UR Medicine's Golisano Children's Hospital

STRONGKIDS NEWS

2016 vol. II

Meet the 2016 Miracle Kids

2016 Miracle Makers | Rita Buzzard gives $2 million | Stroll for Strong Kids preview

Dear Friends —

Every time I write a "Dear Friends" letter for the Strong Kids Newsletter, I search my brain for a word, a phrase, an idea that sums up the content in that issue.

This time, I did not have to search very long! The summative word for this issue of the Newsletter is "community."

We at Golisano Children's Hospital are so very fortunate to have a community around us that shares with us the view that our children are the most important resource our region has and that the roles of a children's hospital in an academic medical center include caring for today's children, improving care through research for tomorrow's children, and training the physicians and scientists who will take over for us in the future. This issue of Strong Kids presents examples of the many children and families for whom we exist; the community leaders and organizations who enable us to do what we do, even when families are unable to pay for care; a superstar physician and researcher who partners with the schools in our community to keep children with asthma out of the hospital and emergency room and in school; and the mother of a Golisano Children's Hospital cardiologist whose generosity honors her daughter and memorializes her late husband. Indeed, we are a community in every sense of that word. And our children and their children will be healthier for it.

Nina F. Schor, M.D., Ph.D.
Pediatrician-in-Chief,
Golisano Children's Hospital,
William H. Eilinger Chair of Pediatrics

2016 Miracle Kids

Every year, Golisano Children's Hospital treats 85,000 children. And every year, a handful of those children defy expectations, fighting long odds to make remarkable gains against their diseases.

In this issue, we spotlight five of those children: Craig Winter, Kinley Severson, Gary Burks, Ryan Stinson, and Daniel Deyo.

Meet the 2016 Miracle Kids.

Miracle Kid

Craig Winter

KIM WINTER PICKED UP THE PHONE. IT WAS A CALL SHE'D BEEN WAITING FOR ALL AFTERNOON. "…I SEE… NO, I JUST KNEW IT. I KNEW SOMETHING WASN'T RIGHT…"

A few hours earlier, she'd waited on the ground floor of Golisano Children's Hospital while her 5-year-old son, Craig, had his brain and spinal cord scanned in the hospital's new MRI.

Craig had smiled when he'd seen the machine for the first time. It was built to look like a pirate ship — "S.S. Rochester" is painted on its hull. But now the scan had come back. The news wasn't good. As Kim hung up the phone, images began flashing through her mind.

Craig, nauseous from round after round chemotherapy.

Craig, too weak to spend more than a few minutes outside.

Craig, enduring biopsies, blood tests, and the rest.

But for Kim, these weren't abstractions. She wasn't imagining her son's future. She was remembering his past.

'They couldn't believe he could walk'

For the parents who have endured it, a child's cancer diagnosis is life's most devastating news.The only thing that's harder is if they've had the conversation before.

"Because they already know what they're in for," said David Korones, M.D., Craig's oncologist at Golisano Children's Hospital.

When the scan last October showed that Craig's tumors were growing again, three years had passed since his initial diagnosis.

Prior to that, he was a normal, energetic 2-year-old.

"He just bounced off the walls," said Kim Winter, a Pittsford resident.

But one day, he began complaining of a headache. Then another. Then he was waking up at night, screaming about how much his head hurt.

His pediatrician referred him to Howard Silberstein, M.D., staff neurosurgeon at Golisano Children's Hospital. A brain scan revealed a cyst — which Silberstein drained — but no tumors. Still, when Craig's headaches returned a short time later, Silberstein knew something wasn't quite right. So he ordered one more scan — this time an MRI of Craig's spine.

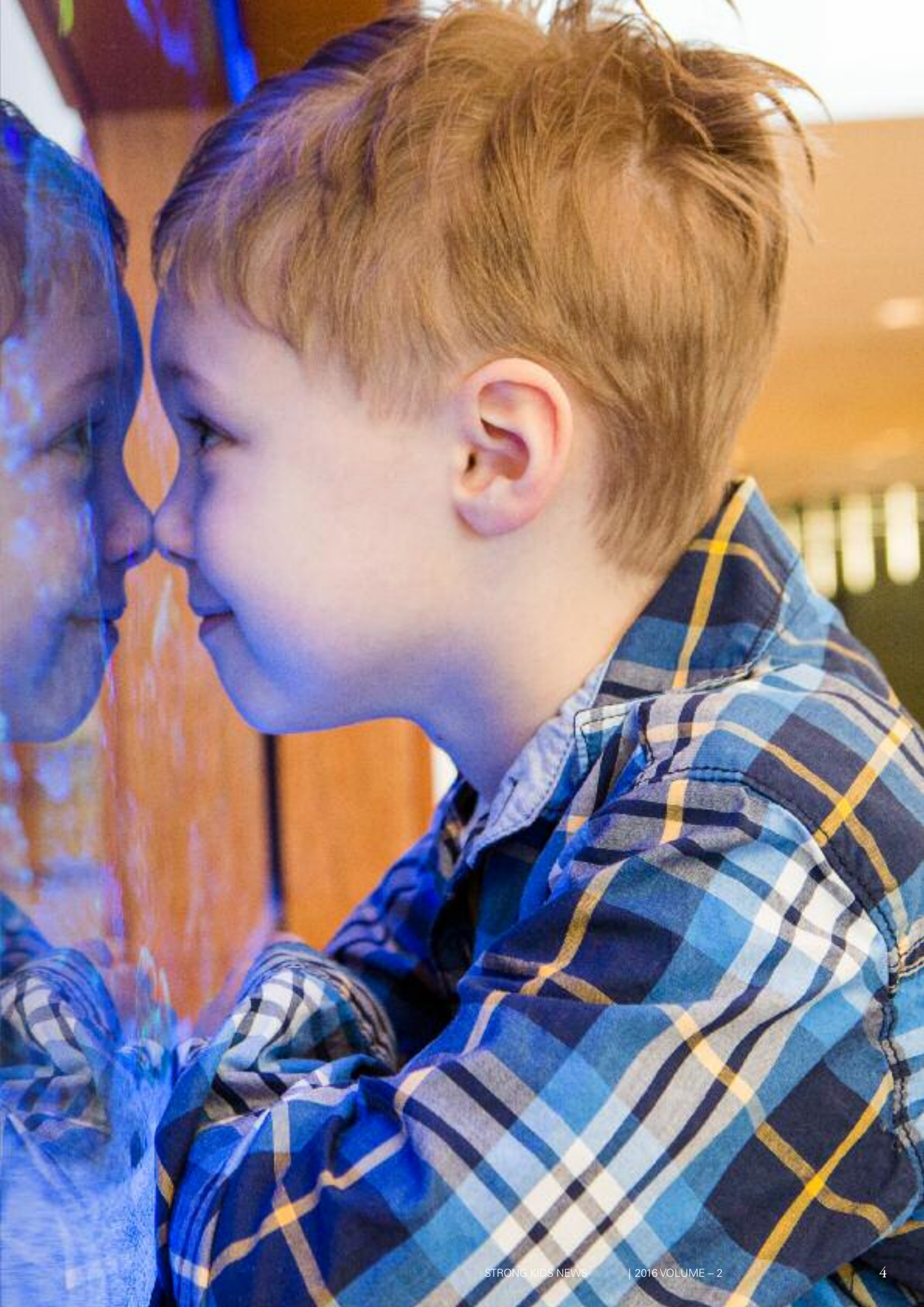
It was an image that his doctors had never seen before.

"Within minutes we had teams of people in his room. He had more spinal tumors than they'd ever seen in a 2-year-old," said Kim Winter. "They couldn't believe that he could even walk."

Soon after, Kim and her husband, Tim, had their first conversation with Korones.

"He said that just because it was very rare doesn't mean it's not beatable," said Tim Winter.

Craig had a disseminated glioneuronal tumor, meaning it had spread throughout his brain and spinal cord.



It was slow-growing, and Korones thought it could be managed, but it was so rare that there wasn't an established treatment.

"This wasn't something you could just look up in the books," said Korones. "What I did was contact several colleagues from around the country to work out a plan."

Surgery wasn't an option — the tumors were too widespread, and removing them would affect too much of Craig's brain and spine. And Craig was far too young for radiation. That left chemotherapy.

Keeping the tumors at bay

For a while, it was working. The tumors were shrinking. But after three months, Craig developed an allergic reaction that forced the end of the first round of treatment.

"It was really doing a number on Craig. His energy levels — he just wasn't the same kid," said Kim. "But it did significant damage to the tumors, so we were devastated when that treatment wasn't an option any more."

Korones switched Craig to a different type of chemotherapy. This one wasn't as effective as the first round, but it did prevent the tumors from growing. For Korones, that was good enough.

"It was always unlikely that chemo was going to cure him," said Korones. "Really, the best treatment, the best shot at curing him is radiation. So the strategy is to get him as old as we can, so that when he undergoes radiation treatment, he has fewer long-term side effects."

After about a year, the tumors started growing again. So Craig moved to a third type of chemotherapy treatment in early 2014. This therapy was the hardest on him.

"We pushed him through it, but it was very harsh on his body," said Kim. "He was having these headaches that almost seemed like he was having a stroke. There were times where he couldn't even communicate."

But all the pain would pay off. Craig came off chemotherapy in December 2014, and for the next nine months, his tumors were stable. He attended the opening of the new Golisano Children's Hospital, where his mother spoke to the gathered crowd about her son's care. Soon after, he began attending kindergarten. Meanwhile, Kim, who had been staying home to care for her son, got a teaching job and went back to work.

Then came the scan last October.

"It was like having post-traumatic stress," said Kim. "We just lived through that. And now we have to do it again?"

The 'invisible cancer' kid

When a child is cured of cancer, it's rightly called a miracle. This variety of miracle may be in Craig's future. But while his story isn't over yet, the life he's able to enjoy every day is a miracle to both his family and his physician.

After the scan last October, Craig started a fourth round of chemotherapy. It's still early, but so far, Craig has responded well. His tumors have again stopped growing and the medication is easier on his body than previous rounds.

"I think this is the first year he really enjoyed sledding," said Tim. "Before, he couldn't be outside for more than a few minutes — he'd just be wiped. But his spirit and the way he accepts things are incredible."

Korones agrees.

"Craig has such charisma, such pizzazz, and to maintain that sparkle and that joie de vivre despite everything he's going through, to me, that's a miracle," he said.

He's still a frequent visitor to Golisano Children's Hospital. James Sanders, M.D., treats his scoliosis, which developed due to the tumor's constant pressure on his spine. Robert Thompson-Stone, M.D., sees him for his headaches and the neurological side effects of his tumors.

And, of course, there are the biweekly chemotherapy treatments and quarterly MRIs. His parents are hoping that the treatment will keep his tumors at bay until age 10 or older, when radiation becomes a more workable option.

It was four years ago that Craig was diagnosed, and it will be four more until his 10th birthday. His parents know that they're all in it for the long haul.

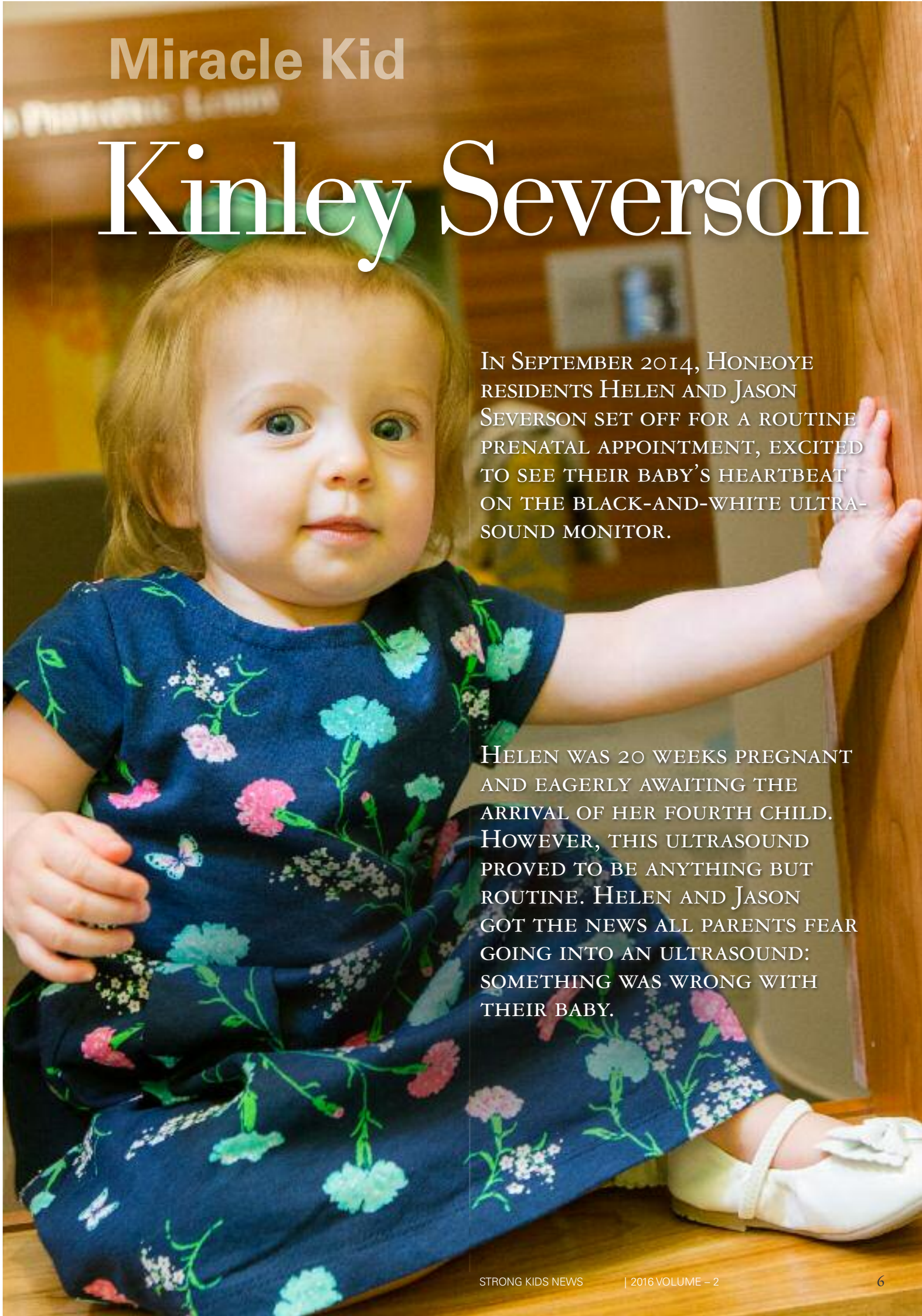
But today, Craig is well. And he's truly living.

"When we saw that scan when he was 2, I never imagined he would still be here," said Kim. "I never thought he'd go to kindergarten. But now he's truly that 'invisible cancer' kid. When you sit back and watch him, you don't know what he's gone through. It's amazing."

Craig with his parents, Tim and Kim Winter, and sisters, Lily and Lauren.

Miracle Kid

Kinley Severson



In September 2014, Honeoye residents Helen and Jason Severson set off for a routine prenatal appointment, excited to see their baby's heartbeat on the black-and-white ultrasound monitor.

Helen was 20 weeks pregnant and eagerly awaiting the arrival of her fourth child. However, this ultrasound proved to be anything but routine. Helen and Jason got the news all parents fear going into an ultrasound: something was wrong with their baby.

The Seversons were told their baby was suffering from a single umbilical artery. After making the hour-long trek to Golisano Children's Hospital, they learned that their unborn daughter, soon to be named Kinley, would likely suffer from VACTERL association birth defects (vertebral defects, anal atresia, cardiac defects, esophageal atresia, renal abnormalities and limb abnormalities).

"It was horrible," said Helen, who had three healthy children at home and never expected to have a baby with abnormalities. "It was probably the worst day of my life."

Helen and Jason quickly began researching VACTERL, which they learned occurs in one out of every 10,000 to 40,000 births. Although they were informed Kinley wouldn't suffer from all of the VACTERL defects, they still were terrified about her diagnosis.

The couple consulted with a team of doctors upon arrival at the hospital, including Eva Pressman, M.D., chair of the Department of Obstetrics and Gynecology, Christopher Gitzelmann, M.D., pediatric surgeon, and Walter Pegoli, M.D., chief of Pediatric Surgery.

Pressman gave Helen and Jason information and explained the plan for Kinley's delivery, and Gitzelmann and Pegoli spoke with them about the surgeries Kinley would need. Initially fearing the worst, Helen and Jason were relieved when Gitzelmann assured them that there were medical procedures that would increase Kinley's chance of survival.

Gitzelmann, along with the help of doctors from pulmonary, radiology, cardiology, orthopaedics, and the neonatal intensive care unit (NICU), developed a care and treatment plan for Kinley so they could be as prepared as possible for her arrival.

On Dec. 6, 2014, Kinley was born at 34 weeks. Kinley's heart was on the wrong side of her body and she was missing her pulmonary artery and her right lung. Kinley had a few fusions in her ribcage and her vertebrae. The biggest problem was her esophageal atresia, which caused her esophagus to close in a blind-ended pouch rather than connecting normally to the stomach.

"Her lungs and her esophagus were our main areas of concern," said Gitzelmann. "Connecting the proximal (top) and distal (bottom) pieces of the esophagus is a complex procedure, and each child reacts differently to it."

Kinley went into surgery just four days after her birth with a gastrostomy tube, which allowed her to feed without having to depend on intravenous fluids. The first surgery was successful but left Kinley very sick, and she would spend a week on a ventilator due to acute respiratory failure.

Kinley began serial esophageal dilations at just 5 weeks of age. Gitzelmann would use two rigid metal rods and attempt to gently push against each end of the esophagus, hoping they would begin to grow toward each other. After 28 procedures, the gap between the two ends of Kinley's esophagus had begun to shorten from 7 centimeters to just 2 — short enough that Gitzelmann could attempt to connect both ends with sutures.

On April 26, 2015, with Kinley just about 5 months old, Gitzelmann began the procedure. He had performed many of these surgeries before, but esophageal atresia is always a unique challenge, as it presents differently in every patient. After a four-and-a-half-hour surgery, Kinley's esophagus was a continuous tube that connected to her stomach.

"Kinley's come farther and is doing better than anyone ever imagined…" Marsha Pulhamus, PNP

The surgery was a success, but Kinley was left on a slew of different medications to get her through some of the pain. Things were very rocky for the next few weeks — Kinley needed multiple blood transfusions, a chest drain, needle aspiration, and was again put on a ventilator as Gitzelmann, along with the NICU staff, worked to get her breathing normally.

"Obviously, a major surgery on an infant with one lung is concerning to begin with," said Helen. "Her right cavity filled up with fluid and it collapsed her lung."

But Kinley was ultimately able to pull through and on July 15 — just over seven months after her birth — she was finally discharged from the hospital. After stays in the neonatal intensive care unit, pediatric intensive care unit and pediatric surgical unit, Kinley was finally able to go home to live with her parents and three sisters, Chloe, Gigi, and Scarlette.

Due to the narrowing of her esophageal connection, Kinley now has routine dilations that are decreasing in frequency, currently just once every two months. Gitzelmann hopes Kinley will eventually no longer need routine dilations, and can just get them as needed.

As for Kinley's other defects, "She's adapted very well," said Gitzelmann, who noted that Kinley's left lung has almost doubled in size in an attempt to compensate for the missing lung.

"The amazing part about Kinley is that nothing appears to be wrong with her," he said. "It means so much that her parents have trusted us with her care and that she is doing so well."

Marsha Pulhamus, the pediatric nurse practitioner who has overseen Kinley's care, was impressed with the love and time Helen and Jason gave their baby.

"Despite how long she was here, they were here on a regular basis," she said. "Kinley's come farther and is doing better than anyone ever imagined when we started this."

"She is doing amazing right now," Helen said. "She's begun speaking. She says 'mama, dada, night-night.'"

Gitzelmann frequently jokes with Helen, asking if they're sure they want to keep her. And though Helen and Jason have never taken Gitzelmann up on his offer to adopt Kinley, he still visits with her prior to her dilations, which continue to decrease in frequency as she grows and adapts to her new digestive tract.

"Kinley's nurses took great care of her! Whenever her monitor beeped, they ran over to Kinley and gave her love while she was in the hospital," said Chloe, Kinley's 11-year-old sister, who wrote a story about her sister while she was in the hospital. "I love my sister. My favorite thing to do is squeeze her nose because it's so cute."

Thanks to the team at Golisano Children's Hospital, it looks like Chloe will be able to squeeze Kinley's nose for a long time.

(Top, right) Gigi Severson holds her younger sister, Kinley.
(Below, right) Kinley with her sisters, Scarlette, Chloe, and Gigi.

Miracle Kid

Gary Burks

Latonya Burks can't suppress her smile when she talks about her son, Gary, an 11-year-old sports fanatic who has always been a source of happiness for people around him. His beaming smile and positive spirit rub off on anyone he meets.

"He lives with the mindset that whatever he is going through, someone else is going through something worse," Latonya said.

That hasn't always been the case, though. All his life, Gary has been living with the pain and complications of sickle cell disease, a serious and lifelong disorder that causes the body to make sickle-shaped red blood cells, which are stiff and sticky. Blood flow in the blood vessels can become blocked anywhere in the body, causing pain, infection, and organ damage.

Latonya, a Rochester resident, knew during her pregnancy that Gary would have sickle cell anemia, which occurs in about one out of every 600 African-American births. Latonya's mother told her at a young age that she was a carrier of the sickle cell trait, but she didn't realize the disease could be potentially deadly if two people with the same trait conceived a child.

The effects of sickle cell disease can vary greatly from person to person. Gary was hospitalized numerous times between birth and age 4 with upper respiratory issues, acute chest syndrome that often came with a fever, excruciating pain crises, shortness of breath, and low oxygen levels.

"I remember the first time he had a crisis. He was almost 2 years old. His hands and feet were a reddish tone, swollen, and he was in a tremendous amount of pain," said Latonya. "That didn't stop him from scooting all over the hospital trying to play with the nurses. He refused to sit still."

When Gary was four, Latonya brought him into his pediatrician with cold-like symptoms. It wasn't until they were sitting in the waiting room that Latonya noticed that her ever-energetic son was sitting slumped, quiet, and withdrawn. Latonya thought it may have been yet another pain crisis of his body or acute chest syndrome.

After being admitted to the hospital and watching her son lay in bed, she noticed that he was drooling, which she had never seen before. It was only during his admission that he showed weakness on his right side, which caused half of his face to appear droopy. Doctors told Latonya her son had suffered a stroke. He was immediately transferred to the pediatric intensive care unit at Golisano Children's Hospital for treatment.

"It was like time had stood still after I heard the word 'stroke,'" said Latonya. "I felt like my thoughts were frozen. I was scared and did not know how this would impact his health or his life."

"The first thing we had to do was to assess the damage," said Laurie Johnson, a pediatric nurse practitioner who has been overseeing Gary's care for the past seven years at Golisano Children's Hospital. "Any child with sickle cell that has a stroke is immediately put on a routine transfusion program. The reason we put him on a transfusion regimen was to prevent him from having another stroke that could have potentially escalated to a deadly situation."

Strokes in children with sickle cell anemia are caused by the progressive narrowing of blood vessels which prevents oxygen from reaching the brain.

Monthly transfusions can help prevent stroke and other complications, but they were very difficult for Gary. Because of his small veins, he needed a central venous catheter placed in his chest to reduce the blocked blood flow caused by the sickle cells.

"By giving him un-sickled blood, we are preventing areas from getting clogged up by the sickled cells," said Johnson.

After his stroke, Gary was tasked with relearning the basic tasks that had previously come so easily to him. He had to work with an occupational therapist to regain usage of his right hand, and has worn a brace on his right foot as a precaution to improve his stability since the stroke.

Gary also underwent tenotomy surgery after his stroke to improve the positioning of his right foot. Because the stroke impaired Gary's growth, it forced his foot muscles to resist development, so his tenotomy surgery cut his tendon partway through, allowing his muscle to be stretched for future growth.

"The overall incidence for stroke in a child with sickle cell is low, occurring in just about 10 percent of children with the disease," said Razia Akhtar, M.D., assistant professor of Pediatrics. "But when it does occur, it can result in long-term effects as seen with Gary."

Akhtar now monitors Gary for iron deposits in his abdomen and liver, a result of transfusions. If iron accumulates in excess in either of these places, it could cause heart problems. Gary undergoes yearly MRIs to monitor his iron level along with numerous other tests that monitor his brain, heart, and lungs to prevent stroke and other health issues.

"Gary has faced morbidity and mortality at far too young an age," said Akhtar. "He has been so poised dealing with his disease throughout his childhood; he's such a pleasure to be around." Akhtar also added that Gary doesn't let his disease hold him back from competing with his friends in athletic activities.

Latonya said that Gary sometimes gets frustrated answering questions about why he walks with a limp, or what is wrong with his arm. "He doesn't want to explain to children what happened to him or why he walks the way he walks," Latonya said. "I remind him of all of his accomplishments and that he can be a help to others."

"I am amazed at how far Gary has come since I've met him," said Johnson. "His smile always brightens my day."

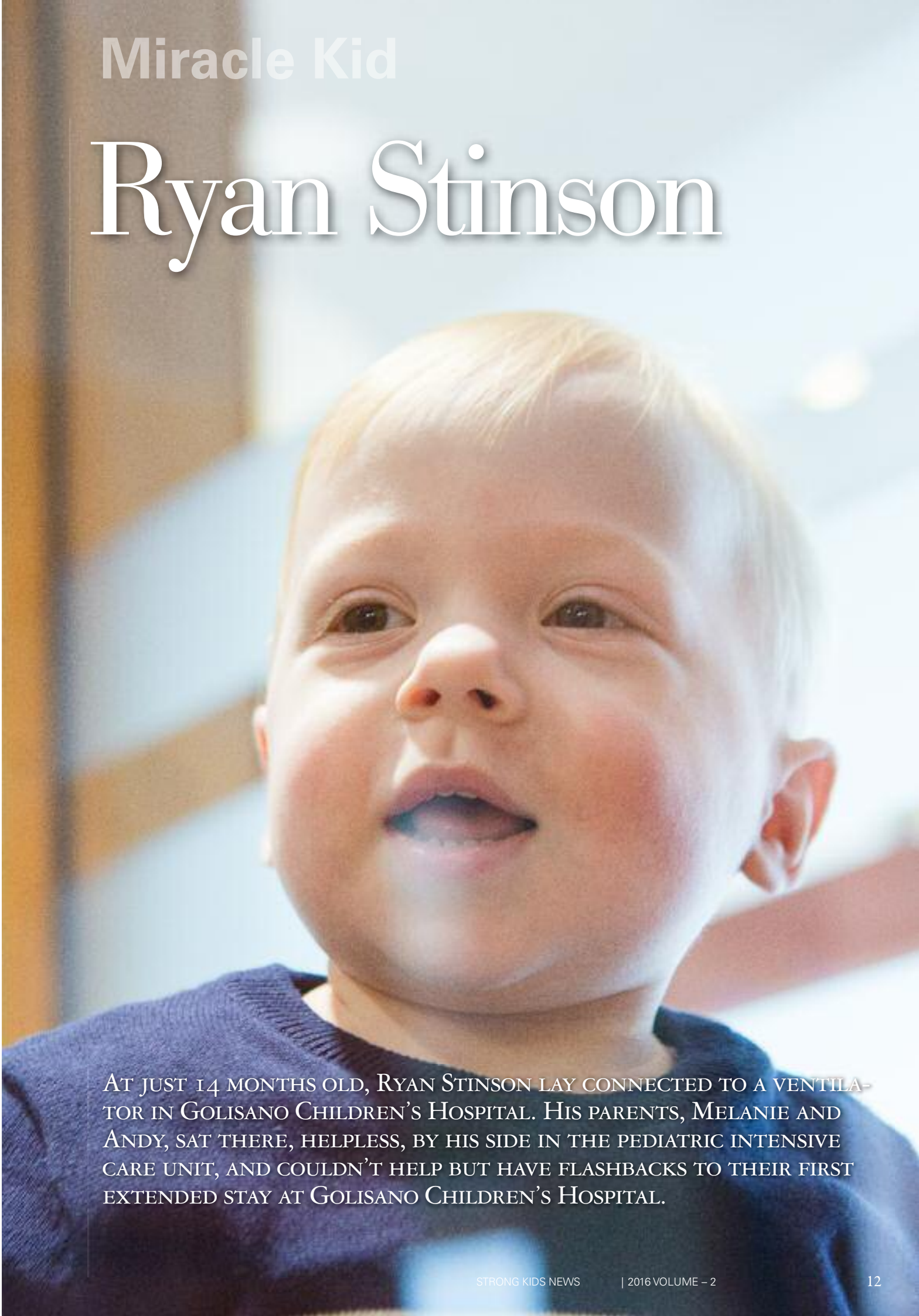
Gary is currently doing what he does best, making people smile and laugh. When asked about his experience at Golisano Children's Hospital, Gary was quick to point out his favorite thing about coming to get treatment: "I love all the doctors and nurses that take care of me when I come to the hospital. I especially love when the girl nurses take care of me," he joked.

Gary will continue to receive monthly exchange transfusions and yearly MRIs to monitor his iron levels. With much prayer, patience, and practice, Gary's been able to adapt to life after having a stroke, and now primarily uses his left hand for throwing, catching, and writing. His huge imagination allows him to accomplish more than anyone ever dreamed he'd be able to.

Gary with his sisters Daja'nae and Johnetta, his grandmother, Doris, and his mother, Latonya, who is holding his niece, Amor.

Miracle Kid

Ryan Stinson



At just 14 months old, Ryan Stinson lay connected to a ventilator in Golisano Children's Hospital. His parents, Melanie and Andy, sat there, helpless, by his side in the pediatric intensive care unit, and couldn't help but have flashbacks to their first extended stay at Golisano Children's Hospital.

Overcoming Short Bowel Syndrome

Rushed to Strong Memorial Hospital after an abnormal ultrasound, Ryan's heartrate was dropping and the Stinsons had to act quickly to ensure their son's survival. Melanie and Andy were told to prepare to deliver their son as he had a better chance of survival in the neonatal intensive care unit. Ryan was born on February 6, 2014 prematurely at 34 weeks weighing just two pounds, nine ounces.

Because Ryan had poor growth in utero, many of his organs were not fully developed, which put him at risk for a number of diseases in the first weeks of life. He was having trouble feeding, and his platelet levels were far below normal. He began to make progress, but after five weeks in the neonatal intensive care unit (NICU), his little body gave out and became sick very quickly.

X-ray tests showed that Ryan had necrotizing enterocolitis (NEC), an extremely serious intestinal illness in babies. Portions of Ryan's small intestine were perforated, causing waste and bacteria to enter his bloodstream and abdominal cavity. Doctors developed a comprehensive treatment plan for Ryan that included multiple surgeries.

Yi-Horng Lee, M.D., along with Marsha Pulhamus and Jennifer Maddison, both pediatric nurse practitioners, followed Ryan's case closely. Lee's treatment plan was to remove all of Ryan's small intestine impacted by NEC, a risky procedure.

Ryan's condition escalated so quickly that Lee operated right in the NICU. At just over 5 weeks old, Ryan had his first of four surgeries to remove portions of his small intestine. The first surgery was the most intense, with over 75 centimeters of intestine removed.

"Every time Dr. Lee went back in, more small intestine needed to be removed," said Melanie. "It got to the point where we had to baptize him in the NICU because we didn't know if he was going to make it." Ultimately, Lee removed over 80 centimeters from Ryan's intestinal tract.

> Ryan was defying the odds, slowly increasing tube feeds and decreasing intravenous nutrition. In September, 2014 he had begun attending Daystar For Medically Fragile Children, where they could care for his medical needs and coordinate therapies. And in no time, he was rolling over and crawling.

Now, the question became whether Ryan could live with such a minimal amount of his digestive tract.

The loss of almost two-thirds of his small bowel meant a diagnosis of short bowel syndrome, something Melanie and Andy knew was evident, which is characterized by a poor absorption of water, vitamins, minerals, proteins, and other key nutrients from food.

"Ryan was at the brink of where we had to wonder if he would ever be able to get off of intravenous fluids because of how much bowel we removed," said Pulhamus. "Although the surgery was successful, Ryan now has just one-third, or 36 centimeters of intestine left."

Ultimately, Ryan was able to pull through. He was discharged from the hospital on May 19, 2014, over three months after his birth. Melanie and Andy learned how to

mix intravenous fluids, change and sterilize Ryan's dressings, and put ethanol in his broviac line to prevent infections.

"We would have done anything at that point just to get Ryan home," said Andy.

Although their house looked like a "mini-NICU," Andy and Melanie were glad to have Ryan home. Ryan was defying the odds, slowly increasing tube feeds and decreasing intravenous nutrition. In September 2014 he had begun attending Daystar For Medically Fragile Children, where they could care for his medical needs and coordinate therapies. And in no time, he was rolling over and crawling.

In October 2014, he underwent his sixth surgery, but this time it was a celebration. Ryan was absorbing enough formula in his g-tube that he no longer needed a central line.

Beating Botulism

March 26, 2015. Ryan lay, again, connected to a ventilator.

The morning prior, Melanie and Andy had thought Ryan had looked exhausted and not his active self. After a few trips to the pediatrician, they brought Ryan back to the children's hospital that evening, where the medical personnel began running tests on him. X-rays hadn't revealed anything unusual, but Ryan remained in the emergency department where he'd receive more tests.

After a few hours, Ryan began deteriorating, as he was losing control of his body.

"We brought him in Wednesday night, and by 10 a.m. on Thursday, he was completely paralyzed," said Melanie. "The only thing that remained functioning was his heart."

Erika Augustine, M.D., assistant professor of Neurology, met Ryan when he was already in the intensive care unit. Ryan had already been put on a ventilator, and Augustine was consulted by doctors in the pediatric intensive care unit (PICU) to evaluate for neurological causes of his condition. She worked closely with other neuromuscular specialists, including David Herrmann, M.D.

After running countless tests with inconclusive results, Hermann performed a nerve conduction study, which measured the speed at which an electrical impulse moved through his nerves. Ryan was subsequently diagnosed with infantile botulism, an extremely rare illness seen in only 100 or so people throughout the United States each year.

"One of the major challenges in caring for Ryan was moving beyond common causes, to very, very rare diagnoses that required specialized testing and specialized treatments." recalled Augustine.

The disease is frightening because it causes muscle weakness and breathing problems. Due to its severity, it's critical to recognize it early. Augustine and her team phoned the California Department of Health, the only center with the immunoglobulin to treat botulism, to get it on a plane to Rochester.

The call was made on Saturday, March 28, 2015 and by Sunday morning; Ryan was receiving the immunoglobulin through an IV. After a two-month hospitalization, Ryan made a dramatic recovery.

"Ryan had already been through a lifetime of medical issues in just 14 months prior to his botulism," said Augustine. "He's truly a remarkable child having survived two prolonged ICU admissions with two separate rare diagnoses."

Ryan's botulism reverted him back to the state of a three-month-old, and he's been tasked with relearning everything from crawling to swallowing. Ryan continues to make new developmental strides every day. He has a slight speech delay, and still requires tube feedings, but Melanie and Andy know he will overcome that, as he has every other obstacle that has been in his way.

"We feel incredibly lucky to have Golisano Children's Hospital in our community," said Andy. "Because of them, Ryan will be able to go to school, have kids, and live a normal life someday."

Ryan Stinson with his parents, Melanie and Andy.

Miracle Kid

Daniel Deyo

5:00…

4:59…

4:58…

THE SECONDS TICK AWAY. DANIEL DEYO'S GAZE LINGERS BRIEFLY ON THE TIMER, THEN DROPS TO HIS BOOK. FIVE MINUTES OF READING WORK MEANT A REWARD — FIVE MINUTES OF TELEVISION.

Not long ago, this was a constant battle. Daniel, who is diagnosed with autism spectrum disorder (ASD), would take a great deal of convincing to settle in with his schoolwork. After a short time, though, he'd stop and return to something he enjoyed more. Efforts to keep him seated resulted in screaming tantrums.

But the timer gives him a focus, a goal. And whenever he looks up, he's a little closer to his reward. For children with ASD, there are no special drugs or surgeries that can fully address all of their needs. Instead, miracles are made one grueling step at a time.

Treatment doesn't always start with the patient. Instead, a parent can learn to observe their child through a new lens and watch for things they weren't looking for before.

They can log their children's behavior. What works. What doesn't. Interactions, behaviors, and tantrums can be tracked and studied.

Every child is different. What's effective for one may not work for another. But once a success is discovered, it is repeated. Again and again and again.

Soon, it's a routine.
Soon, most of the tantrums are a memory.

4:15…

4:14…

4:13…

Daniel Deyo and his mother, Fauna.

Daniel was 2 when he was diagnosed with autism spectrum disorder. His speech, which had begun promisingly, waned. He began repeating certain behaviors — spinning in place or twirling things in front of his eyes. The next few years were a struggle, as gains would often be erased by regressions, none greater than when his father passed away from leukemia when Daniel was 4.

"His father was the one who managed him, who really connected with him when he was younger," said his mother, Fauna Deyo.

For a child who already had trouble expressing his feelings, the grief and confusion that came with his father's death were overwhelming. Meltdowns were near constant.

"Eleven to sixteen times per day," said Fauna, who lives with her son in East Palmyra.

Providers at Roosevelt Children Center in Newark refused to give up on him. Soon, his behavior mellowed and he entered kindergarten on an upswing.

"He was doing really well — he was potty trained and following directions," said Fauna.

But the gains felt short-lived. Upon entering first grade, Daniel's behavior took a turn, and reports reached Fauna that the school couldn't control her son. At home, he was violent, hitting his mother and kicking holes in the wall. Something had to change.

3:31...

3:30...

3:29...

The Behavior Interventions for Families clinic is a 12-week training course for parents at Golisano Children's Hospital's Kirch Developmental Services Center. Here, parents gain support learning how to view their child through a new lens and think critically about their behaviors, both the child's and the parents way of reacting to them. This means closely tracking behavior and logging data on their child's actions, and reactions.

"It's a little nontraditional compared to a lot of what we do here at Kirch in that we don't work directly with the child," said Bryan Harrison, Ph.D., a postdoctoral fellow who works at Kirch within the Behavior Interventions for Families clinic. "Instead, we're basically helping caregivers think about their child's behavior like a scientist."

Harrison has been working with caregivers of children with ASD and developmental disabilities for several years. He began with a research group led by Tristram Smith, Ph.D., that examined the effectiveness of this program and, under the supervision of Laura Silverman, Ph.D., began working with a team to implement this approach in a medical setting at Kirch. He had never seen a parent as committed as Fauna Deyo.

"She doesn't live close by, she works early morning shifts, and recently became a widow," said Harrison. "She showed up, without fail, every week, and was always on time. She put in a lot of work to make this work for Daniel. She has an incredibly resilient attitude and determined focus on helping her son."

In the early going, Harrison met with Daniel once as part of a home visit that is built into the program. The rest of his time was spent in sessions with Fauna and her mother, Vonda.

2:46...

2:45...

2:44...

The first few weeks are spent on foundation work with providers discussing the importance of preventing certain behaviors, reinforcing prosocial ones, and establishing a daily schedule that children can come to rely on.

"Some families get frustrated in the beginning because we don't get to what they want to fix right away," said

Harrison. "But we do this because it's incredibly important, and Fauna succeeded in taking those early sessions really seriously. She took the foundational stuff and built on it."

Each week, caregivers pick a specific behavior, and the week's lesson is adapted to develop a solution that works for the family. Parents also learn how to track that behavior and ensure that they are keeping correct data that can be studied later.

Providers demonstrate how to improve a child's ability to respond to a request the first time, so caregivers don't have to repeat themselves. They share ways to prevent children from wandering off when outside or in a large store. And they discuss how to strategically ignore behaviors.

"Parents of children often need a lot of emotional support for the planned ignoring," said Harrison. "They are so accustomed to responding to their child's needs that it can be very stressful to ignore certain behaviors."

One method that worked well for Daniel was the use of a timer, which became a middle ground for Fauna. Immediately honoring one of his wishes — like, say, a request to watch television instead of doing his homework — could lead to future expectations that Fauna may not have wanted to fulfill. Refusal, meanwhile, could lead to a tantrum. Instead, she could pull out the timer and tell him that he could watch after five more minutes of homework.

1:14...

1:13...

1:12...

Fauna didn't stop there. She'd pulled Daniel out of school for the time being, but she was eager to get him back into an environment where he could learn and socialize with other children. She began taking him to music and art social skills classes at the Family Autism Center in Rochester and enrolled in a 12-week advocacy class with Starbridge, a New York State Parent Training and Information Center.

She learned about the laws and what schools are required to provide for students with developmental disabilities. Armed with this information, she returned to Daniel's elementary school and got Daniel a functional behavior assessment. From there, she worked with his teachers and administrators to make an individualized learning plan for him.

She also shared many of the methods that she'd learned in the Behavioral Interventions for Families training. Now, Daniel is back in school. And nearly all of his behaviors have improved.

"She took what we offered and used it to the absolute fullest extent," said Harrison.

"It's changed our lives," said Fauna.

0:03...

0:02...

0:01...

THE TIMER GOES OFF and Daniel puts his book down. His mother resets the timer for five minutes as Daniel settles in with his tablet to watch a few minutes of television. The cycle will repeat itself until Daniel is done with his schoolwork.

For now, Daniel is happy. The house is quiet.

The 20th Annual Golisano Children's Hospital **Golf Classic** will take place on **August 29, 2016.**

The annual tournament has been one of the largest fundraisers for the Children's Hospital, and last year's event was no exception as $236,000 was raised.

Held at three pristine courses — Monroe Country Club, Country Club of Rochester, and Oak Hill Country Club — the 20th annual event will bring golfers from all over the Rochester region to play for the sick and injured kids at the Finger Lakes region's only children's hospital. Last year's event featured 360 golfers.

The tournament will kick off with registration and lunch from 11 a.m. to noon and a 12:15 p.m. shotgun start.

2015 Miracle Kid Delaney Doyle and her parents Kelly McMillan and Eric Doyle were the honorary guests at last year's dinner, held at Oak Hill Country Club. Diagnosed with high-risk stage 4 neuroblastoma, Delaney was the youngest patient at Golisano Children's Hospital to undergo a stem cell collection and immunotherapy treatment. The 20th annual event will, again, feature another Miracle Kid and their family to share their story with the golfers.

For more information on the Golisano Children's Hospital Golf Classic on August 29th, contact Betsy Findlay, director of special events and Children's Miracle Network Hospitals at Golisano Children's Hospital, at (585) 273-5933.

Miracle Maker Award

The Wegman Family

"Our mission is to help everyone live healthier, better lives, and that begins with children."

The Wegman Family Charitable Foundation has provided an exceptional level of support to the Golisano Children's Hospital and our region's children and families. The Foundation has given more than $21 million to The Meliora Challenge:The Campaign for the University of Rochester, $7 million of which directly supported Golisano Children's Hospital.

While $6 million of the Foundation's gift supported the construction of the new building, $1 million was used to establish an endowment to increase the quality of Child Life programs, services, and facilities. In recognition of this enduring gift, the hospital's Child Life Program was renamed the Wegmans Child Life Program. Child Life specialists prepare and support children and their families for their medical experience in terms they can understand, and help to ease the fear and anxiety that a child often feels in a hospital. The generous support of the Wegman Family Charitable Foundation can be further seen on the seventh and eighth floors of the new children's hospital, where the Wegmans Child Life Zone is named in recognition of their support.

Miracle Maker Award for Outstanding Commitment by Grateful Parents

Patti and Mike Milburn

"From that day, when everything turned around for Cory, we decided we needed to give back."

Cory Milburn was born in 2009 weighing just 1 pound, 8 ounces, and his parents, Patti and Mike, were told that he likely wasn't going to survive. But after a long stay at Golisano Children's Hospital, Cory pulled through, and his parents have spent the last seven years giving back. In addition to speaking at several Golisano Children's Hospital events, the Milburns have hosted a euchre tournament annually. They provide the prizes themselves and then donate 100 percent of tournament proceeds to the hospital.

They also manage to drum up big contributions to the Stroll for Strong Kids every summer, where the "Cruzin for Cory" team is always one of the standouts.

Miracle Maker Award for Outstanding Commitment by a Community Group

Andy Yazwinski and the "100 Innings for Noah Softball Festival"

"If we can save even one life from running this event, then it was well worth doing."

In April 2008, Noah Passero passed away from complications from cardiomyopathy. He was 8 years and 4 months old. In celebration of the 100 months of his life — and in the hopes of helping to raise money to study the disease that Noah died from — his family began hosting the annual "100 Innings for Noah Softball Festival."

For the past eight years, softball enthusiasts have come to Cobbs Hill Park to participate. Passero's grandfather, Andy Yazwinski, the City of Rochester's Softball Commissioner and vice-chair of the New York Amateur Softball Association, took the lead in organizing the game, which is split into ten 10-inning segments and runs for an entire day. Over 300 people participate each year, including Noah's parents, Wendy and Dan Passero, and his brother Nick, who is now 19 years old.

To date, the event has raised nearly $100,000 for pediatric cardiomyopathy research and treatment at Golisano Children's Hospital. Over the festival's eight-year history, 327 people have signed up to be organ donors at the event.

Miracle Maker Award for Outstanding Commitment by a Children's Miracle Network Hospitals Partner

Mark Goldberg and Steve Carl, Dairy Queen

"Supporting Golisano Children's Hospital fits our mission at Dairy Queen to a 'T'. We're incredibly fortunate to be able to support such a wonderful place that does so much for the children in our community."

Mark Goldberg and Steve Carl, business partners at three Rochester area Dairy Queens, have provided tremendous support to Golisano Children's Hospital since they opened up shop in Rochester in 2012. Dairy Queen has provided countless smiles for the kids at Golisano Children's Hospital through many Blizzard and ice cream donations.

Dairy Queen, a supporter of the Children's Miracle Network, holds Miracle Treat Day every summer, where $1 of every Blizzard sold is donated to the Children's Miracle Network. To date, they have raised over $50,000 to donate to the children's hospital, and are committed to a $100,000 pledge that will go toward naming rights in the new hospital.

20th Annual Golisano Children's Hospital Stroll for Strong Kids & 5K Run

Every year, thousands of friends of Golisano Children's Hospital pour into Genesee Valley Park for the Stroll for Strong Kids Walk and 5K Run. This year's 20th anniversary event, taking place Saturday, June 4, will be the first Stroll since the new hospital has opened. The Stroll for Strong Kids is an annual, family-friendly event where participants can choose to run in the 5K race, walk with family and friends, or both.

The event, which will have a Prince and Princess theme, encourages everyone to come dressed in their royal costumes for a royally fun time.

"The participants, the children, and the families are why we do the Stroll," said Stephanie Sheets, Assistant Director of Community Affairs. "Over 10,000 people participated in 2015's Stroll, which was another record-setting year. We are looking forward to another tremendous Stroll in 2016."

"Each and every year we look forward to having a picnic in the park for thousands of the Hospital's closest friends," said Steven Terrigino, Chair of the Stroll committee. "The many volunteers, contributors, and families are what make this event so successful. Stroll is one of my favorite events of the year as it is all about the kids, and really, that's what everything we do at Golisano is about, the kids!"

This year's Stroll will again kick off with the 5K run at 8:30 a.m., and the Stroll will begin at 10:30 a.m. Parking will be available off of Kendrick Road.

Stroll features

- 1.5 mile family-friendly walk around the park.
- 5K Run on a USATF Certified 5K Course — $30 registration fee to participate ($40 the day of the event).
- Bounce houses, carnival games and other entertainment for the kids.
- Many fun activities for the entire family.
- Lunch provided for all participants.
- Incentives for additional fundraising.

To register for the 20th Annual Stroll for Strong Kids visit *www.urmc.rochester.edu/childrens-hospital/giving/events/stroll.aspx.*

Rita Buzzard gives $2 million
for new Pediatric Cardiac Catheterization Suite

Rita Buzzard, formerly of Buffalo, NY, has given $2 million to UR Medicine's Golisano Children's Hospital in honor of her late husband, Clay, and their six children.

The gift will fund the Clay E. and Rita M. Buzzard Pediatric Cardiology Cath Lab Suite, a dedicated pediatric cardiac catheterization suite in the new Golisano Children's Hospital building.

"This is a remarkable gift which will directly impact the care received by pediatric cardiology patients at Golisano Children's Hospital for years to come," said Mark Taubman, M.D., CEO of the University of Rochester Medical Center and UR Medicine and dean of the School of Medicine and Dentistry. "We are extremely grateful to Rita Buzzard and her family for their generosity."

The new suite will allow physicians to insert cardiac catheters in an environment designed specifically for the procedure. Cardiac catheters are used to diagnose and determine the consequences of congenital heart disease, to gauge the success of surgical treatments, and for electrophysiological studies.

The suite will be built as part of Phase II construction of the new Golisano Children's Hospital building. The new areas, which will be located on the fourth and sixth floors of the new children's hospital building, also include six new operating rooms in the William and Mildred Levine Pediatric Surgical Suite, new private pre-op and post-op recovery rooms, and an expanded Pediatric Intensive Care Unit and Pediatric Cardiac Intensive Care Unit.

Construction is scheduled to be completed in 2017.

"Just like everything else in the new hospital, this suite will be built with children and families in mind," said Nina Schor, M.D., Ph.D., pediatrician-in-chief at Golisano Children's Hospital. "In order to attract the best physicians and provide the best for our patients, we need to have the best possible tools available in our facility. This suite sets us up to continue to provide top-quality care and expand the array of procedures and conditions for which children and families will not have to leave the region to get the best."

Clay Buzzard, who died in 2013, was the owner of Middle Atlantic Warehouse Distributor, Inc., an auto parts distributor which began in Buffalo and has since spread throughout the United States. He acquired the company in 1963.

Prior to his business career, Clay Buzzard served in the U.S. Army during World War II. Wounded at the Battle of Saint-Lô in July, 1944, he earned a Purple Heart and Good Conduct Medal. Shortly before his death, he was awarded the French Legion of Honor Medal, which is given to U.S. veterans who helped liberate France during the war.

He would go on to graduate from the University of Pittsburgh and Robert Morris College before acquiring the business that he would soon build into a national enterprise.

"We were very blessed — we had a great life together and had six healthy children who didn't have to use a facility like Golisano Children's Hospital," said Rita Buzzard. "I'm just trying to give back to people who may not be as fortunate, and whose children may need more care."

Five of the six Buzzard children were involved in the family business, leaving her daughter Carol to pursue a career in medicine. A pediatric cardiologist, she has worked at Golisano Children's Hospital since 1992; Rita Buzzard said that her daughter's long tenure and dedication at URMC compelled her to make the gift to the hospital.

Research spotlight

$3.6M grant supports asthma research

Jill Halterman, M.D., professor of Pediatrics at UR Medicine's Golisano Children's Hospital, has received a $3.6 million grant from the National Institutes of Health to research a preventive asthma intervention that could help patients better manage their condition while reducing acute emergency room visits.

The five-year study will help connect pediatric asthma patients to primary care providers for follow-up after an emergency visit for asthma. The follow-ups would occur in the child's school health office via telemedicine, ensuring easy access.

"Asthma is the most common reason for a pediatric emergency visit," said Halterman.

"But many of these patients don't end up getting the preventive medication they need after being discharged, and they wind up back in the emergency department again a month later."

Such recurring visits are nothing new. Direct health care costs for asthma top $50 billion annually in the United States, with hospital stays constituting the largest portion of these costs. But asthma, which affects 1 in 10 children, is a condition that can be effectively treated with appropriate preventive medications, meaning many of the hospital-related costs are avoidable. Upon discharge, emergency departments have always encouraged patients to meet

with their primary care physicians for long-term care. But many pediatric patients, particularly those experiencing disparity and barriers to appropriate care, may rely on emergency rooms for their health care and may have trouble attending a follow-up visit. These children are also much more likely to suffer from asthma.

"It can be very challenging for families," said Halterman. "A caregiver will have just taken unplanned time off of work to bring their child to the emergency room, and now they are expected to find additional time to bring their child in for a follow-up appointment."

Scheduling the follow-ups via telemedicine will help to solve this problem. Using a network that the Department of Pediatrics has established with the Rochester City School District, children who have been referred after an emergency room visit can be seen during the school day, in the school health office, by a pediatric provider working remotely. This allows their caregivers to return to work, if needed, with communication with the provider occurring via teleconference or telephone.

Should the research yield promising results, Halterman believes it can be adopted by health care networks throughout the country, which could help countless children prevent their asthma from reaching serious levels while reducing emergency room volumes.

The research builds on several of Halterman's previous studies, which have attempted to improve the delivery of preventive asthma care, particularly for those from low-income families. She has also explored methods to promote the proper use of and adherence to asthma medications through partnerships with schools and school nurses.

14th annual ski outing a blustery blast

Over 120 skiers trekked to Bristol Mountain on February 8, 2016 for the 14th Annual Golisano Children's Hospital Ski Outing. This annual event has featured vendors from different sectors of Rochester's construction industry and has now raised over $500,000 for Golisano Children's Hospital.

The event was created by Paul Tessoni, an avid skier and former employee of the University of Rochester Medical Center facilities group. "Organizing a ski outing to benefit Golisano Children's Hospital has been a very rewarding experience," Tessoni said. "Bringing friends and business colleagues together for a day of fun and supporting the children's hospital at the same time is a win-win situation."

Golisano Children's Hospital appreciates the continued support from the participants of the Ski Invitational and looks forward to the 15th annual event next year.

Platinum Sponsors
LeChase Construction
Schuler-Haas
Wesco Distribution, Inc.

Organizing Sponsor
John W. Danforth Co.

Gold Sponsors
Billitier Electric, Inc.
Day Automation
Johnson Controls, Inc.
J.T. Mauro Sheet Metal L.L.C.
Rochester Davis-Fetch Corp.
The Pike Company

Silver Sponsors
Bergmann Associates
Crosby Brownlie, Inc.
HBT Architects
Holdsworth Klimowski Construction
Holt Architects
IBC Engineering P.C.
Kris B. Kimmel Construction Drafting, Inc.
Med Assets
R.F. Peck
R.L. Kistler, Inc.
R.P. Fedder Corp.
Sedgwick Business Interiors
Simplex Grinnell
Souperb Catering
T.Y. Lin International
Trane

Bronze Sponsors
A.A.C. Contracting, Inc.
Argus Engineering
Clark Patterson Lee
Green Building Partners
Hunt Engineers, Architects, & Land Surveyors, P.C.
Landsman Development
M/E Engineering P. C.
Otis
SEI Design Group
Spartan Engineering

August **26 - 27**
Friday Saturday

1 Town **2** Days **4** Stages

32 bands

Come party with us in the Village of Fairport on August 26 and 27, 2016. The Fairport Music Festival, which takes place on Liftbridge Lane, will feature music and food from local restaurants. It promises to be a fun-filled weekend that offers music on three stages from over 20 bands and entertainers, and tons of kids' activities.

All proceeds go to Golisano Children's Hospital at Strong.

To date, with your generosity, we have already raised $923,328 for Golisano Children's Hospital. Thank you for helping us help the kids!

In Memoriam

Michael Farr Bryson, M.D.

Michael Farr Bryson, M.D. (M.D. '57), a former pediatric endocrinologist at the University of Rochester Medical Center, passed away in November at the age of 85.

Bryson worked at the Medical Center and devoted much of his time to trying to help children living with diabetes. In the 1970s, Bryson, along with Beverly Faro, P.N.P., and Kathy Ippolito, R.D., started a monthly diabetes clinic held on Saturdays.

"Mike was beloved by the families he served so tirelessly," said Faro. "I'm sure he would have retired with the Department of Pediatrics had he not had a heart attack that forced him to cut back on his workload."

Faro served in the United States Air Force and continued in the Reserves and retired with the rank of Colonel in 1984. He also volunteered his time throughout the community and was a former Chairman of the Board of Directors of the ARC of Monroe County.

Many thanks to these and all generous supporters and event organizers that benefit Golisano Children's Hospital! If you are interested in hosting a fund-raiser please contact Stephanie Sheets at: *stephanie.sheets@rochester.edu* or 585–275-2268

- Thank you to College Town's Roc 'Ella Fashion Show for raising $30.00 for the kids at Golisano Children's Hospital.
- Big thanks go out to Midlakes Jr. Eagles Athletic League, who held a cheerleading competition in October and raised $2,000.00 for the patients and families of Golisano Children's Hospital.
- The Penfield Strikers Soccer Club raised $356.00 for our patients in honor of Craig Demmin. Thank you!
- Kudos to the Red Jacket Jr. Hoops organization for hosting their Jr. Hoops Tournament to benefit Golisano Children's Hospital. You raised $1,000.00 for our kids!
- Mohawk Global Logistics recently raised $500.00 and donated iTunes gift cards and toys for our patients. Thank you!
- Thank you Garber Automotive for your recent $500.00 donation!
- A HUGE heart felt thank you to Nazareth College who recently held their annual Battle of the Beaks and Athlete Semi-Formal. You raised $11,084.01 for our Music Therapy Program. Way to go!
- Thank you to Kate Pocaro for recently raising $2,000.00 at a raffle at her place of employment for Dr. Andolina's research here at Golisano Children's Hospital.
- We greatly appreciate the $1,000.00 donation given by Eastridge High School that they raised at their Homecoming 5K.
- AJ and Ryan Balsamo recently celebrated their birthday and donated their birthday money, $250.00, to Golisano Children's Hospital in honor of their friend Mia. We appreciate your thoughtfulness.
- We greatly appreciate the support shown by Theresa Masiello and the UR Medical Faculty Group. They held an office collection and raised $422.48 for the kids here at Golisano Children's Hospital.
- The 6th graders at Arcadia Middle School through their Taurus t-shirt sales raised $56.74. Thank you for your support!
- A big thank you to the Midlakes Middle School 6th & 7th graders who collected $260.30 for the kids here at Golisano Children's Hospital.
- Thank you to the members of 9 Mile Point Club, Inc. for their latest $750.00 donation.
- Joey B Studio of Dance recently donated $50.00, thank you!
- We greatly appreciate the recent $750.00 donation from the Buddha Foundation of America for two new wheelchairs!
- Thank you to The College at Brockport, who held their annual Stick it to Cancer Gymnastics event in February and raised $2,000.00 for our Bright Eyes Fund. We appreciate your support.
- We greatly appreciate the health class of Honeoye Falls - Lima High School. Thanks for thinking of the kids of Golisano Children's Hospital with a recent fundraiser that raised $600.00.
- Thank you to the Keshequa Central School Volleyball team for organizing a 5K that raised $1,140.00 for our kids.
- Thank you to Cub Scout Den 203 for your quarter collection that raised $155.72 for the kids at Golisano Children's Hospital.
- The Inaugural Bachelor Auction, held at the Mason Jar in Williamson, was a huge success! Despite a snow storm, they raised $4,451.00 for Golisano Children's Hospital. Thank you!
- Thank you to the Scottish Heritage Society of the Rochester Area for recently raised $1,000.00 through their Robert Burns Dinner & Tartan Day Celebration!
- Thanks to the Pittsford Moms in Motion, Robin Hill, and all those who have attended and organized the various fundraisers, over $1,500.00 has recently been raised for Golisano Children's Hospital in honor of Desiree Stockholm.
- Kudos and much appreciation to Joe Franch of Subway for his recent Hair Today Healthy Kids Tomorrow fundraiser. He grew out his hair and then cut it for the kids, and raised $13,000.00 for our Bright Eyes Fund in the process. Thank You Joe!

Upcoming Community Events

- **May 27 to 30, Roc City Rib Fest**
  1000 East River Road, Genesee Valley Park.
  Starting at 5 p.m. Friday, May 27, the BBQ and music festival will host more than 100 professional barbecuers from across the country competing to win a portion of more than $22,000 in prizes. $1 of every paid entry goes to Golisano Children's Hospital. *www.roccityribfest.org*

- **June 4, Stroll for Strong Kids**
  Genesee Valley Park, 1000 East River Road
  The 5K race begins at 8:30 a.m., followed by the walk at 10:30 a.m.
  The event will continue until 1 p.m. with family-friendly activities, including over a dozen bounce houses, carnival games, photo booths, and much more! The event is presented by Abbott's Frozen Custard. Register, create a team, and fundraise on the Stroll for Strong Kids. *www.givetokids.urmc.edu/stroll*

- **June 11, Team Ali-Gaiter Clambake**
  321 Monroe St., Honeoye Falls
  Honeoye Falls Fireman's Training Grounds from 2 p.m. to 7 p.m.
  Attendees will enjoy clams, pulled pork, hot dogs, salads, desserts, and drinks. There will also be live music, raffles, bounce houses, costume characters and pony rides. Tickets are available in advance and at the door. For more details, please contact Jackie Klube at (585) 704-4124.

- **July 19, RBC Golf Tournament**
  The Rochester Business Classic (RBC) is a charity golf event tournament hosted by the Rochester Businessman's Charitable Organization (RBCO). One of the beneficiaries is Crosby's Fund which benefits Golisano Children's Hospital. For information, please contact Kristi Wenner at *kwenner718@gmail.com*

- **Aug. 26 & 27, Fairport Music Fest**
  This fun-filled event, located along Fairport's Liftbridge Lane, is great for the whole family! Enjoy two days of good music and food for a great cause. Fairport Music Fest has impacted Golisano Children's Hospital in a number of ways and is committed to supporting a patient room, furnishings, and a nurses workstation in the new building. Stay tuned for more information!

- **Aug. 29, Golisano Children's Hospital Golf Classic**
  Monroe Country Club, the Country Club of Rochester, and the Oak Hill Country Club on the West Course
  Golfers from across the Finger Lakes region will come together to play for kids at the 19th annual Golf Classic. Save the date and stay tuned for more information!

- **Save the Date – 2016**
  Oct. 22 – Golisano Children's Hospital Gala

Golisano Children's Hospital Advancement Office
585-273-5948 • www.givetokids.urmc.edu

Scott Rasmussen
Sr. Assistant Vice President for Advancement
585–273–5932

Betsy Findlay
Director of Advancement, Special Events and Children's Miracle Network
585–273–5933

Linda Shillabeer
Gift Processor
585–276–3568

Katie Keating
Office Assistant
585–273–5931

Jennifer Paolucci
Program Manager, Special Events and Children's Miracle Network
585–273–5936

Stephanie Sheets
Assistant Director of Community Affairs
585–275–2268

Sean Dobbin
Senior Public Relations Associate
585-273-2840

Phil Martello
Communications Coordinator
585–276–4298

Mitch Christensen
Public Relations Graphic Design
585–276–5248

Find us on social media:
www.facebook.com/GolisanoChildrensHospital

Twitter: @urmed_gch

Instagram: @urmed_gch

UR MEDICINE | GOLISANO CHILDREN'S HOSPITAL

Non-Profit
US Postage
PAID
Permit No. 780
Rochester, NY

University of Rochester
Office of Advancement and Community Affairs
300 East River Road
PO Box 278996
Rochester, NY 14627–8996