The program provides patients being treated for cancer and a range of other chronic and acute conditions and their families with lunch, creative crafts, performers, electronic game systems and magazine subscriptions for children of all ages.

"It's such a simple idea and it makes such a difference in the lives of kids and their parents," said Eileen Grossman, president of the Cancer Wellness Spa and founder of the Better Day Buddies program.

Grossman's daughter, Lisa Curwin, coordinates the program, which brings volunteers into the Pediatric Treatment Center a few hours a day, four days a week. She noted that the collaboration between the hospital and the program has been wonderful.

"It has really been a positive experience for patients, nurses and volunteers," said Curwin.

Curwin puts together special themed gift bags for patients, which are made up of craft projects and books that have been supplied by CompassionNet Excellus/Blue Cross Blue Shield. She also organizes the program calendar to make sure two volunteers are scheduled for each shift to work with patients on craft projects and reading books and to distribute lunches that have been provided by a grant from Ronald McDonald House Charities.

"The volunteers bring to the program compassion, sincerity and patience," said Wendy Lane, program coordinator of Child Life at Golisano Children's Hospital. "They let the child be a child during a time that can be overwhelming and fearful."

In addition to the program's superb volunteers, Better Day Buddies lends patients electronic video games and supplies a variety of magazine subscriptions to the treatment center's waiting room.

"The Better Day Buddies program brings local celebrities and leaders to Golisano Children's Hospital at URMC to read to and interact with our children and their families," said Nina F. Schor, M.D., Ph.D., chair of the Department of Pediatrics at URMC and pediatrician-in-chief at Golisano Children's Hospital. "This very clearly sends the message to our kids and families that they and their well-being matters intensely to us all."

To find out more about opportunities to volunteer through the Better Day Buddies Program, please contact the Cancer Wellness Spa at (585) 473-2964.

> *"The volunteers bring to the program compassion, sincerity and patience," said Wendy Lane, program coordinator of Child Life at Golisano Children's Hospital. "They let the child be a child during a time that can be overwhelming and fearful."*

Dr. Gitzelmann brings skills to pediatric surgical team

Rochester is a long way to move for a pediatric surgeon in Zurich, Switzerland, but Christopher Gitzelmann, M.D., didn't mind when it gave him the opportunity to work with Walter Pegoli, M.D., again.

Gitzelmann was a research fellow in Pegoli's lab during his time at John's Hopkins. They remained in touch for the past 15 years while Pegoli built a prestigious pediatric surgery program at the University of Rochester Medical Center's Golisano Children's Hospital and while Gitzelmann became an expert at minimally invasive pediatric surgery in Switzerland.

"It's a wonderful opportunity to be able to work with Dr. Pegoli again," said Gitzelmann.

Pegoli was equally eager to add Gitzelmann to the team because of his highly specialized laparoscopic surgery skills. Gitzelmann was the director of Zurich's University Children's Hospital's minimally invasive pediatric surgery program. He specializes in laparoscopic "pull-throughs" for colorectal birth defects, such as for Hirschsprung's disease in which a section of the intestines doesn't work properly or for newborns with "High Imperforate Anus." The technique requires less cutting, fewer surgeries, and it results in less scar tissue.

While Golisano Children's Hospital offered laparoscopic surgery before the addition of Gitzelmann, pediatric laparoscopic pull-through surgery is new to the Rochester region.

"Dr. Gitzelmann has very advanced laparoscopic skills, which are in high demand. We're excited that bringing him here allows us to offer more minimally invasive surgery options to our families," Pegoli said.

Gitzelmann started his new position as a pediatric surgeon at Golisano Children's Hospital on Feb. 1.

2008 Miracle Kid family is still keeping hope strong

The third annual Keeping Hope Strong event, held by Scott and Despina Mitchell, raised $13,000 for the Pediatric Surgical Division at Golisano Children's Hospital. The event, which took place on February 6 and included a 50/50 raffle, a live auction and live entertainment from John Akers, was generously hosted by Joe Bonafede, owner of J.B. Quimby's. An added fundraiser took place on February 28, when Webster and Pittsford Five Guys restaurants donated a portion of their proceeds, which amounted to more than $600, to the Keeping Hope Strong fund.

The event was held in honor of Mason Mitchell, a toddler treated at Golisano Children's Hospital for an extremely rare condition called congenital diaphragmatic hernia. Mason, now 3, is doing very well today, thanks to Golisano Children's Hospital's Neonatology and Pediatric Surgery Divisions. Mason was honored in 2008 as a Miracle Kid. To read more about Mason, visit *http://bit.ly/masonmitchell.*

Funds raised by the Mitchells and their many supporters will help the Pediatric Surgery Division purchase laparoscopic surgical equipment, which is minimally invasive. A new member of the pediatric surgical team, Christopher Gitzelmann, M.D., is an expert in pediatric laparoscopic surgery. Laparoscopic surgery can be very advantageous for children and their families, since it requires fewer incisions and fewer surgeries and results in less scar tissue. For more information on how to support the Pediatric Surgery Division, call (585) 273-5948.

Adventures of pioneers for pediatric patients

Photo courtesy: Girotto and Emerson

In November 2008, a 16-member group of health care providers set off for Barrancabermeja, the home of Columbia's biggest oil refinery, to change the lives of more than 40 families they had never met.

The group, headed by John Girotto, M.D., chief of pediatric plastic surgery at Golisano Children's Hospital at the University of Rochester Medical Center (URMC), volunteered to take one vacation week to travel to Columbia to repair cleft lip and palate malformations for children.

Cleft lip and palate malformations are birth defects that occur when one's lip and/or palate doesn't completely fuse together during fetal development. Cleft lips leave a gap between the upper lip to the base of the nose and cleft palates leave an opening inside the mouth, between the roof of the mouth and the nasal cavity.

"In Columbia, a lot of people with cleft lips and palates can't afford the complete plastic surgery they need. Often, families can afford to fix a child's lip, but not [his or her] palate, so the child remains unable to speak," said Girotto.

Finding medical staff to join in on the adventure was the easy part of the planning process, despite the fact that the trip was essentially one vacation week of "working your tail off," explained Christine O. Emerson, nurse practitioner at URMC who coordinated the trip to Columbia.

Emerson spent about six months working closely with national and international organizations to secure accommodations and necessary equipment for the trip. Smile Train paid for travel and the shipment of medical supplies; a Columbian rotary club in Barrancabermeja hosted the group and provided accommodations, and Cardinal Health donated many of the medical supplies. Emerson's time was well-spent, because in the end, everything came together perfectly.

The group got right down to business as soon as they arrived. They worked 12 to 14 hour days in two operating rooms in an effort to help as many children as possible during their week in Columbia. They brought along enough surgical kits for 60 surgeries, so that Columbian surgeons could operate on an additional 20 children after the group had returned home.

"[The staff was] extremely accommodating and met us with open arms," said Emerson. Members of the rotary club stayed with the group as they worked to translate between the American visitors and the Columbian nurses in the hospital.

After the week had ended, the group left Columbia exhausted, but with a strong sense of accomplishment.

"Despite all the hard work, it was incredibly rewarding to impact people's lives in such a positive way," Emerson concluded, "We did something that needed to be done. I can honestly say this trip was the highlight of my career."

Girotto's Quest to Offer Quality Care Has Continued

About a year after his trip to Columbia, Girotto travelled to the beautiful but impoverished nation of Bhutan for his next adventure. There in Bhutan (east of Nepal), Girotto and his fellow volunteers took on a new set of challenges to improve the lives of children on the other side of the globe.

"Despite the less-than-ideal conditions [in Bhutan], we tried to set up the OR we worked in to be as close to Strong's ORs as possible," said Girotto.

Girotto was joined by Jeffrey L.

> *"Despite all the hard work, it was incredibly rewarding to impact people's lives in such a positive way. We did something that needed to be done. I can honestly say this trip was the highlight of my career."* Christine Emerson

Marsh, M.D., a pediatric plastic surgeon from St. John's Mercy Health Care Services, along with a URMC resident, a German-Canadian anesthesiologist and nurses from Calgari Children's Hospital. The group combined their experience and know-how to optimize conditions for surgery, for instance. The anesthesiologist had long ago learned to assess a patient's level of comfort through basic observation, so he had no need for expensive equipment in more modernized hospitals.

The group also adapted to having no running water and periodical bouts without electricity. The group used a hand ventilator to make sure patients could still receive oxygen when the power went out, made a make-shift post-anesthesia care unit out of a closet and kept a fly swatter handy to get rid of unwelcome visitors to the hospital's screened-in OR, which lay couched in the Himalayas.

In just eight days, the group repaired cleft lips and palates of 70 Bhutanese children. Some of the families had travelled for up to two days to see the medical team.

Girotto is far from finished sharing his gift with families in developing nations. In March, he traveled back to Asia, but this time, to Vietnam. There, along with URMC alumni Mark H. Weinstein, M.D., general and plastic surgeon at Yale-New Haven Hospital, and staff from Yale's Department of General Surgery, Girotto and his fellow miracle-makers worked their magic for a new set of children.

"During our brief visits, we have been able to change the lives of many children who otherwise would not have had this opportunity," said Girotto.

To help support Girotto's missionary surgery work abroad and in our community, contact Changing Faces — Changing Lives at 585-273-FACE.

Two Dedicated Supporters Jump on Board for the Children's Hospital

Mike Smith and Jack Goodrich Join Golisano Children's Hospital's Board

Mike Smith

Mike Smith has been very involved with Golisano Children's Hospital at the University of Rochester Medical Center for a number of years. In 2008, he and his wife, Alice, were honorary chairs for Golisano Children's Hospital's annual Gala event – the biggest annual fundraiser for the children's hospital. That same year, Smith offered to have his company, The Cabot Group, be the presenting sponsor for the Gala for the next 10 years, ensuring the success of the event for years to come.

"The gala is both a celebration of the children's hospital and an opportunity to raise funds so the children's hospital can continue to do its good work," said Smith.

Smith, who has also been part of the Gala's sponsorship committee, is continually impressed and moved by the enormous impact the children's hospital has on our region. He has spearheaded his company's efforts to support the hospital, which has included sponsoring the Golf Classic. The Cabot Group has been awarded the 2010 Miracle Maker Award for outstanding commitment by a corporation in recognition of its efforts.

"It's easy for us to participate. We don't really do the hard work like the many wonderful doctors and nurses and volunteers, but we like to contribute," said Smith. "You walk through life and you see so many needs, but when you see a kid with medical needs, it just makes your heart skip a beat. We don't do much, but I truly believe in Golisano Children's Hospital and so we do what we can to help."

Jack Goodrich

As senior vice president of LeChase Construction and the company's liaison to the University of Rochester, Jack Goodrich has had a longstanding relationship with Golisano Children's Hospital. Goodrich first became involved with Golisano Children's Hospital in 2004, when LeChase Construction helped build the new pediatric intensive care unit.

"When the project was completed, we immediately saw the value this state-of-the-art unit added to this already thriving hospital," said Goodrich. "I knew this was just the start of something great for this top-rated children's hospital."

During Goodrich's tenure at LeChase, the company has become increasingly involved with Golisano Children's Hospital's fundraising events and building projects. Last year, Goodrich showed his dedication to the cause by serving on the Golf Classic committee, for which LeChase Construction was the presenting sponsor. LeChase Construction was awarded the 2009 Miracle Maker Award for Outstanding Commitment by a Corporation for their long-term and ever-growing support for the children's hospital. The company also served as the 2010 presenting sponsor for the annual Ski Outing.

Goodrich looks forward to serving on Golisano Children's Hospital's board. "I have always been impressed with the dedication of the doctors, nurses and staff and moved by the stories of what they do for the children of our region," said Goodrich. "I will do whatever I can do to enhance this phenomenal institution."

Children's Miracle Network Sponsor

Children's Miracle Network®
hospitals helping kids

Blockbuster raised nearly $5,000 for Golisano Children's Hospital at the University of Rochester Medical Center. Blockbuster managers visited the hospital's play deck in December to deliver gifts of video games and DVDs to patients.

Tim Horton's sold $1 smile cookies during the week of Feb. 3 with great success. Employees were excited to support the fifth annual event, which raised nearly $10,000 for Golisano Children's Hospital.

Local IHOP restaurants celebrated the 4th National Pancake Day, Feb. 23. serving up free stacks of delicious pancakes to guests, inviting them to make donations to Golisano Children's Hospital in lieu of the cost of breakfast. IHOP restaurants on Jefferson Road and North Goodman Street celebrated the day with local families and hospital supporters. After sharing stories with the CW-WHAM morning show, Jose Abarca, manager of the Jefferson Road IHOP, invited the mom of NICU graduate, Christine Hood, and her two younger sons to come in for free pancakes. The day raised more than $2,100 for Golisano Children's Hospital.

special thanks

- Special thanks to Ida Wheeler for holding the third annual Holiday Showcase on Dec. 5. This all-star local youth talent show raised a record $3,047 for our region's only children's hospital. Ida also held the eighth annual Talent for Tots and Teens on April 10 – thank you for your tireless commitment, Miss Ida.
- Many thanks to Longhorn Steakhouse for holding its grand opening to benefit Golisano Children's Hospital.
- The ninth 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 $21,450 to continue to fund Katelyn's Connections in memory of their classmates, Katelyn Pasley and Ryan McCluski.
- Feb. 6 marked the sixth annual Cycle for Hope. This spinning fundraiser held at a dozen health clubs around the Rochester area raised $25,230 for Golisano Children's Hospital and Camp Good Days.
- The third annual Battle of the Beaks was a great fundraiser again for Golisano Children's Hospital! Proud parents, Becky and Mike Fahy, spearheaded this event two years ago with the help of Kim McCluski, children's hospital board member, in honor of their NICU miracle baby, Kelsey. The Battle of the Beaks basketball games were played by rivals Nazareth and St. John Fisher and were organized by student athletes. Through admission tickets, raffles, t-shirt sales, concessions and a student athlete dance at Nazareth, the colleges raised $20,000 for Golisano Children's Hospital.
- Many thanks to Paul Tessoni and Mark Schwartz for organizing the infamous ski outing! The eighth annual Ski Invitational at Bristol Mountain raised $43,600 for Golisano Children's Hospital! Nearly 100 people hit the slopes and enjoyed a beautiful sunny day, all for the kids.
- Brockport High School held the 37th annual Brockport High School Leukemia Dance Marathon for leukemia research at Golisano Children's Hospital. The high school kids were happy to dance for 12 hours to help beat leukemia and raised a staggering $13,000.
- Patti and Mike Milburn organized a casino trip and raised approximately $1,000 to go towards their total for their team, Cruzin' for Cory, at this year's Stroll for Strong Kids. They also organized the third annual Euchre Tournament and rolled funds raised from that event into their team totals as well.
- Nicole Mastrosimone organized a fashion show called Clothes for a Cause. The event raised money and awareness for Golisano Children's Hospital. Thank you, Nicole.
- The Pittsford Crew organized the annual Row for Strong Kids fundraiser and aimed to row 1 million meters again this year! Thank you Jill Lennox and others for continuing to support Golisano Children's Hospital through this exciting and unique event.

We'd like to offer many thanks to these folks and to our many generous supporters and event organizers that work so hard to help Golisano Children's Hospital. We recognize that economic times are tough and we appreciate every bit of support. Thank you!

upcoming events

May 28–31, Roc City Rib Fest, Ontario Beach Park. This rib extravaganza, which draws heavy competition from barbeque fanatics around the East, has expanded to four days. The event will open up at 5 p.m. Friday, May 28, and will continue until Monday, May 31. For more information, visit *www.roccityribfest.com.*

July 24, 21st annual Ten Ugly Men, Genesee Valley Park. Get in on the fun with this highly anticipated tribute to summer, which has live music, sports competitions like volleyball and kickball and much more. Tickets are $30 in advance and $40 at the door. For more information, visit *www.tenuglymen.com.* To volunteer, call (585) 273-5948.

Aug. 28, 6th annual Fairport Music & Food Fest, Lift Bridge Lane. Founders of this community-wide event received a 2009 Miracle Maker Award for their tremendous work in growing this event into a full-fledged fundraising festival with three stages for live music, more than a dozen food and drink vendors and all sorts of family-friendly activities. Tickets are $10 in advance and $15 at the door. Kids 12 and younger will get in free. For more information, visit *www.fairportmusicfestival.com.* To volunteer, call (585) 273-5948.

Sept. 15, Miracle Jeans Day. Businesses and schools across the region are invited to join in on this second annual fundraiser, which encourages employees to donate $5 or more to Golisano Children's Hospital to wear jeans for the day. To sign up, visit *www.miraclejeansday.com.*

Oct. 10–17, Cruise for a Cause, Carnival Valor. This special promotion, which donates a portion of proceeds to Golisano Children's Hospital, is the perfect opportunity to take the family on an unforgettable vacation to visit beautiful tropical locations, including the Grand Caymans and Belize. For more information, visit *www.cruiseforacause.org.* To make reservations, call 1-888-461-2628 ext. 276.

Oct. 30, 23rd annual Gala, Rochester Riverside Convention Center. Golisano Children's Hospital's Gala delivers a dazzling evening for hundreds of guests with food and libation, entertainment and a live and silent auction. The event will begin at 6 p.m. and run until midnight. For more information or to order tickets ($175 per person), call (585) 273-5948.

Golf Events

For more information on the following golf events, call Golisano Chidren's Hospital's Office of Advancement at (585) 273-5948 or visit *www.givetokids.urmc.edu.*

May 19	Golfing for Kids Tournament sponsored by Walmart and Sam's Club
June 21	22nd annual Kiwanis Charity Golf Tournament
June 23	B&L Wholesale Golf Tournament
July 15	WNY Optics Golf Tournament
July 26	3rd annual Cheshire A/V Golf
Aug. 2	11th annual Tim Milgate Golf Tournament
Aug. 2	8th annual Kittelberger Charity Golf Tournament
Aug. 31	Ed Kaufmann Golf Tournament
Sept. 13	14th annual Golisano Children's Hospital Golf Classic

back from the brink

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a regular rhythm.

Three days after the surgery, PCICU staff again started to wake up Addison while his mother, maternal grandmother and paternal grandmother stood by the bed. He immediately called out to his mother, and even though he hadn't seen his paternal grandmother in 18 months, he recognized her immediately.

"I told him his heart broke but the doctors fixed it and now he has a computer in him, like a superhero," Lisa said.

Addison has earned his superhero chops. He survived a cardiac arrest from which many children don't come back. He underwent a major surgery and now has a sophisticated piece of machinery inside him. He rebuilt his muscles to walk again.

Although it's apparent soon after meeting Addison that he's a very special boy, his positive, bounding energy belies all this Miracle Kid has been through.

toddler's bout with cancer

Continued from page 7

through the stomach into the abdominal wall, meant another surgery for little Hailey, but Bruckner and Pegoli agreed that it would make it easier to manage her treatment in the long run.

On Aug. 11, Pegoli worked with the Division of Pediatric Gastroenterology to insert a feeding tube. The decision proved to be beneficial for everyone involved. Hailey was getting everything she needed more easily and she no longer saw her parents as "the bad guys." Hailey has since come to love her "tubey," which looks like one of Mickey Mouse's buttons, as if it were always part of her.

During her many visits to the hospital, Hailey also came to adore her surgeon, "Dr. Goli." When Halloween came around, she decided to dress up like her "boyfriend" and proudly sported a surgeon's outfit when she went out trick-or-treating. The nurses on 4-3600 came to know and love the bright-eyed little girl who liked to sit with them at the nurses' station.

"Hailey was pretty good about being her own advocate," said Melissa. She described how Hailey learned how to unhook herself from IV tubes properly and always asked, "What's this?" when nurses or doctors gave her a dose of medication.

Hailey's positive outlook on her hospital experience reflected the kind, appreciative and receptive demeanor of her parents.

"You see the best in people and you see the worst in people when their children are sick," said Pegoli. "Some parents exercise such grace and dignity not only to rise to the occasion, but to rise above and think about others."

Pegoli recalled that despite the difficult position Melissa and Jason found themselves in, they often brought candy and cookies in for the residents and nursing staff. The Conibers recognized that providers were doing their best to help their little girl and were grateful for it.

The Conibers worked with Pegoli and Bruckner to determine the best options for Hailey. A CT scan Oct. 28 showed that Hailey had another spot on her right lung. Pegoli suggested waiting to do the surgery, since Hailey was neutropenic, which meant she had an abnormally low number of neutrophils, an important white blood cell that fights off infections, and her platelet counts were also very low.

Pegoli told Melissa and Jason that with a blood transfusion, they could give Hailey the red blood cells and blood-clotting cells she needed to do the surgery to remove the lesions, but that Hailey would have a better chance at recovering if they waited until Hailey's immune system had strengthened on its own. The Conibers agreed.

"Dr. Pegoli was always honest and had very strong standards," said Melissa, as she recounted the story, "I really admired that."

After a few weeks, Hailey's blood count levels were high enough for the surgery, which the family scheduled for Nov. 12. Pegoli removed a lesion, located in a hidden area of Hailey's lung that was difficult to access, along with two other suspicious-looking spots.

After completing the six cycles of chemotherapy prescribed by Bruckner and the most recent surgery with Pegoli, there are no cancerous cells to be found in Hailey.

"I think we're at the best possible place we could be right now," said Bruckner. "We have no evidence of any disease."

"It was a positive experience, thank goodness," said Melissa, "We're still close with everyone. We still visit the nurses and see the doctors. Things happen and it stinks but so far, we've had a good outcome."

a gift from his sister

Continued from page 9

marrow from Amanda's hip bone, and Michelle stayed with Connor while he awaited the bone marrow infusion from his sister.

Connor was given several types of chemotherapy treatment during the week leading up to the transplant to rid his body of old bone marrow cells, so that the body would be more likely to accept the new bone marrow cells from his sister.

Amanda's bone marrow was extracted just in time for the family to go upstairs to see Connor and cheer him on as he received a sample of his sister's bone marrow. The transplant was successful, but Connor's journey towards good health was far from over.

Connor stayed at Golisano Children's Hospital for about three weeks, where providers monitored Connor's progress as the donor cells began to replicate. Those weeks are usually the hardest part, according to Mullen, with high risks of infection and bleeding. Patients also usually need a lot of help with antibiotics and medications that weaken the immune system to keep it from rejecting newly infused cells.

Connor's health care team of bone marrow transplant floor nurses and staff were "a total blessing," Michelle said. "He absolutely loved his nurses and always had a smile for them."

Connor's dad stayed with him during Thanksgiving and his mom took the girls to be with family to have some normalcy amidst the stress that had surrounded the transplant. Connor returned home after Mullen saw that Connor's body was pro-

Continued on page 30

"Without a match within Connor's immediate family, there was a high probability the transplant wouldn't work or that there would be severe immunological problems afterwards," said Mullen.

a gift from his sister

Continued from page 29

ducing fully functioning cells.

Connor's parents monitored him very closely during the first year after the transplant. There was still the danger that his body would reject the donor cells. Connor was also still on medications that compromised his immune system, so his parents were very careful to make sure Connor wasn't around too many germs. When it was clear Connor's body was ready, Mullen took him off the medications that had been weakening his immune system.

Four years after Connor's transplant, the disease hasn't progressed. Connor still sees Mullen and Mink for follow-up visits, but he is doing so well that visits are only once a year.

Today, Connor is a happy, healthy 14-year-old with an enormous amount of gratitude for his big sister. He loves to share that she saved his life and often insists that "the donor" get special treatment.

Despite the uncertain path Connor's diagnosis took his family and providers on, everything worked out for the best. "This has been a terrific therapeutic relationship," said Mink. "The Tillapaughs had faith in us, and we had faith in them."

inspiration to friends and family

Continued from page 11

direct their support for the Merrimans to Ethiopian children in need of cancer treatment.

Along with her "can-do" spirit, Korones described Bridgette as "uncommonly resilient." Besides the hair loss that resulted from chemotherapy, Korones said that Bridgette's cheery attitude made it difficult to tell whether Bridgette was ever really experiencing any side efforts or discomfort.

Bridgette finished her radiation treatments in the middle of June 2009. Mike said that they became so fond of the hospital staff and the care was so top-notch that on Bridgette's last day of receiving chemotherapy, she said to her father, "I am going to miss coming here."

Korones shared Bridgette's sentiments. "The only downside to having someone do so wonderfully is that they don't come to visit as much," he said. Bridgette, who once came in every week, now sees Korones for check-ups every four months.

Bridgette continues to spread goodwill where ever she goes. Last summer, Bridgette attended Camp Good Days to share her success story with peers in hopes of raising their spirits. She and her family continue to support children in Ethiopia with their Chemo for Kids Fund.

Bridgette is back at school full-time now and she is flourishing with high academic grades in advanced classes, a seat on her student council board and a spot on the swimming and lacrosse teams. The amazing go-getter is also playing viola in Hochstein's Sinfonia Orchestra, taking Irish Dance classes and is an active member of her church.

"It's incredibly scary for parents to hear the words, 'Your child has cancer,'" said Tracey. "We truly feel that in light of such an awful situation, we've had the best experience anyone could possibly hope for, thanks to the wonderful doctors, nurses, families and friends that have supported us."

a little fighter gets a strong future

Continued from page 13

Owen for the first time. She was overcome but, on the eve of Thanksgiving, she was also thankful for her brand new baby and wondered if the cyst appeared for a reason.

"We knew that we were supposed to be there … If we were going to be anywhere and give our son a chance for survival, we knew we were in the right hospital."

April and Nick had done a lot of research on the surgery Owen would undergo, but seeing his bowel in, essentially, a plastic bag suspended over his belly was difficult. Over the next week, Pegoli's team, including Heather Goetzman, P.N.P., worked to push Owen's bowels into his tiny abdomen. When the last of it fit, it was time to close his belly, but there wasn't enough skin and muscle to cover the defect's hole.

Pegoli placed an absorbable mesh over the hole and put a special dressing over it to encourage natural tissue to grow. Once that tissue grew enough, Owen underwent another surgery to place a skin graft over his abdomen. It would be a temporary fix because all that was between Owen's bowels and the world was a very thin piece of skin. But after 100 days in the NICU, on March 5, Owen finally went home.

April and Nick worked hard to give Owen as much normalcy as possible at home, knowing that he'd need more surgery very soon. In June, he came back to Golisano Children's Hospital for surgery with John Girotto, M.D., a pediatric plastic surgeon. Girotto's aim was to stretch Owen's belly skin enough to remove the skin graft and close the defect with thicker skin. That meant placing two tissue expanders, essentially expandable balloons, into either side of his belly.

"Tissue expanders require a lot of attention and work. We modified our surgery so that Mom and Dad could perform some of that daily work while at home," Girotto said. "They became an important part of our team. Nothing fazed them at all."

April and Nick, with the help of Christine Emerson, P.N.P., gradually filled the balloons with saline, stretching his skin over time. The expanders were cumbersome for the active boy as he grew more mobile and they grew bigger. April had a comically hard time getting his clothes to fit, and he had a bout with an infection around one of the expanders. But he fought off the infection and the expanders worked. On Sept. 17, Girotto removed the expanders and stitched Owen's belly shut. He was finally whole.

"He has a large scar, but from what it looked like before to what it looks like now, it's beautiful," April said. "It's just beautiful."

Today, Owen is a happy, active toddler, who not only walks, but runs at a surprising clip. He has hit his developmental milestones with gusto like the tiny hero he is.

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