STRONG KIDS NEWS

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

FEATURED STORIES:

Miracle Kid Hallie Engebrecht

Miracle Weekend on the way

Sat., May 31

Sun., June 1

If the African proverb is true, and it takes a village to raise a child, then the corollary must apply, too.

It takes a whole community to make a child healthy.

The first weekend in June — or Miracle Weekend — celebrates this cooperative, curative spirit by sharing miraculous stories of families, medical experts and donors uniting to heal kids.

An infant returns home after a life-threatening head injury. A 3-week-old baby takes his first breath on his own. A preschooler finishes the last of three surgeries to rebuild her heart. A teenager, after a brush with bleeding to death, gussies up for her prom. A two-year-old battling a rare brain tumor hears the magic word "remission." A one-year-old, desperate for a new liver, receives one in time for Christmas Eve.

Known as our Miracle Kids, this issue of our newsletter shares the heart-wrenching stories of six fearless children, their supportive families and their dedicated pediatricians, nurses and specialists.

And, of course, some of the biggest players in these kids' stories — though often behind the scenes — are our faithful donors and fundraisers. In fact, to specially celebrate such "Miracle Makers," we've profiled a few in this issue *(see pages 10 and 11)*.

We look forward to celebrating our

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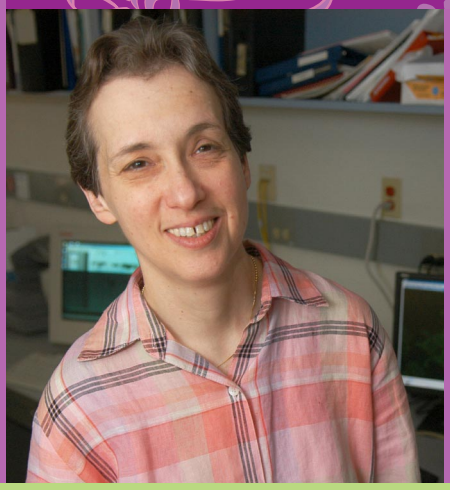

Dear Friends —

This issue of our newsletter celebrates our miracles. Miracles that could not have happened without all of you. Children and families who placed their fates in our hands and won their battles.

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Corporations and individuals who spontaneously made an investment in this community and the welfare of its youngest members without certainty of direct return on their dollar. Healthcare workers who dedicate their lives to ensuring that "medicine of the highest order" makes it all the way down the road to our smallest and youngest treasures. These are truly miracles worthy of celebration.

But for every miracle, there is a mile more we have to go. For every "good" in our portfolio, there is a "great" yet to be attained. We owe our children and their families nothing less. We cannot rest while 15 percent of children in Monroe County are obese. We cannot rest while the most severe asthma exacerbations requiring hospitalization occur in children under 24 months of age who live in inner cities like Rochester. And so we at Golisano Children's Hospital at Strong are partnering with community organizations to launch an obesity prevention and treatment initiative. We are working with regional and national organizations to stop cigarette smoking in homes around the state and country. We are developing novel ways to perform bone marrow transplants in children with cancer, to diagnose, follow, and treat complex genetic diseases that destroy children's nervous systems, and to combat infections that occur in children with abnormal immune systems.

As Senator Clinton once wrote, and as all of you know, "It takes a village…" None of us could walk this walk alone. Each and every one of you own a piece of our success. And I know that each and every one of you will continue to partner with us as we ensure that all of our children receive the very best care available, not just today, but in the future, too.

Yours truly,

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

Anders Swanson: Youngster fights brain tumor with zest, grace

A year ago in January, 18-month-old Anders Swanson was running up and down Florida shores with his parents, Amy and Garth. It would be the last family vacation before his little brother, Beckett, would be born in mid-spring.

After returning home to Batavia, Amy became aware that something was wrong with young Anders. What had seemed like airsickness — he was vomiting on the plane — didn't ease up when they touched down. And as the month drew on, Anders began shaking and stumbling.

On a Saturday in February, on a hunch, Amy drove Anders to the children's hospital, where doctors ran a battery of tests and came back to Amy with news she never expected: There was a mass in his brain, and they were admitting him immediately.

Later that night, Anders started anti-seizure medications and steroids to help relieve the hydrocephalus, or excess fluid that was putting pressure on his brain. After a biopsy and spinal tap, the Swansons sat down with David Korones, M.D., and Howard Silberstein, M.D. — pediatric oncologist and pediatric neurosurgeon at Golisano Children's Hospital, respectively — for the first of many heart-to-hearts.

Anders had a rare, aggressive brain tumor near the center of his brain, Korones told the Swansons. Called pineoblastoma, the mass was the size of a large gumball.

"They were very honest with us," Garth said. "Most childhood cancers are curable, but this one would be an uphill battle."

Korones began poring over research publications and tapping colleagues nationwide to synthesize a treatment plan just for Anders: first, a few rounds of intensive chemotherapy to tackle the cancer cells in his brain and spinal fluid; then, radiation to shrink the tumor itself and surgery to remove it; and finally, two more sessions of strong chemo-

therapy, this time, paired with a technique called "stem cell rescue" (Anders' own blood stem cells, harvested at the beginning of treatment, would strengthen him later on).

A week after his biopsy, Anders was discharged home to rest up, but he was only home a day before fever struck — rotavirus, a staph infection and thrush brought a triple-threat, landing him back in the hospital for a six-week stay, during which he began treatment.

"It was really rocky. He's a powerhouse of a kid, but suddenly he was only wanting to be held, too sick to even eat. He fell from 27 pounds to 20; at points he was even fed intravenously," Amy remembered.

Thankfully, the second and third rounds of chemotherapy went more smoothly. Soon, it came time for "conformal radiation." This high-tech procedure uses computer simulation to construct an image of a tumor, then shapes beams to the exact contours of the treatment area, sparing healthy tissue and minimizing risk for long-term cognitive effects.

Soon the tumor had shrunk enough so that, now four months along in his treatment plan, surgery had become feasible. Again, Anders came through with strength, and Silberstein was able to excavate at least 90 percent of the tumor.

Days later, Amy delivered Beckett. Anders' doctors came down to congratulate the Swansons on their second baby,

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Anders Swanson with his family.

Hallie Engebrecht: Baby receives liver in the nick of time

Victor residents Jodi and Jeff Engebrecht knew their daughter, Hallie, was small for her age — at 2 months old, she only placed in the 25th percentile on the weight charts. Up to that point, Hallie's pediatrician had thought the problem — failure to thrive — likely stemmed from nursing complications.

However, the Engebrechts soon learned something more was at work.

"At her 2-month checkup, Hallie's doctor saw her eyes were turning yellow," Engebrecht said.

Alarmed, Jeffrey Eisenberg, M.D., of Fairport Pediatrics, ordered tests and blood work to be done; the results pointed to Hallie suffering from biliary atresia, a condition in which her liver held onto bile rather than drained it. Without the help of the bile, her small intestine could not digest fat the way it should and, if untreated, might lead to liver damage and cirrhosis.

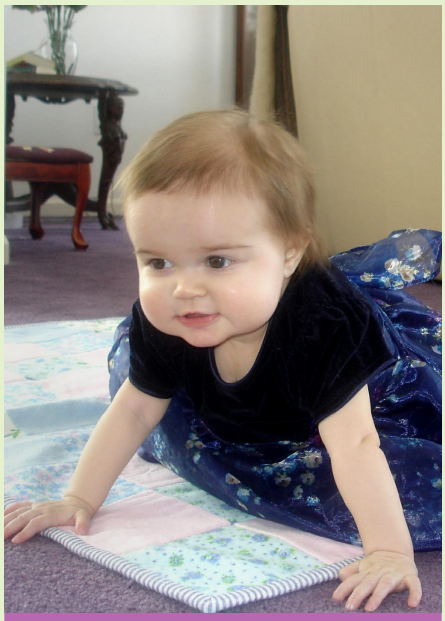
Hallie was immediately admitted into Golisano Children's Hospital, where she underwent a surgery called the Kasai procedure to create artificial bile (drainage) ducts from her liver to her intestine. Surgeons also removed her gall bladder and appendix and fixed a malrotation of her intestine (if a normal intestine made an 'S' shape, Hallie's made a backwards 'S').

But Hallie wasn't out of the woods: six days later, she suffered a bowel obstruction, needing more surgery.

"The recovery after the second surgery was the hardest for all of us," Engebrecht said. "She had acute problems with her blood pressure afterward, and she recovered so much slower than she had the first time. Still, the intensive care team answered all our questions, assuring us they had a plan for her."

Hallie left the hospital May 7, knowing that the Kasai procedure would only buy time — no one could tell how long it might help.

"She was home, gaining weight, for about two and a half months," Engebrecht said. "But in the middle of July, she turned yellow again."



Hallie Engebrecht

A couple of weeks later, Hallie returned to the hospital with high fever and her stomach abnormally protruded with fluids from her failing liver.

On August 2, her name went on the top of the liver transplant list.

"Nationally, there are only 400 to 500 kids on that list. It isn't that common for pediatric patients to have liver problems, so when they do, they are given priority," said Adel Bozorgzadeh, M.D., director of transplant services at Strong Memorial Hospital and Hallie's transplant surgeon.

Jeff and Jodi had their livers screened as possible matches for their daughter, but both were too large to transplant into little Hallie's body. Their 19-year-old son Kyle had a successful screening, but due to the intensity of the surgery and recovery, Bozorgzadeh suggested Kyle only be a last resort.

While the family waited for an alternative liver, they controlled Hallie's digestive troubles with medications. She was uncomfortable, but her liver functioned enough to keep her going.

"She was on a lot of Motrin," Engebrecht said. "And we always knew when she was due for another dose. She wasn't eating well and she wasn't gaining weight because her liver was getting big and hard, which made it hard for her to fill her stomach up."

Finally, relief for baby Hallie came. On December 2 — exactly four months after she went on the donor list — she had a liver transplant.

"On the night I found out there was a liver available, I flew on a small plane, in a snow storm, to New York City, to retrieve it," Bozorgzadeh said. "I came back to operate immediately. It was tiring, a real marathon session, but I'd do it 100 times every day, if I could."

On Christmas Eve, Hallie returned home.

"She's our family's Christmas miracle," Engebrecht said.

She and her husband speak highly of the team of doctors and nurses at Golisano Children's Hospital.

"I just can't express how terrific they are," she said. "Everyone was so warm and caring, they really loved Hallie. The nurses gave her Christmas gifts, and even I got lots of hugs. And Dr. Bozorgzadeh — he's my hero."

The admiration is mutual; Bozorgzadeh keeps pictures of Hallie on his cell phone.

"This is one of the joys of coming to work," he said. "I run into angels like Hallie, I meet such committed families like hers."

Today, Hallie is thriving. Thanks to a physical therapist, she is learning to crawl. She returns to the hospital every week for blood work, and to see Bozorgzadeh twice a month.

"She knows everyone. The nurses come over to say hi to her, and she's all smiles," Engebrect said.

That kind of courage is remarkable. As Bozorgzadeh put it best, "Hallie is the essence of what miracles are about."

Jack Albanese: Infant heals after life-threatening fall

One chilly weekday morning last December, Rochesterians Christyn and Jeff Albanese were juggling getting themselves ready for work with keeping an eye on their bubbly 7-month-old, Jack.

Christyn had set Jack down on her bed, boosted by a Boppy pillow and outfitted with a couple favorite toys. Turning around for brief moment to thread cuff links through her blouse, she heard a thud.

"That noise has replayed a million times in my mind," she said.

Jack was laying face-down on the floor, crying. She scooped him up, and he began nuzzling into her arms, whimpering; only his cry wasn't fierce enough.

"It wasn't the howl you'd expect," she said.

In no time, the couple brought Jack to see Laura Price, M.D., a pediatrician at Pathway Pediatrics, in Rochester, and a former chief resident at Golisano Children's Hospital. Price had treated Jack for an ear infection just the week before, and was shocked to see the lively boy now behaving like a rag doll.

Price told the couple that she would phone ahead while they took him straight to the children's hospital; within 15 minutes, Jack was having his first CT scan. Though it showed a small bleed, his actions hinted more was at stake — he couldn't hold his head up, and he wasn't getting enough oxygen.

"Doctors inserted a breathing tube, and panic hit us," Albanese said.

Thankfully, successive tests soon shed more light on Jack's condition — a dye used in the scan was seeping out of the blood vessels, suggesting that the vertebral artery, near the base of the brain, had torn.

Lucky for Jack, that particular artery has a "spare" of sorts. If part is damaged, the blood can be rerouted through a new course, posing little to no trouble later in life.

But two hurdles needed to be cleared first — and fast. Jack needed a tube to help drain excess fluid away, so pressure didn't mount inside his skull. And, to help clot the bleeding, interventional radiologists would have to thread a catheter through his artery — sacrificing part of it, and directing blood along the "spare" route instead.

Jack Albanese

"With a baby like Jack, this is all a delicate balancing act," said Jonathan Mink, M.D., chief of Child Neurology at Strong and one of Jack's specialists.

Thankfully, both interventions worked; the bleeding stopped later that night, and the inner-skull pressure eased. But more obstacles loomed — especially the risk of vessel spasms, in which blood that leaks outside the arteries can irritate vessels and potentially trigger stroke. After a short honeymoon period, these spasms could onset within four to 14 days.

"We watched Jack like a hawk," Albanese said.

On his fifth day, a grand mal seizure shook him for eight minutes.

"I remember the hopelessness of waiting that out," she said. "Every time we were warned that Jack 'wasn't out of the woods' was a kick in the stomach. But we needed this honesty."

After beginning medicines to help ward off the vessel spasms and seizures, another question rose: whether or not Jack could live without a permanent shunt.

"Sometimes, after injury, children are able to begin absorbing and draining their own brain-spinal fluids — and sometimes, we have to implant a shunt to help," Mink said.

After a few days of careful monitoring, doctors realized Jack's case was one of the latter; they installed a valve inside that helps him send fluids to other parts of his body.

Meanwhile, Christyn's mom had

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Fahris Wyand: Five-year-old proves she has courage, heart

Five years ago in May, Brenda and Kevin Wyand of Bloomfield gave birth to their second baby girl.

"I kept repeating, 'Is she perfect?' over and over," Brenda remembered. "I was hoping for 10 fingers, 10 toes. Never did I imagine that she could not have a perfect heart."

But that's exactly what the Wyands soon learned. Only moments later, a nurse at FF Thompson Hospital in Canandaigua noticed that newborn Fahris was slightly blue — a clue that her heart was not delivering the oxygen her body needed.

In a whirlwind, Fahris was transported to Golisano Children's Hospital, where she was diagnosed with constellation of heart defects — hypoplastic right ventricle (an underdeveloped right side of the heart, resulting in inadequate blood to the lungs, and thus in Fahris' blue coloring), hypoplastic pulmonary arteries (underdeveloped heart arteries that bring blood to the lungs), and total anomolous pulmonary venous return (oxygenated blood is returned to the wrong side of the heart, overworking the heart and depriving the rest of the body of oxygen).

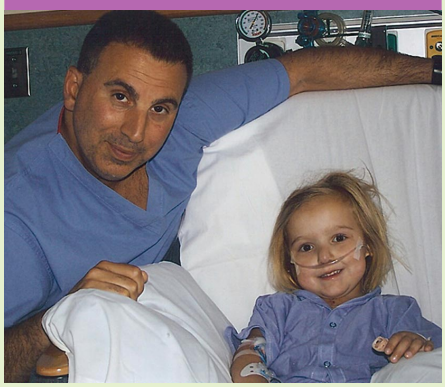
"Essentially, she had only half a functioning heart," said George Alfieris, M.D., director of Pediatric Cardiac Surgery at Golisano Children's Hospital at Strong, and one of New York's busiest pediatric heart surgeons. "The stress on her heart was incompatible with life, so our first goal was to ease it and stablize her. Then she could go home, grow and prepare for two more major heart surgeries she'd undergo before the age of 5."

Alfieris performed the initial phase of a three-step surgery when Fahris was only 2 weeks old, creating larger pulmonary arteries, reconnecting her pulmonary veins and providing adequate blood to her lungs through an artificial tube. For four weeks, the Wyands made the 40-minute trip to the hospital daily.

"There were stretches when Fahris was probably the sickest child here," Alfieris said. "But her family was vigilant, supporting her at every turn."

When Fahris was 4 months old she underwent the second stage of her open-heart surgeries. Alfieris completed a "Bidirectional Glenn" — a procedure that allows the blood from the head and upper limbs to flow directly to the lungs, bypassing the underdeveloped right ventricle altogether and greatly relieving the strain on the half a heart she had.

Dr. George Alfieris with his miracle patient Fahris Wyand.



Fahris spent two weeks recovering and for the next few years, periodic visits to cardiologists kept her healthy. Last September, when she was a little over four years old, she was stronger — and her veins were large enough — for her final surgery, the "Fontan." Alfieris connected the large blood vessels (which are normally attached to the heart) directly to the lungs.

Fahris spent three weeks in the pediatric ICU, battling pneumonia and healing her rebuilt heart. She spent weeks on a ventilator, and at one point, needed surgery to remove scar tissue that had formed in her lungs and was pocketing fluid, making it even harder for her to breathe.

"I turned to Fahris and asked her, 'How do you stay so brave and strong?'" Wyand said. "And she said 'Mommy, I just take a deep breath in.' Her wisdom stunned me. How could someone so small be so bold?"

In mid-November, after 79 days in the hospital, Fahris was discharged with a chest tube to collect fluids draining from her lungs, a specially inserted home IV (PICC line) and oxygen.

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Michelle Plotzker: Girl proves she's "got guts"

Two years ago, in May, Fairport teen Michelle Plotzker noticed some bleeding in her stool.

It was an off-putting surprise, but Michelle had a good idea of what might be to blame — a rare inflammatory bowel disease called ulcerative colitis, that, in part genetic, had already needled its way into her family tree.

Later that summer, tests confirmed that 16-year-old Michelle indeed had this type of colitis, which causes open sores in her large intestine and colon, making certain foods extremely painful to digest.

"With the worst flare ups, I would only be able to stomach Rice Krispies and chicken soup," Michelle said.

Since ulcerative colitis — much like its cousin sickness, Crohn's disease — brings a rollercoaster of periodic flare up and remission, Plotzker and her parents, John and Cindy, hoped that a medication might help manage it. Michelle tried that route for a while, playing varsity volleyball and beginning a course of oral steroids diagnosed by her pediatric gastroenterologist at Strong, Thomas Rossi, M.D.

"For a stretch, that was enough," Michelle said.

But by the first of November, the steroids weren't enough anymore; Michelle became unusually sick and so severely dehydrated, she was admitted to Golisano Children's Hospital. There, specialists tried a steroid enema, hoping that it would be more effective than the oral medications and bring the disease back under control.

But that didn't work, either. Nor did Remicade, an advanced infusion treatment hailed for stalling the disease and reducing pain. By then, Michelle had lost 25 pounds and was suffering intractable bleeding that, without intervention, could ultimately lead to death.

Transfusions sustained Michelle for some time, but they weren't a permanent solution. So, after much

counsel and 34 days of test-driving treatments, Michelle decided to forgo a chemotherapy drug (her last non-invasive resort) and get straight on with surgery to remove her colon.

"I wanted to be better," she said. "I had missed my Thanksgiving dinner and my grandmother's peanut butter chocolate pie."

Decided on this course, Walter Pegoli, Jr., M.D., pediatric Surgeon-in-chief at Golisano Children's Hospital at Strong, met with Michelle and her family to explain what would happen. First, he would remove Michelle's colon, and temporarily bring her small intestine through her abdominal wall while she healed. Then, two follow-up surgeries the following summer, would reconnect her intestine to her anus.

"A nurse told me to bring in my favorite pair of jeans, and we'd decide where we wanted this all to happen," Michelle said. "And after a make-believe run through on a pillow, I was as ready as I could be."

Michelle's surgery on Dec. 4 went smoothly. Soon after, she was feeling better, though sore.

Four days later, she was home, celebrating a make-up Thanksgiving and finally able to relish bits of everything for the first time in months. Come January, she was back to school and getting on with traditional teenage fare — prom, dizzying college decisions, and her spring sport, softball.

Finally, last summer, after Michelle sailed through her two follow-up surgeries, she was declared cured.

"As an adolescent, Michelle's maturity and grace is beyond her years. To come through such a stressful period of her life with such humor, such spirit — that makes her a miracle," Pegoli said.

Michelle, always on the move, lives life full-tilt — she's an Explorer program volunteer at the fire department, holds down a part-time job and plays two sports each year. She enjoys science, and is considering a career in veterinary medicine or zoology.

She's also found a way to thank the hospital that helped heal her; unashamed of her scars, she coaches other kids through similar procedures.

"I tell them it's going to be okay. If I can make them just a fraction less scared, I've done something," she said.

Mason Mitchell: Baby diagnosed in-utero beats odds and won't stop smiling

Mason Mitchell with his dad, Scott Mitchell.

In December 2006, Webster residents Despina and Scott Mitchell set off to a prenatal appointment, excited to learn if they were having a boy or a girl.

But the mid-point ultrasound showed something they didn't expect—a black mass on the screen hinted that their baby son would be born with a congenital diaphragmatic hernia, or CDH. Only 1 in 3,000 newborns are born with this defect, which has a forbidding survival rate of only 50 percent.

Thomas McNanley, M.D., an associate professor of Obstetrics and Gynecology at the University of Rochester Medical Center, who specializes in obstetric testing at the University's affiliate, Highland Hospital, explained to the couple that their son, Mason, would be born with a hole is his diaphragm—the sheet of muscle just below the lungs. To live, Mason would need surgery soon after being born.

"That hole had allowed Mason's organs to drift up into his chest, squeezing on his lungs and keeping them from growing," Despina Mitchell said.

After testing to make sure nothing else was awry, McNanley sent the Mitchells to meet Timothy Stevens, M.D., M.P.H., a neonatologist who directs the Neonatal Intensive Care Unit at Golisano Children's Hospital at Strong.

"Dr. Stevens toured us through the NICU, comforting us, but not sugar coating anything," Mitchell said.

The couple braced themselves for the very real chance that, even with every medical intervention available, Mason might not survive.

"We waited to paint the nursery," Mitchell said.

Three days after he was born, Mason was put on ECMO, a heart-lung machine that helped deliver the oxygen his body needed. Nine days later, he underwent surgery to place his liver, stomach, spleen and intestines back where they belonged.

It seemed to be a success, and two days later, he was taken off ECMO.

But for two weeks, Mason still struggled to wean off intensive breathing support. It wasn't until June 2—the day of the hospital's annual Children's Miracle Network telethon—that he achieved freedom.

"They announced during the broadcast, that 'Mason Mitchell is finally, for the first time in his life, breathing on his own,'" Mitchell said.

Mason continued to improve. He practiced feeding, phased off pain relievers and on July 3, he headed home from his 56-day stay.

But a few months later, Mason began vomitting and Mitchell's mommy-radar sensed something was wrong.

The couple brought Mason back in, learning that his scar tissue had caused a bowel obstruction—a slight risk from the initial surgery. Mason underwent his second operation, spending another two weeks in the hospital, struggling to regain weight he'd lost.

In December, after he'd been home again for little more than a month, Mason coughed in a way that again piqued Despina's concern.

She was right. An X-ray showed that something extremely rare had happened: Mason's diaphragm patch, along with the patch in his abdomen that held his organs in place, had both dissolved, causing him to re-herniate. Now an expert in hospitalization and healing, Mason would spend just five days recovering after a double-duty surgery to mend both tears.

A little more than a week before Christmas, Mason headed home, whole. Thankfully, he has been healthy since.

"Holding him in our arms was the best gift imaginable," Mitchell said.

The Mitchells, eager to make the NICU a more welcoming place for other parents, have raised $8,300 toward renovating the unit's parent waiting room.

Despina has also plugged into an online support group for parents of children with CDH, called Breath of Hope, Inc. Her dream is to develop a network of her own, providing access to experts, information on the best therapies and the latest research.

Miracle Weekend

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joint successes with them, with you, and with the so many other groups who have been instrumental in transforming this hospital into a place where miracles can happen daily.

We hope many of you will join us to commemorate the strides we've made together by marking your calendars for the Miracle Weekend festivities mentioned at right. Again, thank you for all you do to support the children whose journeys fill these pages — and the so many others whose stories are too many to tell.

25th Children's Miracle Network Telethon on News 10NBC
presented by Perkins Restaurants

We're proud to present our annual CMN telethon, which broadcasts live from the Strong Memorial Hospital lobby, 10 a.m. to 1 p.m., and 7 to 11 p.m., Sunday, June 1.

The telethon is a platform for children and their families — our six Miracle Kids, of course, but plenty of others, too — to share their stories of trials turned triumph at Golisano Children's Hospital at Strong.

To make a pledge during the event, please dial (585) 241-KIDS, or log on to *www.gchas.org* and make a gift electronically.

12th annual Stroll for Strong Kids
presented by JPMorgan Chase

Our annual Stroll for Strong Kids is guaranteed fun — rain or shine!

The morning kicks off at 9 a.m. Saturday, May 31, and supercharges your weekend with family fun, including clowns, inflatable play sets, kids crafts and costumed characters.

Later on, a walk through Genesee Valley Park ends with free Subway sandwiches and dance-worthy tunes from Gary the Happy Pirate.

To learn how you or a team of friends can sign up — or how you can make an online donation in support of your favorite Stroll team — visit *www.gchas.org* or call (585) 273-5948.

Anders Swanson

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and a few days later, the whole family was discharged together.

Anders' treatment continued smoothly, finishing with final rounds of the chemotherapy, now with the "stem cell rescue" to give him extra vigor.

Finally, in mid-September last year —after a seven month whirlwind of every cancer-blasting weapon imaginable—Anders was declared cancer-free. He is still being monitored on a fairly regular basis, but he continues to enjoy waking up in the wee morning hours to eat "beegles and wiffles" for breakfast. Every morning he looks forward to sending cell-phone videos back and forth to his Grandma and Umpa (Grandpa) in Florida.

In addition to his team at Strong, Anders is also receiving great care from his Rochester-based pediatrician, Molly Hughes, M.D., who works at Westside Pediatrics in Gates. Hughes has taken on an incredible advocacy role for Anders and his special health needs.

"Anders is a miracle—he's the kind of kid that screams almost everything he says, just bursting with joy," Korones said. "But I suppose it is in part genetic, because his parents are just as special."

Jack Albanese

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friends spreading the word; prayer chains were taking root internationally, and they seemed to be helping.

"Jack was babbling, and his strength was returning," Albanese said

Three days after shunt surgery, Jack was cleared to go home. The family packed piles of get-well cards, a zoo's-worth of stuffed animals, and even a miniature Christmas tree from Jeff's parents (both sets of grandparents had come bearing gifts and food, determined to not let Jack's first holiday get lost in the shuffle).

"What a joy it was to send him home after a potentially life-threatening injury, knowing that everyone else would see him as just another healthy baby," Mink said. "We'll follow up with him, but we have good reason to believe he'll go on to live a full, regular life."

Just weeks later, Jack was back to being an 8-month-old wiggle-worm — grabbing at things, eating voraciously, acting so curious, so alert, that it was almost as if he were trying to make up for the month he had missed.

His parents are overjoyed to see their little boy back to his old, nosy self.

Fahris Wyand

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Just before Christmas, she spent three days in the hospital battling an infection in her PICC line — both that line and her chest tube were soon removed. After that, she began returning weekly or bi-weekly to have fluid removed from her lungs.

"Her heart is growing stronger, but this marathon of surgeries was draining. We still rely on other's people's strength — our friends, our nurses, our doctors," Wyand said. "Everyone at the hospital — even the housekeepers — is rooting for her."

Today, Fahris has good days and hard days. On the good ones, she catches frogs in the creek behind her house with her older sister, Morgan, or pieces together puzzles, or colors.

"She's outgoing and likes to explore," Wyand said. "She's so joyful. In spite of everything, she soldiers on, knowing nothing different. She's quite matter-of-fact about all of this, telling us it is worth it — 'It's going to help my heart boo-boo,' she reminds us."

Alfieris is also optimistic that better days await Fahris. "We're hopeful that soon, she'll be able to live an active childhood and a full life," he said.

Miracle Maker Awards

Each year, countless individuals, businesses and organizations champion the needs of Golisano Children's Hospital at Strong. In an effort to spotlight some of our most devoted supporters, we have a tradition of choosing "Miracle Makers" who have made creative and passionate strides for children here.

Hammer Packaging Corporation: Helping Spread the Word

Outstanding Commitment by a Corporation

The annual Gala hosted by Golisano Children's Hospital at Strong requires careful planning and an extensive network of friends in order to make it as smooth-running as possible. An important part of the behind-the-scenes work is sending out invitations, and thanks to Hammer Packaging Corporation, the children's hospital has one less thing to worry about: For the last 10 years, the family-owned company has donated the Gala invitations to Golisano Children's Hospital, as well as "save-the-date" cards and other printed materials for the event.

"We donate those things to support what I consider to be a very important element in the care of children in our area," said Jim Hammer, president and chief executive officer of Hammer Packaging.

The nationally-known, highly-respected packaging printing company has been named a Best Workplace in America by Master Printers of America for the past five years because Hammer's culture is deeply rooted in the fact that "the right people are our most important asset."

People clearly are an important asset to Hammer outside of his work, as well—he is a contributor to many major charity programs throughout Rochester. He supports Golisano Children's Hospital's annual Gala and golf tournament. His wife, Donna, and daughter-in-law, Selma, serve on the planning committee for the Gala, and his son Jason helps to plan the golf tournament, which he attends. Hammer also has two daughters, Lisa and Ashley.

"Children are our future, and I know how important it is to have a talented, reliable facility like Golisano Children's Hospital," Hammer said. "We need to support and capitalize on this valuable and truly important facility."

Philip C. Gelsomino, II: Putting the 'Perk' in 'Perkins'

Outstanding Commitment by an Individual

No matter where Philip Gelsomino's day takes him, he keeps a smile on his face.

A self-proclaimed "people person," Gelsomino has been a vital part of the children's hospital family with his support of the annual Gala and golf tournament, as well as with his purchasing much-needed items from the children's hospital's Wish List, which provides comfort items and medical equipment to patients. He has also purchased two kite sculptures and a bed space for the children's hospital's Pediatric Surgical Suite.

Although he has two children now—daughter Sophia, 9, and son Vincenzo, 2—Gelsomino said his interest in Golisano Children's Hospital began before he became a father. His interest was strengthened later on, when his family found themselves in need of exceptional health care and Golisano Children's Hospital came through.

"The more I found out about the care provided at the children's hospital, the more I wanted to help," he said.

When he is not busy giving back to his community, Gelsomino enjoys traveling "anywhere, whether it's to Phoenix, California, Aruba, Florida or even Buffalo," and spending time with his two children and his wife, Beverly.

"Anywhere is new and exciting for me because every day is a new day," he said.

His positive attitude extends into his workplace, as well. As chief executive officer of The Restaurant Group, LLC, Gelsomino oversees the construction and daily operations of western New York Perkins franchises; this year, Perkins is the presenting sponsor for the 10NBC telethon. Gelsomino's latest contribution is naming a procedure room in the soon-to-be-renovated Pediatric Treatment Center, where kids come to receive chemotherapy, blood transfusions, and many other invasive treatment procedures.

"I view children as our future, and the children's hospital is something that this community should be very proud of," he said. "It's rewarding to be able to have some of the best care in the country right here in our backyard."

Ten Ugly Men: Providing Beautiful Opportunities

Outstanding Commitment by a Community Group

It's been said that when one door closes, another opens; in the case of Ten Ugly Men, it has never been truer. When veteran "Ugly" John Fitzsimmons' first wife passed away from a brain tumor in 2003, the group began donating money to the Bright Eyes Fund, set up for pediatric brain tumor treatment at Golisano Children's Hospital at Strong. To date, the men have raised more than $100,000 for the fund.

"Before, we only gave to one primary charity," Fitzsimmons said. "When my first wife passed away, we made the Bright Eyes Fund a co-beneficiary."

Ten Ugly Men formed in 1989, when a group of Nazareth alumni threw a party for friends and family. Surprised by the turnout, they decided to move the get-together to a park the next year, charge a couple of dollars for refreshments and donate the proceeds to a charity.

"The concept grew exponentially; by its third or fourth year, there were a few hundred people attending," Fitzsimmons said.

This year, the group will celebrate its 19th festival with a toga theme. The games, food, beverage, live music and entertainment for guests of all ages—including sports tournaments in kickball, volleyball, bocce and a 5K run—make the all-day picnic in the park seem more like an over-the-top block party.

"We start planning in February or March," Fitzsimmons said. "We start getting together and seriously making plans in April."

Although the group now has 11 members who are not all Nazareth College alumni, their generous spirit and fun-loving habits are the common bonds of their friendship. The self-proclaimed "Uglies" are original members Michael Hartman and Mark Palvino, as well as Fitzsimmons, Michael Perrotta, Alan Wood, Larry Casey, Brad Quigley, Mike Geisler, Dwight Barksdale, Alan Lagonegro and Kerry Gotham.

This year's festival is set for 11 a.m. to 8 p.m. Saturday, July 26, at Genesee Valley Park. For more information, to purchase a ticket or to donate, visit the Ten Ugly Men Web site at *www.tenuglymen.com.*

Kiwanis: Sharing Talents for 25 Years

Outstanding Commitment by a CMN Sponsor

In the spirit of honoring the generosity of two local volunteer legends, Rochester's Kiwanis Clubs are marking their silver anniversary of supporting Golisano Children's Hospital.

Twenty-five years ago, Jack Harden and Bob Calabrese had a vision of extending their volunteer program to help children through the Children's Miracle Network, a non-profit organization that provides a way for businesses, customers and community groups to rally behind more than 170 children's hospitals across North America.

As members of Kiwanis International—whose name literally means "we share our talents"—it made sense to Harden and Calabrese that Kiwanis groups join the network. Today, their dream has taken firm root. In the last five years, the Genesee and Finger Lakes divisions of Kiwanis have raised more than $100,000 for Golisano Children's Hospital. Their fundraisers include golf tournaments, auctions, raffles and their "Quarter Mile of Quarters" event that took place March 8 at Eastview Mall.

"We reached our goal of $4,000—which equals 16,000 quarters and extends one-quarter of a mile if you line them up," said John Hanratty, Finger Lakes Kiwanis Club coordinator for CMN programs.

In the future, Hanratty said the two divisions hope to coordinate more activities together in order to bring in more money.

Kiwanis have also donated activity bags, books, baby beanies and pizza parties for Golisano Children's Hospital.

"We believe that the future rests with the children. Among the most in need are children who are ill," Hanratty said. "Kiwanis is there to help in any way we can."

Dinner dance fundraiser pushes Team Taylor past $100,000 mark

Stacey Vaccaro, Pam Brunelle, Carrie Moriarty and Jen Brush remember Taylor in a way that helps future NICU patients.

More than 335 guests—including more than 40 members of the NICU staff—braved snow and ice to help celebrate the 6th annual Taylor Brush Dinner Dance, held Saturday evening, March 8, at the River's Edge Restaurant & Party House.

The night brought dinner, DJ tunes, dancing and raffles (a Tahitian peal and diamond necklace and an autographed Buffalo Bills football were up for grabs), garnering more than $9,000 to benefit the NICU at Golisano Children's Hospital at Strong in loving honor of Taylor Brush.

This year's dinner dance pushed "Team Taylor's" total fundraising efforts—a combination of dinner dance proceeds, Stroll for Strong Kids pledges and various other endeavors held throughout the year—past the $100,000 mark.

And it's clear that charity runs deep in the family—Justin Stundtner, one of Jen and Tim Brush's nephews, won $450 from the night's 50-50 raffle; immediately, he decided to donate the funds back to the hospital.

Community Fundraising Round-up

Junior Girl Scout troop helps make NICU cozier In March, Troop 129 made blankets for the NICU at Golisano Children's Hospital at Strong. The blankets are dark colored on one side—so as to simulate the darkness of a mother's womb for the premature babies—and cheery on the other, to help parents identify their baby's area in the busy unit.

Thousands of pennies: a lesson in math, caring Ms. Christina Hartford's third grade class at Village Elementary School, in Hilton, learned a lot more than how to work with numbers in thousands—they learned how their generosity can help kids at Golisano Children's Hospital.

Their class coin collection set out to collect 1,000 pennies and dimes. But, by pouring their heart into the project, these ambitious students stunned their teacher, meeting the goal six times over by gathering more that 6,000 coins—$122.

Knighthawks brighten hospital stay for young fans Rochester Knighthawk Chris Schiller makes big plays both on and off the field for patients at Golisano Children's Hospital. Every home game the lacrosse team plays, Schiller gives his box seats to a young sports fan who is receiving care at the hospital. After the games, he takes the time to meet the patients and their families, give gifts, sign autographs and introduce them to his teammates.

"It's rough to see what these kids go through, but it makes me appreciate what I have even more," he said.

Children's Miracle Network partners keep plugging away

IHOP Pancake Day

Kudos to the short-stack scarfing public — specifically those who ventured out to Rochester's two local IHOP restaurants on Feb. 12, our 2nd National Pancake Day Celebration. The day-long hotcake fundraiser served up hundreds of free pancakes, putting customers in a giving mood. The day raised more than $1,400 in donations to Golisano Children's Hospital at Strong.

Tim Hortons' "Chocolaty Charity" Wildly Successful

Heartfelt thanks to hungry area cookie-monsters who purchased chocolate chip Smile Cookies during Tim Hortons' week-long fundraising effort (Jan. 29 to Feb. 6). Thanks to your sugar cravings, our 27 area stores were able to raise more than $10,000 for Golisano Children's Hospital at Strong.

This brings Tim Hortons' three-year fundraising total to an impressive $21,000.

Wal-Mart Keeps Plugging Away towards Pledge Goal

Our 12 local Wal-Mart and two local Sam's Club stores are among our most fastidious partners; in just a few months, they will close in on the $1 million gift toward the Pediatric Cardiac Intensive Care Unit, a pledge they began in 2002.

Last year alone, their annual fundraising total surpassed $230,000; a sizeable portion was gathered in just four weeks in May (our "Miracle Month"), when employees rallied to raise an impressive $47,217.

"For us at Sam's Club, supporting our Children's Miracle Network hospital is really a reflection of who we are — both as individuals, and as a Sam's Club family," said Daniel Brook, market manager for Rochester-area Sam's Club stores.

"I can't say enough about the hospital and the work it does — I hear about the healing and hope it brings to families all the time," added Tim Bernard, a Rochester-area market manager for Wal-Mart stores. "Between hearing the success stories and touring the corridors first hand, our associates have cultivated meaningful personal relationships both with the hospital and the community we serve."

Dan Meyers of the Waterloo Wal-Mart scans a CMN balloon.

New open MRI scanner puts kids at ease

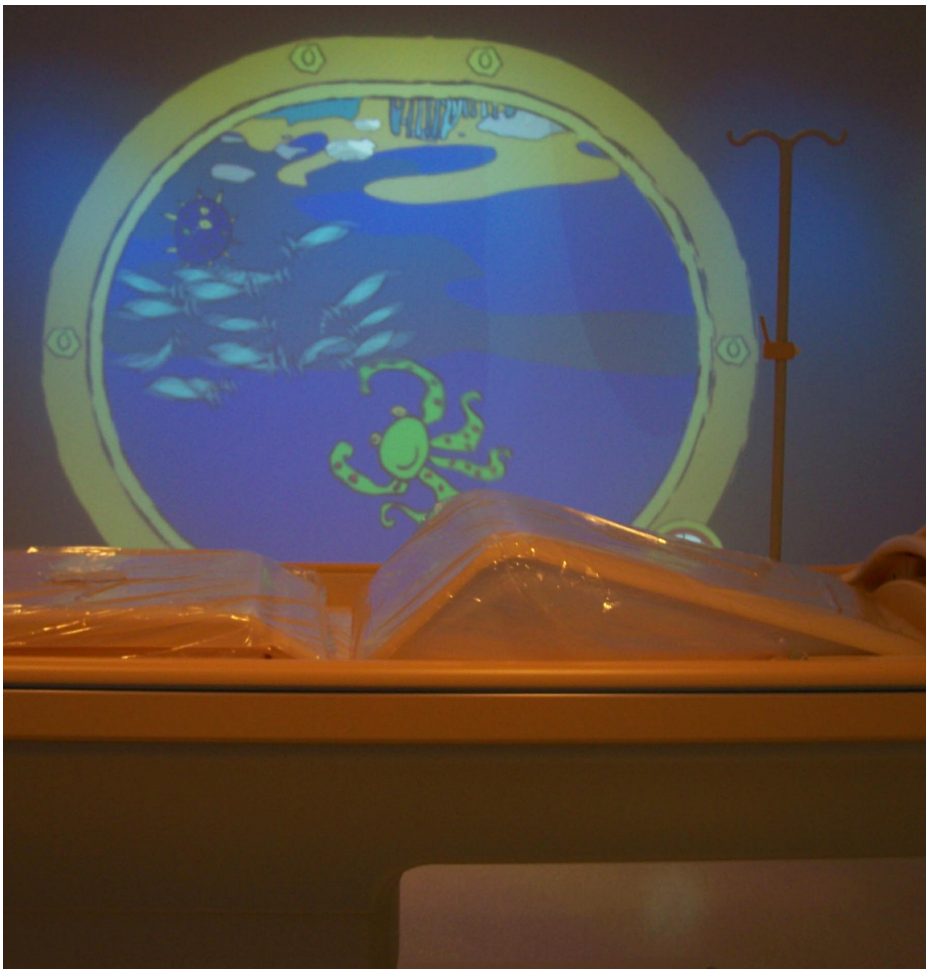
After years of waiting for technological evolution to yield a superior product, Golisano Children's Hospital now has access to the latest in magnetic resonance imaging (MRI) scanners — an open MRI scanner.

This newest addition to the hospital — thanks to the Department of Imaging Sciences at the University of Rochester Medical Center — blends top-notch medical care with superior patient comfort for local children who, each year, rely on more than 2,000 scans to help monitor ailments like seizures, sports-related injuries and childhood cancers.

Conventional MRI scanners consist of a long tube, known as a bore, which is three to five feet long. Patients usually lie on their backs as they slide into the bore through an opening only 19 inches in diameter — a terrifying prospect not only for claustrophobic adults, but also for most children.

However, the open MRI scanner is more physically welcoming than the traditional scanner. The open version resembles a clamshell on top, with open sides around the bore, so as to eliminate nerve-racking snug spaces.

"Aside from a high-quality machine, a successful scan requires patient cooperation," said Connie White, clinical operations director for the university's Department of Imaging Sciences. "Unfortunately, lying perfectly still for up to five minutes at a time for at least 30 minutes can be challenging for kids, especially if they are afraid of the machine."



William Badger, supervisor of clinical laboratories, said, "With the new machine, a parent or other adult may stay in the imaging suite right next to the pediatric patient, maintaining constant physical contact with the child throughout the entire exam.

"We anticipate that the new scanner will reduce the current need to scan pediatric patients under conscious sedation or anesthesia by 20 percent."

This will reduce the overall procedure and recovery time, he added.

But the open design is just part of what makes this new scanner child-friendly. Scans will also include a laser-light show of sorts called the Ambient Experience, a concept invented by Philips Electronics that will go hand-in-hand with the new machine.

Thanks to rounded corners, as well as halo lighting — which will allow patients to choose a color to be reflected around the whole room — the new scanning room will create a calm space for children and their families. It will also include one wall on which technologists can project pictures, and patients can choose the picture — jungle, beach or cartoons, just to name a few.

"The logic behind the Ambient Experience is that if you distract the patient long enough to watch a peaceful scene, it puts them in the right frame of mind going into the scan," White said. "Also, a soothing effect is enhanced further by taking away the sharp corners and bright, fluorescent lighting typical of a hospital room."

White said she anticipates that the scanner will be available to patients this spring.

To learn more about how you can help keep Golisano Children's Hospital up-to-date with the latest high-tech care equipment, please call (585) 273-5948.

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 Rochester Razorsharks Premier Basketball League donated more than $3,000 to purchase outdoor furniture for the play deck at Golisano Children's Hospital. Congratulations to the Razorsharks on a great season.
* Jen and Tim Brush surpassed the $100,000 mark with the 6th annual Taylor Brush Memorial Dinner Dance on March 8. Despite the weather, more than 300 people attended and raised over $9,300 for the NICU. Team Taylor has been raising money for the NICU for six years.
* Students at Brockport High School danced until they dropped March 14 to 15 at the 35th annual Brockport High School Leukemia Dance Marathon. More than 120 students danced for 12 hours and raised $14,000 for leukemia research underway at Golisano Children's Hospital.
* On March 29, Vasisht Srinivasan raised $4,353 for Golisano Children's Hospital at his Strong Spells Magic Show. Vasisht is a current medical student at the University of Rochester Medical Center.
* The 6th annual Talent for Tots & Teens raised $,2716 on April 4. The event, organized by Ida Wheeler, featured dozens of performances.
* The Pittsford Crew team organized an Erg-A-Thon fundraiser at Eastview Mall on April 5. The high-school rowers collected $16,500 in pledges for rowing on stationary machines. Proceeds went to Golisano Children's Hospital.
* Tops Markets organized the 2nd annual Monte Carlo Night on April 12 at Eagle Vale Country Club. This casino-style fundraiser garnered $7,500 for the hospital.

Upcoming events

All of May, Amanda Padgham Photography Fundraising Month. Amanda Padgham, a natural-light child and infant photographer, will donate 10 percent of proceeds from all sales from May sessions to Golisano Children's Hospital at Strong. Don't delay, sessions will book up quickly. Call (585) 764-2341 to capture precious memories of your children while helping other kids, too. To see Amanda's natural light portraiture, visit *www.amandapadghamphotography.com.*

May 31 and June 1, Miracle Weekend (10NBC telethon and annual Stroll for Strong Kids). On Saturday, join in the fun at the 12th annual Stroll for Strong Kids at Genesee Valley Park, Rochester. On Sunday, tune into 10NBC's annual telethon to raise money for Golisano Children's Hospital at Strong. For more information on either event, call (585) 273-5948 or visit *www.gchas.org.*

June 7, 2nd annual "NICU Tile-Painting Party," Flaum Atrium. Back by popular demand, this tile-painting party will benefit the NICU at Golisano Children's Hospital at Strong. Meet with current and "graduate" NICU families who also wish to make their mark in a way that will be permanently displayed outside the unit. For more information, call (585) 273-5948.

June 14, 5th annual Clambake Fundraiser, presented by Team Ali-Gaiters. Join us for this family-fun clambake in honor of Ali Klube, to be held 2 to 7 p.m. Saturday, June 14 at the Honeoye Falls Fireman's Training Grounds on Monroe Street. The day promises live music by Alabye, DJ services by Top Spin, a bouncy house, face painting, costumed characters for the kids, raffles and door prizes. Tickets cost $20 in advance, $25 at the door, and benefit Golisano Children's Hospital at Strong. Children 12 and younger are free. To reserve your ticket in advance or for more information, call (585) 624-4759 or (585) 346-3744.

July 26, 19th 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, bocceball and kickball tournaments—not to mention a 5K race and tunes by the Gin Blossoms. Visit *www.tenuglymen.com* for more information or to purchase tickets. To volunteer, call (585) 273-5948.

Aug. 23, 4th 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, and a smorgasbord of Fairport foods. Learn more by visiting *www.fairportmusicfest.com.*

Golf events

June 5, "Holes for Hope" Golf Tournament (presented by RE/MAX and sister company, Prime Mortgage Corp.)

June 21, 8th annual Screaming Beaver Hockey Club Golf Tournament

June 25, B&L Wholesale Golf Tournament

July 17, 8th annual WNY Optics Golf Tournament

Aug. 4, 9th annual Tim Milgate Golf Tournament

Aug. 4, 6th annual Kittelberger Charity Golf Tournament

Aug. 25, Ed Kaufmann Children's Hospital Classic

For more information on the golf events above, call (585) 273-5948.

Sept. 8, Golisano Children's Hospital Classic. Join us for one of Rochester's largest golf tournaments of the year! We'll start the day with lunch and registration at 11 a.m., and then spread over four area courses – Monroe Golf Club, the Country Club of Rochester, Irondequoit Golf Club and Ravenwood Golf Club – with a shotgun start at 12:15 p.m. Dinner follows at Monroe Golf Club. For additional information, to purchase tickets or to become a sponsor, call (585) 273-5948.

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