

# STRONG KIDS



# NEWS



GOLISANO CHILDREN'S HOSPITAL AT STRONG  
University of Rochester Medical Center

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Thomas Golisano at  
a reception for former  
Pediatrician-in-chief,  
Elizabeth R. McAnarney, M.D.



## Miracle Weekend June 2 & 3

A teenager shakes his coma, opening his eyes for the first time in three months.

The day before Halloween, a toddler's chest scans show that his heart is healthy enough for him to go trick-or-treating.

A second-grader is only months shy of being declared "cancer-free."

A 1-lb. preemie grows strong enough to head home — on his due date.

A grateful mom gives the world's longest hug to the surgeon who has made her baby whole.

Many people must come together for these miracles to happen — doctors, nurses, families and friends. Some of the most important people are our donors. From our largest and most famous, like Tom Golisano, who gave a historic \$14 million gift to the hospital,

to our youngest donors and their incredibly heartfelt donations, like that of Michael Ramirez, who raised \$15 dollars at a lemonade stand last September — donors like you power our miracles. Without your loyal backing, we wouldn't be able to provide patients with state-of-the-art equipment, like new Giraffe bed isolettes that help premature babies like Miracle Kid Jude Bryne grow strong, or new facilities, like the William and Mildred Levine Pediatric Surgical Suite, that proved life-saving for Miracle Kid Tristan Lewis. With your help, we have the technology and the expert staff to help children right here in Rochester, close to home.

The first weekend in June — or Miracle Weekend, as we've dubbed it —  
*Continued on page 6*





# Dear Friends —

*Not a day goes by without one or more of our Golisano Children's Hospital at Strong family members achieving major honors in the local, regional, or national arena.*

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*In the past few weeks, we have celebrated a new Robert Wood Johnson Foundation Fellow, several new National Institutes of Health grant awardees, a Rochester Business Journal Healthcare Achievement Awards honoree, the Mentor of the Year awardee from the Eastern Society for Pediatric Research, and a ranking of 20 for our Department of Pediatrics from among the approximately 150 such departments nationally ranked by U.S. News and World Report. We have sent welcome letters to 15 prospective Pediatrics and eight prospective Internal Medicine-Pediatrics residents from around the country — indeed, around the world — who will join our house staff this July. We have hosted leading scientists from around the country in our Pediatric Biomedical and Translational Research Seminar Series. Exciting times; wonderful opportunities; and a heavy responsibility.*

*The responsibility involves the stewardship that must accompany each exciting new achievement. We must sustain and even surpass our current level of excellence in provision of care to the children and families who entrust their health and well-being to us. We must nurture and mentor the new physicians who join us this summer. We must keep our physician-scientists motivated, productive, and supported both fiscally and intellectually in this leanest of times for biomedical research. And we can do this only through our partnership with our lay community, our colleagues in the medical, service, and educational*

*arenas, and our sister institutions around the globe. That is why we joyously joined with you at the Red Tie Gala for the Ronald McDonald House. That is why we join with you in demanding of our local, state, and Federal officials the best possible funding for our children, our aged, and our families. That is why we join with you in educating the children and adolescents and their parents about smoking cessation, optimal nutrition and immunizations.*

*And that is why we ask you to join with us. We need your help in endowing our novel programs and promising faculty, expanding and upgrading our inpatient and outpatient facilities, and luring the best and the brightest physicians, nurses, social workers, therapists, and students to upstate New York. This October, we will rejoice at our 20th annual Gala — a celebration that marks, not an end, but a new, bright beginning!*

*Thanks to you all for always being there for our kids and their families — including our five Miracle Kids and their families, whose stories comprise the bulk of this issue.*

*Your support keeps generating good news of triumph through care and cure. Again, thank you, and best regards.*

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



# Study shows fevers increase with chronic stress

A physician-psychologist team at Golisano Children's Hospital at Strong found that children whose parents and families suffer ongoing stress have more fevers with illness than other children, suggesting an association between family stress and susceptibility to infectious diseases.

Published recently in the *Archives of Pediatric and Adolescent Medicine*, the study also uncovered something unforeseen — that children's natural killer cell function, part of the body's first line of immune defense, actually increases under chronic stress, unlike in adults, in whom it does the exact opposite, or decreases.

"These findings are somewhat surprising to me but also exciting because they show us possible new avenues for improving children's health," said Mary Caserta, M.D., associate professor of Pediatrics in the division of Pediatric Infectious Diseases

at Golisano Children's Hospital at Strong.

Caserta undertook the study with collaborator Peter Wyman, Ph.D., associate professor of Psychiatry at the University of Rochester. The study is one of the few that have examined the effects of stress on children's immune function.

The more unexpected finding of the study, that children's natural killer cell function increases under chronic stress, remains to be explained. Natural killer cells are part of the immune system that exists before a new germ is introduced and serve as the first, generic line of defense for the body until the immune system adapts to find better-tuned ways to fend off a specific bacteria or virus.

"It may have something to do with the fact that children's immune systems are still developing," Caserta said. "Or maybe they're compensating for a defect someplace else. More research is

needed to figure out why.

"Once we understand these connections we can design interventions that lower family stress, or help families to better manage stress in their interactions — and lead to healthier kids," she said.

## Other research

\* Carl D'Angio, M.D., associate professor of Pediatrics at Golisano Children's Hospital, recently published a study that showed vaccines for measles-mumps-rubella and varicella, or chicken pox, are effective in extremely preterm infants, even though preemies' immune systems are not as developed as full-term babies. This confirms a long-held assumption by pediatricians and neonatologists across the country.

\* Sanjiv Amin, M.D., assistant professor of Pediatrics at Golisano Children's Hospital, recently published a study that showed preemies between 28 and 32 weeks were not harmed by multiple treatments that are no longer used to help their lungs mature before birth. Even though previous observational studies suggested that repeated courses of steroids in the womb may result in brain damage, this study shows that the babies' brains are virtually unaffected.



# Program connects violence victims to services

Too many teens were coming through the doors of the emergency room at Golisano Children's Hospital at Strong with gun shot and stab wounds, so Mark Gestring, M.D., trauma surgeon, and Jeff

Rideout, social worker, decided to stretch beyond their regular roles and help the teens outside the hospital.

Now, every pediatric victim of violence who passes through the emer-

gency room is evaluated for more than just medical concerns. The team identifies immediate and long-term issues that may have put them in the position of being injured, such as the need for protection or housing. But the evaluation doesn't stop there — contributing factors are also considered, such as an undiagnosed psychological problem or issues around supervision.

"We want to make sure that when we send these children home they aren't in danger," Gestring said. "We want to address all safety concerns so they don't come back through our doors again."

Once the issues are identified, the team sets into motion a series of referrals to outside agencies and governmental agencies to ensure the teens get the help they need. Among the key partners in the program are Pathways to Peace, PAVE (Partners Against Violence Everywhere), Rochester General Hospital Pediatric Emergency Department, Camp Good Days and Special Times, the Mayor's Office, Rochester Police Department and Monroe County Child Protective Services. With the help of these organizations, the program creates a safety net to prevent another violent injury.

This program is only part of an increasing community response to address the issue of violence in our community. Still in its infancy, the program will continue to change to meet the unique needs of victims, but the primary goal will be to stop victims from being revictimized or becoming perpetrators. Additional resources are now being mobilized to help the entire family.

"In a couple cases, we've actually had to help a child change school districts and the families do not return to their homes," Rideout said. "We'll do whatever we can to keep them safe."



*We want to make sure that when we send these children home they aren't in danger... We want to address all safety concerns so they don't come back through our doors again.*

CELEBRATING TWENTY YEARS OF MIRACLES

*20<sup>th</sup> Annual Gala*

— TO BENEFIT —

GOLISANO CHILDREN'S HOSPITAL AT STRONG  
UNIVERSITY OF ROCHESTER MEDICAL CENTER

OCTOBER 20, 2007  
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# Clinic treats kids with adult-like health issues

As more children are diagnosed with high blood pressure or unhealthy cholesterol levels, the need for specialized services has grown. That's why Golisano Children's Hospital has meshed its hypertension and lipid clinics to provide a more integrated and convenient way for families to seek care for their children with high blood pressure, high cholesterol, or both.

"Although the causes and health effects of hypertension and high cholesterol can be very different, the diagnostic tools and treatments are similar," said Marc Lande, M.D., a pediatric nephrologist with Golisano Children's Hospital at Strong and an expert in pediatric hypertension. "By combining our clinics, families can cut down on the number of appointments they need to make."

Left untreated, hypertension and high cholesterol in children can lead to coronary artery disease, heart attack or stroke in adulthood.

All patients of the combined clinic are seen in the Children's Heart Center, where they can receive echocardiograms, 24-hour ambulatory blood pressure monitoring and other specialized tests not generally available in most pediatric and family medicine offices.

Often hypertension and high cholesterol in young children are family traits, but a growing number of cases are the results of lifestyle.

"The rise in the percentage of children with hypertension parallels the rise in obesity," Lande said. "About 10 percent of overweight kids have hypertension."

There has also been an increase in children diagnosed with high cholesterol, which can be partially attributed to parents getting screened earlier. If parents' blood tests show significant problems, their children are often tested so that issues can be addressed in childhood when it's easier to make a difference in habits and long-term health.

"The first step is always to try to

make changes in diet and exercise if problems are identified," said Kathleen McGrath, P.N.P. "Pediatricians and family practitioners often try this route before referring to us."

As the pediatric nurse practitioner with the clinic, McGrath counsels families of children with cholesterol or blood pressure problems to begin with small changes, such as taking walks several times a week or limiting trans fat, saturated fat, juice and soda in their diet. If changes in exercise and dietary habits don't improve the conditions,

medications may be considered.

"You want to educate children and their families as much as possible, that what they eat does matter, that whether they exercise does matter," said Roger Vermilion, M.D., pediatric cardiologist with the clinic and the Children's Heart Center. "It's much easier to make these changes as a child than as an adult."

To learn more about the Pediatric Hypertension and Lipid Clinic, please call the Children's Heart Center at (585) 275-6108.

Left untreated, hypertension and high cholesterol in children can lead to coronary artery disease, heart attack or stroke in adulthood....

Often hypertension and high cholesterol in young children are family traits, but a growing number of cases are the results of lifestyle.



June 21  
to  
June 24



THE  
**DRIVE**  
FOR  
**MIRACLES**  
RADIOTHON

To Benefit Golisano Children's Hospital at Strong



**100.5**  
THE DRIVE



## Miracle Weekend packed with fun activities

*Continued from cover*

brings us the chance to celebrate the great strides we've made together. We select a handful of patients with gripping stories and are delighted to introduce them to you as our Miracle Kids. Their candid accounts represent those of thousands of other children treated at Golisano Children's Hospital every year. It's your constant support that helps make these miracles happen.

Check your calendar and be sure to mark down these dates: June 2 and 3 for the 24th annual telethon and 11th annual Stroll for Strong Kids.

### Children's Miracle Network Telethon on 10NBC

Proudly producing our 24th annual CMN Telethon, 10NBC will broadcast live from the Strong Memorial Hospital lobby. The telethon serves as a platform for parents and children, including the families of our five Miracle Kids, to share their stories of trials turned

triumph at Golisano Children's Hospital at Strong.

This year's telethon will be held Saturday, June 2, from 4 to 8 p.m., and Sunday, June 3, 7 to 10 p.m. To make a gift during the event, please dial (585) 241-KIDS, or log on to [www.gchas.org](http://www.gchas.org).

### Stroll for Strong Kids

Our 11th annual Stroll for Strong Kids promises a surefire way to kick-start your Saturday morning with loads of family fun—clowns, inflatable toys, special characters, and a scenic two-mile walk, topped off with a free lunch courtesy of Subway and a dance-worthy concert by Gary the Happy Pirate. Help us reach our goal of 2,200 walkers raising \$250,000.

The fun begins with registration at 9 a.m. on Saturday, June 2. For more information on how you or a team of friends can register—or on how to support your favorite Stroll team—visit [www.gchas.org](http://www.gchas.org) or call (585) 273-5948.



## Children's Miracle Network Telethon

to benefit  
**Golisano Children's Hospital at Strong**



June 2 and 3  
on 10NBC

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

4–8 p.m. Saturday, June 2  
7–10 p.m. Sunday, June 3



# Tristan Lewis: Ready for a game plan, while still in the womb

This past September, five months along in the pregnancy of their son, Tristan, Cheryl Bristol and Marc Lewis received obstetric test results that piqued doctors' concern.

"Only halfway along, imaging techniques were already able to look inside me, to look inside Tristan, and register spots on his bowels that posed threat of blockage," Bristol said. "And immediately, we were encouraged to begin talking with a surgeon—just as a precaution."

That's when the couple met Walter Pegoli Jr., M.D., surgeon-in-chief at Golisano Children's Hospital, who warned them that there was risk that the entire line of Tristan's "plumbing"—from top to bottom—might have problems. Tristan would likely suffer from any number of non-random birth anomalies recognized as VATER syndrome (an acronym representing: vertebral problems; imperforate anus, where the rectum doesn't open to the outside of the body; tracheoesophageal fistula, or a persistent connection of the windpipe and feeding tube; and renal anomalies). How many of these anomalies Tristan would experience, and to what extent, wouldn't be known until he was born.

So, at a time when most expectant parents would be putting finishing touches on their home nurseries, Bristol and Lewis were talking through the what-if scenarios with Pegoli. They would need to give consent for any necessary surgeries, perhaps almost immediately after Tristan was born, and they wanted to be ready with thought-out answers.

It was time well spent. When Tristan was delivered, doctors noticed right away that his anus did not open to the outside, and that his belly looked swollen—the result of his feeding and breathing tubes being joined together, causing him to suck air past his lungs and into his stomach.



Tristan Lewis

"The first time I saw him, he was surrounded by a crowd of doctors, and his tummy was so large," Bristol said. "As it turned out, he had more of the VATER symptoms than Dr. Pegoli had suspected. I was instantly thankful for all the conversations we'd had in advance."

Tristan immediately underwent a six-hour surgery to separate the two tubes (tracheoesophageal fistula), which saved his life. He then spent the better part of two months in the Neonatal Intensive Care Unit recuperating from surgeries including a colostomy, a gastrostomy, and creating a spit fistula (a hole in his neck that would help mucus to drain to the outside).

He went home for two months, only to return to the children's hospital for more surgeries, including one to construct him a new anus, and another to reconstruct his esophagus (using a part of his colon) and close his colostomy.

"That whole time, Tristan kept us on our toes," Bristol said. "We would progress his feeding from IV and electrolytes to formula, and then he'd vomit, which was upsetting, because his

surgeries hadn't yet healed and we'd have to start the feeding progression all over again. Another time, he pulled out his gastrostomy tube, and we had to have it reinserted. Nothing was simple, even on the more straight-forward visits. The last one turned into a 22-day stay, because of these little, inevitable setbacks."

But at last, the lineup of surgeries—so many, Bristol says, that she keeps count and has almost run out of fingers—came to an end.

"After Tristan's final surgery, I gave Dr. Pegoli the biggest hug; I didn't want to let go," she said. "How do you thank a man who has lifted such a weight off your shoulder, who has tended to a child with so many needs and given them complete and total healing, a future?"

The horizon looks hopeful for Tristan. He's a smart 14-month-old, who likes to play copy-cat; he's learning to crawl and, after a long wait, is eating and drinking with his mouth, just the way he should.

Best of all, he's healthy.  
And, he's home.



# Cal Livingston: After a year-long journey, this champ heads home

To say that 17-year-old Cal Livingston is fond of the great outdoors would be an understatement. He grew up riding dirt bikes, jet skis and snowmobiles, not to mention, camping and hunting. And as far as high school sports are concerned, Cal, a Geneseo Central tri-athlete, ate, slept and drank baseball, hockey (his favorite) and football.

That's why, last December, when he began experiencing flu-like muscle soreness after a hockey game, no one thought too much of it.

"Like a tough sport, he had mustered his game strength while admittedly feeling a little under the weather," his mother, Micki Livingston, said. "He even scored the winning goal."

But when Cal's condition worsened, she and her husband, Dave, soon sensed that something more serious was at play. Doctors in Geneseo sent Cal to Golisano Children's Hospital at Strong.

In Rochester, test after test shed little light on the mysterious illness that had struck without warning, and Cal's health was slipping so fast and his breathing had become so labored that doctors feared it might sap his much-needed strength. To conserve it, he was sedated and placed on a ventilator.

Soon, enough clues came together. Cal was diagnosed with macrophage activation syndrome, a rare inflammatory condition related to his otherwise low-lying juvenile rheumatoid arthritis, which hadn't bothered him much since his initial diagnosis after experiencing sore joints as a 7-year-old.

"His body was attacking itself,"



Livingston said.

Cal's condition grew worse with time—bringing multiple organ system failures, and complications that caused the need for more than 15 skin grafting procedures, which were performed by Christopher Lentz, M.D., part of Golisano Children's Hospital's team of surgeons who handles complex wounds, burns and critical care.

Cal and his family fought for his life. His parents stayed close by, taking turns staying in his room, or only minutes above it in the hospital's Ronald McDonald "House within the Hospital."

People began rallying for Cal back at home. Hundreds of t-shirts were made that bore a "Cal" logo across the front, and people could be spotted wearing them all over Geneseo. Hockey players, even on opposing teams, would routinely gather at the rink's center to pray for Cal's health after games. Friends even formed a group called "Friends of Cal" that held fundraisers and garnered support for Cal in Geneseo. In February—and after Cal had spent nearly three months in the hospital in a medically-induced coma—the Friends organized a special benefit. In the middle of it, the Livingstons sent an urgent message to be read to all in attendance: that very day, Cal had opened his eyes!

Celebration broke out; Cal had missed a few months' time, his hockey season and Christmas, but this was the first of many miracles for the Livingston family.

Heartened, they pressed on. Cal, now awake, quickly developed a friendly rapport with his nurses.

"They're the first line in any

*Continued on page 12*

Cal Livingston's family is happy to have him home—finally!





## Timothy Eaton: Checking into 'Hotel Strong'

Five years ago, July brought 3-year-old Timothy Eaton hugs and sunshine, thanks to a family reunion in Tennessee. It also introduced big words, like “leukemia” and “chemotherapy,” into his growing vocabulary.

Upon returning from the trip down south, Timothy, the youngest of three Eaton boys, was running a temperature and not feeling well. His pediatrician initially thought it was hand, foot and mouth disease, a common viral illness among kids his age that would likely just run its course.

But it didn't. It ran, ran and ran some more, and soon led to vomiting. “At that point, I brought him back to see the doctor again, and they took finger pricks, but didn't like what they saw,” said Timothy's mom, Michele Eaton.

The doctor's office asked for another finger on the other hand.

“And when that brought troubling results, too, they told us that it might be leukemia and that my husband, John, and I were to pack a bag and head straight to Golisano Children's Hospital at Strong,” Eaton said.

In Strong's pediatric emergency department, the Eatons met Yesenia “Jessica” Ocampo, a child life specialist who brought coloring books, toys and games that would help pass time while Timothy waited for yet more blood draws. Soon, Timothy was brought upstairs, where a bone marrow test confirmed that yes, he did have leukemia — ALL, or acute lymphoblastic leukemia, which affects white blood cells that normally fight off infection. Fortunately, this once-fatal disease is now quite curable, and more fortunately still, it had not spread to Timothy's spinal fluid.

“Our doctors were ready to field all our questions and talk about treatment, medicines and routines, but we weren't ready for answers just yet,” Eaton



remembered. “It was still very raw.”

Respecting that, doctors continued to treat Timothy and only versed the Eatons in the absolute essentials. The rest could wait until they were ready.

“A diagnosis of leukemia is a time of crisis for the whole family, presenting an enormous amount of information for the whole family to take in,” said Barbara Asselin, M.D., one of Timothy's pediatric oncologists. “But, in time, the Eatons stepped up to the challenge with determination, embracing the new treatments and routines with amazing

strength of spirit. Timothy, especially; there's nothing that can make your day like Timothy's winning smiles!” Timothy began receiving platelets by blood transfusions, along with chemotherapy.

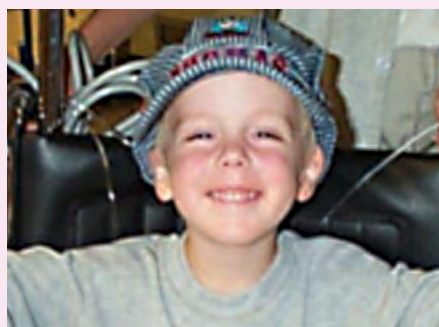
“He lost his hair, but John and Tim's brother, Andrew, shaved their heads, too,” Eaton said. Timothy's other brother, Steven, helped him keep busy by playing video games.

Unfortunately, Timothy began experiencing an aching inflammation of his pancreas, or pancreatitis, just three days after chemotherapy began — most likely an obscure reaction to his medicine. The only way to treat it was to keep him from eating for four to five days.

“John and I felt like the worst parents in the world, denying him that,” Eaton said. “He still was receiving nutrition through tube, but it wasn't the same, and he was crying, begging.”

The cycle continued: chemotherapy, blood work to check progress, and more bouts of pancreatitis' gut-wrenching pain and food-and-drink fasts to beat them. In August, a little more than three weeks after being admitted, Timothy

*Continued on page 12*



Timothy Eaton is known for sporting a winning smile — even in the tough times.

# Andrew Monrad: Three-stage surgical fix works wonders for this kid rock star

Five years ago this August, Cathy and Mark Monrad were 20 weeks along in the pregnancy of their first child and struck with one of those rare pieces of news that halt everything.

The mid-point ultrasound checkup revealed that the left side of their baby's heart and aorta would not fully develop and that, to survive, their son would require a three-stage surgical fix at Golisano Children's Hospital at Strong almost immediately after he was delivered.

*His smile attracted fans, and soon nurses and doctors were calling him a "rock star" ...*

The couple decided to press on with the pregnancy and give their son a chance. Just a week before Christmas 2002, little Andrew entered the world by emergency C-section and immediately was brought to the Neonatal Intensive Care Unit (NICU) for monitoring. It proved a rocky start—doctors discovered that he had incurred a skull fracture during labor.

"The next day was touch and go," Cathy Monrad said. "They were determining if he had suffered brain damage. But he hadn't; for us, this was the first of many miracles."

With Andrew's brain looking healthy, it was time for his first, eight-hour phase of corrective surgery. George Alfieri, M.D., the hospital's leading pediatric heart surgeon, assured the Monrads that he would treat their boy like his own.

"I know that's something you'd expect to hear," Monrad said. "But underneath, there was more than words. There was an authenticity we can't put

our fingers on, and we immediately knew he really meant it."

Andrew was sent home in mid-January, but would return to Golisano Children's Hospital in March for the surgery's second phase. Due to scar tissue, his aorta had narrowed so much, it had virtually closed.

In the hospital, Andrew battled a blood clot and an infection. Both put surgery on hold. But when Andrew was finally ready for the operation, he sailed through, and even bounced back quickly enough to be featured on a television spot with Tom Golisano and Rich Funke of 10NBC.

But then the tide turned again. Andrew would need more surgery—this time, not on his heart, but to remove part of his intestine which had died from lack of oxygen during earlier heart troubles. A temporary ostomy would allow Andrew's belly time to heal, and he stayed at the hospital straight through his parents' first Mother's Day and Father's Day.

"In typical Andrew fashion, there were a couple more bumps in the road," Monrad said. "A mass was found in his abdomen, which they planned to promptly remove."

But when the chief pediatric surgeon, Walter Pegoli, M.D., operated to reverse the ostomy, the mass wasn't there anymore; it had dissipated on its own. By this point it was clear that Andrew was being sustained by something more than just good science.

"We were starting to think of him as some sort of superhero," Monrad said. "We were waiting for his next feat."

Thankfully, that July marked the last of his stays for a stretch. Just more 6 months old, Andrew returned home and, with the help of physical and occupational therapy, began running, climbing and doing normal little boy things. He avoided long stays in the children's hospital for more than three years.

Then, last September, a few months before Andrew's fourth birthday, the third and final surgery was performed—again, problem-free. Within mere days, Andrew was ventilator-free and walking circles around the unit. His smile attracted fans, and soon, nurses and doctors were calling him a "rock star," because of the way he made rounds, "touring" the floor.

The day before Halloween, his chest images looked extraordinary—at last—and Andrew was cleared to resume all normal activities.

"Which meant, he promptly donned his cop costume and made good on his clean bill of health by trick-or-treating," Monrad recalled.

Andrew, now nearly 4 and a half, loves to sing, play outside, put together puzzles and attend preschool, where he "absolutely thrives," Monrad said.

"He loves music, and really is a rock star, as they tease him," Monrad said. "He's just as famous, too. Every time we visit that floor, so many people call out to him, saying hi. More people than I can remember the names for. That's the sort of support that you need, and it's refreshing to know it's still there waiting in case we—or anyone else—ever needs it."





# Jude Byrne: A feisty little fighter from the get-go

In January 2005, Carole Woodlock and her husband, Peter Byrne, gave birth to their son Jude when he was just more than 24 weeks along in the pregnancy.

"We were told that there was a 50 percent chance of survival, and an 80 percent chance that he'd suffer severe disabilities," Woodlock said. "I'll never forget those numbers."

Woodlock, who was suffering from the sudden onset of complications related to H.E.L.L.P. syndrome, a rare obstetric complication, struggled to stave off labor to give Jude even just one more protective day in the womb. Bed-rest and courses of steroids only bought hours.

Soon, it became absolutely necessary to deliver Jude, who was four months early and at 11 inches long, weighed only 1 pound. He tried to breathe on his own, and made a tiny cry.

"The nurses and doctors were stunned; it's a rare feat that a baby so small even attempts to cry," Woodlock said. "Right away, we knew he was a feisty little guy that was willing to fight."

They couldn't have been more right. Jude proved to be spirited all right—he preferred to be positioned certain ways, and kept setting off monitor alarms, testing the nurses again and again.

"But they were so good-natured about it, and made a game of it," Woodlock said.

After a whole week, the parents could finally touch their son; though his skin was still translucent and he looked too delicate to handle, NICU nurse Val Roach assured the couple that they could—and should—touch him.

"He needed us too, Val said. Jude looked fragile, but craved our touch," Woodlock said.

When Jude was 6 weeks old, his

parents could hold him outside the incubator. Woodlock and Byrne were thrilled to begin connecting with their son through skin-to-skin holding and the daily feeding and changing regimes. Roach continued to prove a stalwart advocate for the family, and for the couple being involved in the critical decisions about Jude's care.

"When you first come to the NICU, it's intimidating; the medical language can be absolutely foreign," Woodlock recalled. "But our nurses, especially Val, and our doctors made sure to empower us. They explained everything and took time to educate us so that we could make informed choices. They also reminded us that with any NICU baby's journey, there would be peaks and valleys, and that it's important to not get too caught up in either, but to ride it through."

Jude did traverse those valleys. In his second week, he turned stone-grey, and came very near to stopping breathing altogether. He was able to be revived.

He also couldn't take breast milk until he was 6 weeks old, and consequently, had trouble gaining weight and strength through the IV nutrition alone.

And, after phasing off his breathing devices until he needed less and less help (at 12 weeks, finally breathing on his own), there came the daunting question of whether or not he should have eye surgery to fuse his retinas, which typically only start to develop during the last couple of weeks of pregnancy. Surgery would save him from being blind altogether, but the cost was giving him only limited vision.

"As parents, we had hopes that his vision might improve on his own, and dreaded making that big, liminary decision. We wanted to give Jude some



more time," Woodlock said.

That blend of all opinions—theirs, and that of the physicians and the nurses—was the best way to make decisions, Woodlock said. Nurses like Roach kept reminding them that as parents, they knew their child better than anyone else.

"Carol and her husband took advantage of our NICU's longtime emphasis on family-centered care," said Gloria Pryhuber, M.D., who specializes in acute and chronic lung diseases in preemies like Jude. "Carol was always thinking, 'what about this, and what about that?' She was clearly Jude's advocate."

The time came where Jude, at 3.5 pounds and after a 100-plus day stay, was strong enough to head home. Miraculously, his vision did improve with assistance of an early intervention vision specialist.

Today, it is perfect.

"Carol and Peter spent so many hours spent at Jude's bedside—waiting, talking to Jude, encouraging him,

*Continued on page 12*



## Cal Livingston

*Continued from page 8*

hospital,” Livingston said. “Cal’s were phenomenal!”

Cal’s care required coordinated expertise, drawing from physicians and surgeons from many of the children’s hospital’s departments.

“Each one knew what the other was doing,” Livingston said. She credits this synchronization in large part to David Siegel, M.D., M.P.H., Cal’s pediatric rheumatologist (also the hospital’s chief of Pediatric Rheumatology and Immunology), whose efforts, Livingston adds, with Cal were wonderful, very reassuring.

Cal also forged a unique bond with Rob Humphreys, M.D., a pediatric nephrology fellow who was willing to speak at Cal’s level, not above his head.

Humphreys ran the New York City Marathon as a fundraiser in Cal’s honor, and presented Cal with his finisher’s medal—encouraging Cal to keep running his own race, to keep chasing after health, to head home.

Finally, on the last day of November, after nearly one year in the hospital, he was discharged. In Geneseo, he was greeted by a cheering crowd outside his high school, a trail of well-wishers’ signs in store windows and a sign with “Welcome Home Cal!” in gallant, blue lettering adorned the front of his home.

Cal is keeping busy with physical therapy and catching up with his course work.

“He has an iron will,” Livingston said. “I think he’s proven that. Only an iron will—coupled with the care we found at Golisano Children’s Hospital—could have brought him back home.”

## Timothy Eaton

*Continued from page 9*

was able to go home and receive his medicine as an outpatient, first weekly, then bi-weekly, then monthly, and then, in October 2004, he no longer received any at all.

In October, barring no surprises, Timothy will join the ranks of many childhood cancer conquerors.

“He’s the ‘bounce-back kid,’ he’s so resilient,” Asselin said.

The pancreatitis attacks, however, continue. The day after last Thanksgiving, Timothy experienced one that was so agonizing, he begged to be taken to the hospital.

“We checked into ‘Hotel Strong,’ as I’ve come to call it,” Eaton said. Timothy stayed for another three weeks. To prevent future attacks, Timothy receives enzyme therapy and is kept on a low-fat diet that Eaton admits is tough for an already-skinny 7-year-old. Still, most of the time, it helps him to keep feeling good, and to keep smiling—scoring 101 percent on a recent second-grade math test, taking up lacrosse and swimming as often as he can.

“We’ve only found the best at Golisano Children’s Hospital,” Eaton said. “The doctors made a point to make sure we were comfortable, whether it meant arranging a room with an extra bed or two, so we could be right there with Tim, or kidding around with him to make him feel comfortable, poking his nose with a stethoscope to examine him for ‘nose-itis.’”

It’s true family-centered care, she said, “and it was only 10 minutes away from our home, virtually in our backyard. You really couldn’t ask for much more.”

## Jude Byrne

*Continued from page 11*

enduring the tough times when things weren’t going so well and celebrating the successes as they came,” said Tim Stevens, M.D., M.P.H., the NICU’s medical director. “Jude’s health is a miracle we’ll share with the Byrne family forever.”

Today, Jude jumps, runs and is extremely active. “He and his brother Brendan are great buddies, and they read and play together,” Woodlock said. “He still receives speech therapy, and still battles some sensory issues, but there are none of the looming challenges we were so worried about.”

Roach, known to Jude and his family as “Auntie Val,” is now Jude’s honorary godmother.





## Our sponsors' balloons take us to new heights

They serve flapjacks, sell dream homes, twist pretzels and more, but the common thread knit between the diverse businesses and groups below is that they love Rochester's kids and want to keep them healthy.

As Children's Miracle Network sponsors, many of them are at it again this spring, selling our orange-and-yellow CMN balloons for only \$1 each. These balloons, paired with our sponsors' other creative fundraising tactics, really add up, too: over the past year, our CMN sponsors have raised more than \$345,780!

Best of all, since the hallmark of the CMN organization is that all money stays to work locally in the community in which it's raised, your faithful support of their charitable endeavors is benefiting kids right here at Golisano Children's Hospital at Strong.

### A heartfelt thanks to CMN sponsors

Ace Hardware Corp.	IHOP Corp.
The American Legion	Kinney Drugs
Auntie Anne's	Kiwanis & Key Club
Blockbuster	Laidlaw Transit, Inc.
Coca-Cola North America	Marriott
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Eckerd Pharmacy	Rite Aid Corporation
Golf Galaxy	Sam's Club
The Hershey Company	Sunoco
HMSHost	Wal-Mart
Foresters	

### Wal-Mart rings in 20 years of partnership

As longstanding sponsors, our local Wal-Mart stores have proven stalwart partners, raising more than \$1.3 million to support the region's only children's hospital since they came on board in 1991. Most impressively, most of that was raised only a dollar at a time, and giving has ramped up in recent years—making it clear that customers and Wal-Mart employees alike are working harder than ever for the sake of children. Nearly half of these dollars were raised in the past four years!

On a national scope, Wal-Mart celebrates 20 years of partnering with children's hospitals across the country.



Brenda Sandy, of Kinney Drugs, is helping to change lives in Canandaigua.



Asha Lawhorn and Kathy Cushman smile, representing Auntie Anne's Pretzel's at Eastview Mall and their strong wall of support.



Rebecca List and Liza Eider, of Canandaigua Wal-Mart, help kids.

## Upcoming events

### June 2–3, Miracle Weekend (10NBC Telethon and annual Stroll for Strong Kids)

Tune into 10NBC's annual Telethon on Saturday and Sunday evening to raise money for Golisano Children's Hospital at Strong. On Saturday, join in the fun at the 11th annual Stroll for Strong Kids at Genesee Valley Park, Rochester. For more information on either event, call (585) 273-5948.

### June 21–24, 8th annual The Drive for Miracles Radiothon

Tune in to 100.5 The Drive as we broadcast live from the Strong Memorial Hospital Lobby Thursday, June 21 and Friday, June 22, and from Eastview Mall on Saturday, June 23 and Sunday, June 24. For more information or to learn about sponsorship opportunities, call Betsy Findlay at (585) 273-5933 or Angela Pullen at (585) 273-5937.

**June 30, High Fidelity Summer Band Jam,** High Fidelity (formerly Milestones). Join Mommies for Miracles as they help to raise funds for Golisano Children's Hospital at Strong with this summertime concert, 5 p.m. to 1 a.m. Admission is \$10 and includes a free drink token. To learn more, call Jill Orologio at (585) 507-5367.

**July 28, 18th annual Ten Ugly Men Festival,** Genesee Valley Park, Rochester. Ready to have some fun and support Golisano Children's Hospital at the same time? Venture out to the TUM Festival from 11 a.m. to 8 p.m. for some serious dodgeball, bocce ball and kickball tournaments—not to mention a 5K Race. Visit [www.tenuglymen.com](http://www.tenuglymen.com) for more information or to purchase tickets. To volunteer, call Karen Eisenberg at (585) 273-1462 or Linda Dirksen at (585) 273-5939.

**Aug. 6: Tim Milgate Charity Golf Tournament,** Deerfield Country Club, call (585) 352-6543.

**July 17: Otter Lodge Golf Tournament** Victor Hills, call Darren Cummings at (585) 747-2501.

**Aug. 25, 3rd annual Fairport Music and Food Festival,** Fairport Junction Canal Area. Tempt your taste buds and hear tunes at this all-day festival, featuring multiple bands, kids' activities, karaoke, a smorgasbord of Fairport foods. Learn more by visiting [www.fairport-musicfest.com](http://www.fairport-musicfest.com).

**Sept. 10, 11th Annual Golisano Children's Hospital Golf Classic,** at Monroe Golf Club, Irondequoit C.C., Ravenwood Greystone Golf Clubs with dinner following golf at Monroe Golf Club. For more information, call (585) 273-5948 or [www.gchas.org](http://www.gchas.org).



## 'An Evening of Wine and Wishes' Raises Glasses, Funds

"An Evening of Wine and Wishes," the first black-tie benefit for the Neonatal Intensive Care Unit at Golisano Children's Hospital at Strong, celebrated the tiniest, neediest premature and newborn babies in the Finger Lakes region. Together, we raised funds, awareness and even wine glasses to support their special care needs March 3 at Artisan Works.

The evening paired wine tasting from several Finger Lakes wineries, hors d'oeuvres, dessert, a silent auction and jazz music together with emotional video footage, portraiture and speeches.

Together, we raised \$40,000—enough to purchase an additional Giraffe bed, the most advanced incubator available. Giraffe beds create unsurpassed thermal heating environments and include special features,



Board member Al Chesonis, and wife, Amy, sample a wine up for bid.

including a Lazy Susan style mattress that rotates 360 degrees, a built-in scale and more access portholes, which reduce all the need to disturb delicate babies while administering care.

You can continue helping to support the purchase of additional Giraffe beds

by purchasing a fundraising t-shirt from Doodle Bugs! Children's Centers. Learn more at [www.gchas.org](http://www.gchas.org).



# Special Thanks

*Many thanks to all of these groups and the countless others that continue to support our region's only children's hospital!*

- The 3rd annual Cycle for Hope on Feb. 3 was held at Penfield Racquet and Fitness Club, The Iron Butterfly, Midtown Athletic Club, Rochester Athletic Club, Flex Gym, Gold's Gym, PHA Fitness Club and World Gym, and raised more than \$19,000 for Golisano Children's Hospital and Camp Good Days and Special Times!
- The 5th annual Ski Invitational, held Feb. 5 at Bristol Mountain and organized by Paul Tesson, raised \$28,000!
- Paychex held a Super Bowl party and raised \$510 for Golisano Children's Hospital!
- East Irondequoit Middle School held their annual "Break a Rule" fundraiser and raised \$836 for the kids at Golisano Children's Hospital!
- Kudos to LeRoy Hearth and Home who held an open house and donated \$124 from their 50/50 raffle to Golisano Children's Hospital.
- Elim Baptist Church in Lima raised \$1,250 for the NICU from their Ladies Holiday Brunch.
- Pactiv Corp. raised \$81 from their "Biggest Loser" fundraiser.
- Area Tim Hortons stores sold their double-sized chocolate chip Smile Cookies, raising \$6,000 for the region's only children's hospital.
- Melinda Farina organized a "Fluff and Stuff" party for the children in the hospital on Feb. 16 in memory of her classmate Shari Alent.
- Two local IHOP restaurants participated

in the National Pancake Day Celebration. The stores gave away free short stacks to customers, who in turn responded generously, and donated \$2,100 to Golisano Children's Hospital.

- The University of Rochester Medical School's class of 2010 raised \$264 for our Child Life department.
- Congratulations to Martha Brown Middle School in Fairport. The school held its 3rd annual Kid-2-Kid fundraiser on March 15 and 16—a dance marathon, which raised more than \$17,000 for Golisano Children's Hospital!
- Peter Ryan, an eighth grade student at Sienna Catholic Academy, sold candy hearts to his classmates for Valentine's Day and raised \$500!
- ADT Security Services held a fundraiser for Golisano Children's Hospital and raised \$386.
- The 34th annual Brockport High School Leukemia Dance Marathon raised \$15,391 for Leukemia Research currently underway at the children's hospital.
- The 5th annual Taylor Brush Memorial Dinner Dance was held on March 10 at the Diplomat Banquet Center and raised \$5,800 for the NICU! Thank you to Tim and Jen Brush for organizing this!
- Geneseo Youth Hockey League held their annual shoot out fundraiser and raised an astounding \$12,075 for Golisano Children's Hospital!
- Thank you to Craig Charron for organizing

the 2nd annual Sabres vs. Amerks Alumni Game on March 25 at the Blue Cross Arena. The event raised more than \$4,000 for Golisano Children's Hospital! Thank you!

- Thaddeus Mack organized a Toast and Roast birthday celebration on March 25 and raised \$2,600 for Golisano Children's Hospital.
- Fleet Feet's 15K Spring Forward race held on April 1 donated \$1 from every race entry to Golisano Children's Hospital.
- Dave Hill, bartender at Spikes Bar on Monroe Avenue, held a "Monroe Avenue Cares for Kids" fundraiser April 6 and donated all of his tips back to Golisano Children's Hospital. Thanks, Dave!
- The 5th annual Talent for Tots and Teens, organized by Ida Wheeler, was held on Friday, April 20 and raised \$2,231. All proceeds benefited Golisano Children's Hospital.
- Mud About You, a new paint-your-own-pottery spot in Penfield, held its grand opening in May and proceeds from the night were donated to Golisano Children's Hospital.
- Throughout the entire month of May, Amanda Padgham Photography donated a percentage of sales to Golisano Children's Hospital!



## Support from the Senator, Kiwanians

Senator Jim Alesi (R-Perinton) and his fellow Penfield-Perinton Kiwanians showed support for Golisano Children's Hospital in March at a special luncheon. Together with the club, Alesi secured and presented a \$12,500 check to be used for the William and Mildred Levine Pediatric Surgical Suite, which opened to patients in July.

The surgical suite continues to provide a brand of child- and family-friendly care that has revolutionized the surgical experience—making procedures less daunting and more comfortable for children that need them.



**GOLISANO  
CHILDREN'S  
HOSPITAL  
AT STRONG**

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Non-profit

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