



STRONG KIDS NEWS

Hospital embraces family-centered care

“I DIDN’T KNOW WHAT A PRIVILEGE IT WAS TO HOLD MY HEAD UP AND BREATHE UNTIL I HAD MY SON,” SAID FINA SANTIAGO, MOTHER OF NICOLAS, WHO HAS CONGENITAL FIBER-TYPE DISPROPORTION, A NEUROLOGICAL NON-DEGENERATIVE MUSCULAR DISORDER.

She said the experience of having a sick child is traumatic and that being in a hospital where families are part of the care team is essential to feeling less powerless. That is one of the many reasons Golisano Children’s Hospital at the University of Rochester Medical Center is moving toward family-centered care.

“Family-centered care” may sound like the latest buzzword in healthcare, and while it’s definitely gaining popularity, it’s not just a word; it’s a whole philosophy of care, one that Golisano Children’s

Hospital is embracing with gusto.

Family-centered care puts the family on the same team with the doctors and nurses. It envelopes families into rounding and makes them feel empowered to care for their children. It puts them into positions of influence within the hospital and takes their input seriously.

“This is not just about being kind to patients and families,” said Carla LeVant, pediatric social worker and part of the team spearheading the hospital’s efforts toward providing family-centered care. “This philosophy puts the focus on the patient and family, and it requires the patient and family to be part of the team.”

Santiago recalled one of the 17 times her son has been intubated and extubated. The team was having trouble and Santiago remembered a trick that worked once before. She told the team, and even though it wasn’t in her son’s chart, they trusted her, and it worked.

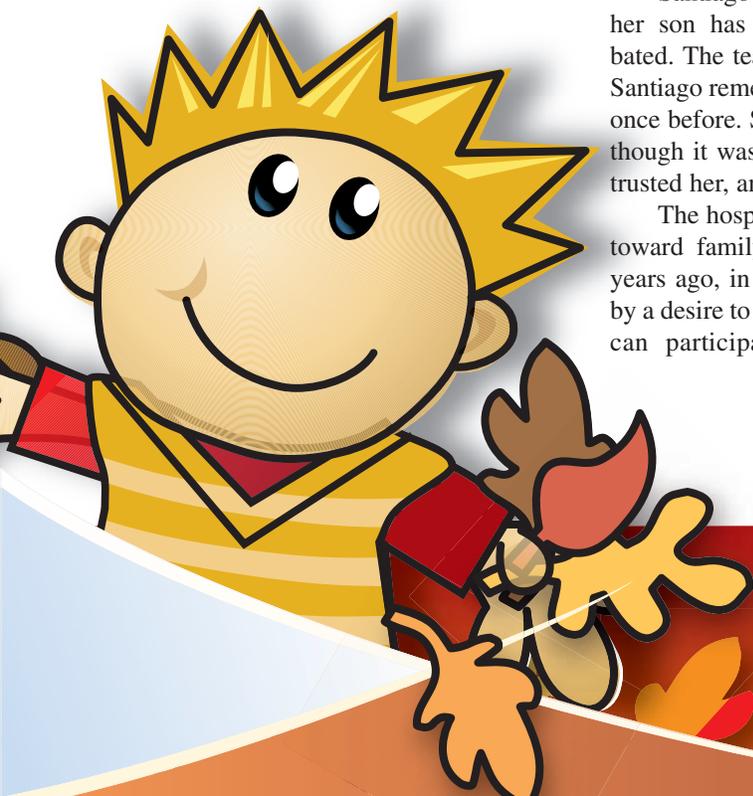
The hospital began its formal efforts toward family-centered care about five years ago, in part driven by parents and by a desire to improve accuracy. Families can participate in the daily rounds,



providing much-appreciated expertise about their children. As a teaching hospital, this means a lot of people in the room, but it also means a lot of opportunities to gather input.

Michael S. Leonard, M.D., associate chief for Pediatric Hospital Medicine, said parents are essential members of the care team. He said that parents help the team by ensuring that information is accurate and complete, providing insight into the patient’s history, and helping providers incorporate patient/family preferences into the treatment plan.

“Parents are the experts about their own children,” Leonard said. “In order continued on page 14



- New board members p. 3
- Record Gala p. 4
- EquiCenter therapy programs p. 6-7



Dear Friends —

Remember those old jokes? “How many (whatever) does it take to screw in a light bulb?” We could do the same thing with healthcare! But how many people does it take to keep a community healthy and safe?

Board of Directors

Mark Siewert, Chair *
Howard Jacobson, Vice-Chair *

Michael Amalfi	Nick Juskiw
Joseph L. Carbone, D.P.M.	Arnold Klinsky
Al Chesonis	Todd Levine
Jeffery Davis	Scott Marshall
John L. DiMarco II	Gary Mauro
Harvey B. Erdle	Kim McCluski*
Roger B. Friedlander	Kathy Parrinello
Jay W. Gelb	Phil Pecora
Jack Goodrich	Gail Riggs
Mike Goonan	Mike Smith*
Jim Hammer	Steve Terrigino
Robert G. Jacobson *	James G. Vazzana

Faculty

Susan Bezek, M.S., R.N., P.N.P.-B.C.
Richard E. Kreipe, M.D.
Thomas K. McInerney, M.D.
Jeffrey Rubenstein, M.D.

Honorary

Jeffrey D. Blanchard
Dave Christa
Judy Columbus
Diane R. Doniger
Wanda Edgcomb
Timothy Fournier
Heather A. Goodbody
John L. Green, M.D.
Deborah Haen
Richard A. Insel, M.D.
Joseph E. Klarberg
Elizabeth R. McAnarney, M.D.*
Donald P. McNelly
Brian Pasley

Ex-Officio

Bradford C. Berk, M.D., Ph.D.
Steven I. Goldstein
Chad Gobel
Douglas Phillips
R. Scott Rasmussen *
Susan Salvador, Ph.D.
Nina F. Schor, M.D., Ph.D.*

How many doctors, nurses, therapists, counselors, teachers, social workers, parents, grandparents, siblings, architects, engineers, philanthropists, policemen, firemen, inventors, scientists, and on and on and on? So many aspects of our lives and our surroundings influence our health. Some we can name today; others impact us in ways we do not yet understand.

What makes a child who would have succumbed years ago live into adulthood today? What will make that child healthy tomorrow? It will take the efforts of many, many people. People who discover what makes a difference for the better. People who translate that discovery into reality. People who teach children and families how to live healthier, safer, more productive lives. People who design and build healthcare facilities and schools and homes. People who provide the funding

that makes it all possible.

In this issue of our Newsletter, you will read about people reaching out to families, people connecting with nature’s creatures, people giving money, people hoping to give back to a system that gave them new life, all for the good of our children and their families. In this Holiday season, we thank you for all you do and look forward to working together with you all year long and in the years to come ... for the sake of our kids.

Sincerely,

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



* Executive Committee

Committed, caring new members join board

WE'RE PROUD TO WELCOME FOUR NEW MEMBERS TO THE GOLISANO CHILDREN'S HOSPITAL'S BOARD. EACH MEMBER HAS A LONG-STANDING RELATIONSHIP WITH GOLISANO CHILDREN'S HOSPITAL AT THE UNIVERSITY OF ROCHESTER MEDICAL CENTER, A PASSION FOR GIVING BACK TO OUR LOCAL COMMUNITY AND A COMMITMENT TO HELP THE HOSPITAL CONTINUE TO GROW AND THRIVE. WE'RE PLEASED TO ANNOUNCE KATHY PARRINELLO, NICK JUSKIW, PHIL PECORA AND JIM HAMMER AS GOLISANO CHILDREN'S HOSPITAL'S NEWEST BOARD MEMBERS.



Kathy Parrinello's leadership skills as chief operating officer at URM and Strong Memorial Hospital have translated well in her work with Golisano Children's Hospital. A strong advocate of the hospital, Parrinello has been a huge help with getting the word out to the Medical Center community about events like Miracle Jeans Day, the Golf Classic and the Ski Outing. We look forward to having her on board.



Jim Hammer, president and CEO of the Hammer Packaging Corporation, has been a supporter of Golisano Children's Hospital for more than 12 years. Hammer Packaging has been a major sponsor of both the Golisano Children's Hospital Gala and the Golf Classic. The company has generously donated the services for printing invitations for the Gala for many years and was awarded the Miracle Maker Award for Outstanding Commitment by a Company in 2008.



Nick Juskiw, president and CEO of Trident Manufacturing, has played a significant role in helping build Golisano Children's Hospital's pediatric intensive care unit, pediatric transport unit and the waiting room in the pediatric surgical suite. Juskiw and his wife, Barb, are supporters of URM's Wilmot Cancer Center as well. Juskiw has been very impressed with Golisano Children's Hospital and looks forward to getting more involved as a board member.



Phil Pecora, the president and CEO of Genesee Regional Bank, is grateful that such an impressive and unique institution is right here in Rochester, should his children ever need its services. He is excited to work towards making a difference in the lives of our community's children by helping Golisano Children's Hospital grow and improve as a board member.

For more information on the new and current Golisano Children's Hospital board members, visit: <http://bit.ly/GCHboard>.

Joyful and gracious Gala guests raise a record \$874,000



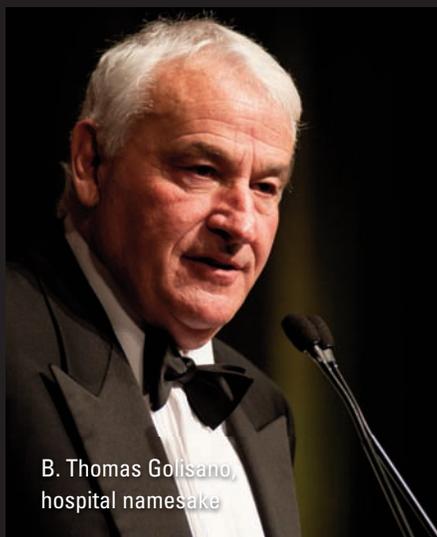
Dr. Nina F. Schor,
pediatrician-in-chief



Dr. Walter Pegoli,
Mason Mitchell and
Howie Jacobson,
Gala auctioneer



Beverly and Wayne LeChase,
honorary chairs



B. Thomas Golisano,
hospital namesake

Just a few weeks before his big night out at the 23rd annual Golisano Children's Hospital Gala, Mason Mitchell had been recovering from yet another surgery performed by Walter Pegoli, M.D., chief of Pediatric Surgery. To the unknowing eye, one might have never recognized that the happy toddler, donned in a kid-sized tux, was born with a congenital diaphragmatic hernia. Much like the Gala itself, Mason's jubilant spirit and underlying gratitude for the hospital was palpable.

This year's Gala was a remarkable one, to say the least. More than 800 guests helped raise a record-breaking \$874,000 for Golisano Children's Hospital. The event was held in honor of Peter Formicola, a devoted hospital supporter and board member, who sadly passed away shortly after the 2009 Gala, which he chaired with his wife, Allison. The fund-in-need, new anesthesiology machines to help kids undergoing procedures breathe more easily, was fulfilled within minutes. Seven machines were purchased by Honorary Chairs Wayne and Beverly LeChase, Board Member Roger Friedlander and his wife Carolyn, Board Member Gail Riggs and her husband Patrick, Heron Hill Winery owners John and Jo Ingle, the Fairport Music and Food Festival group, the pediatric anesthesiologists and pediatric surgeons and Mason's parents, Despina and Scott, who raise funds through the Keeping Hope Strong fundraiser in honor of their beloved son. Special thanks to our major sponsors: The Cabot Group, Castle Office Group, Tops Markets, William and Mildred Levine Foundation, Hammer Packaging, LeChase Construction, and MVP Healthcare.

Pediatric nurses inspire leukemia patient to follow in their footsteps

JUST TWO MONTHS BEFORE HER HIGH SCHOOL GRADUATION, PAIGE DURHAM STARTED FEELING A HORRIBLE PAIN IN HER LEFT LEG. “I’M NOT ONE TO COMPLAIN, SO WHEN I ASKED MY MOM TO TAKE ME TO THE E.D., IT WAS A BIG DEAL,” PAIGE RECALLED.

Paige’s instincts about the urgency of her situation were spot on. Some tests, x-rays and blood work at the Pediatric Emergency Medicine Department at the University of Rochester Medical Center (URMC) revealed a scary truth: Paige had leukemia. There are a lot of ways that an 18-year-old could take such jarring news. As the senior class president at Lyons High School with a few college credits already under her belt, Paige had a world of possibility in front of her. It’s hard to imagine having the content of one’s character tested at such a hope-filled age.

Yet Paige’s optimistic spirit endured. She doesn’t remember much about the physical and emotional pain she felt when she first learned of her life-threatening diagnosis. What she does remember speaks worlds of the powerful spirit behind the once ailing teen. Paige remembers the kindness of the nurses at URMC’s Golisano Children’s Hospital who treated her.

“I really, really liked it, honestly,” said Paige. “Getting used to any hospital is difficult, especially when you’re thrown into it, but I loved all the nurses

up there and the atmosphere — the biggest thing was the nurses and how friendly everyone was.”

Paige stayed in the hospital six weeks after her initial admission. Her weakened immune system brought Paige back to the hospital several times, but she graduated on time, with her friends. Laurie Milner, M.D., associate professor of Hematology and Oncology at Golisano Children’s Hospital, saw Paige frequently to help her fight the leukemia with chemotherapy treatment and on July 28, Milner assisted Paige with a successful bone marrow transplant.

Today, a year and a half after Paige began her battle with cancer, Paige is doing remarkably well and is on her way to getting a Bachelor’s degree in nursing at Roberts Wesleyan College.

“I’ve always wanted to go into the medical field,” said Paige, “Getting to know the nurses on the pediatric and bone marrow transplant units inspired me that much more. I know what type of nurse I want to be because of the wonderful nurses I was touched by at the hospital.”



Carlos Carballada



Joe Floreano holding sculpture made in honor of Peter Formicola.



“I know what type of nurse I want to be because of the wonderful nurses I was touched by at the hospital.”

— Paige Durham



Paul Bullen on Harley after the Special Olympics

EquiCenter's therapy programs help patients grow

THE EQUICENTER FEELS A WORLD AWAY FROM THE BUSY, METROPOLITAN CITY OF ROCHESTER AND YET ITS CLOSE PROXIMITY ON 178 ACRES IN MENDON FOR PATIENTS, FAMILIES AND VOLUNTEERS MAKES THE CENTER ALL THE MORE PRICELESS.

"I don't know if Rochester realizes they have a gem," said Beth Bullen, a nurse at the Kirch Center at Golisano Children's Hospital.

Over the course of the past year, Beth's son, Paul, has had weekly sessions at the EquiCenter with a nationally certified therapeutic riding instructor, Sara Drennen, and a horse named Harley. Eleven-year-old Paul has unique abilities, having been diagnosed with autism. Beth has been amazed with the progress Paul has made over the course of his therapy sessions. Paul's self-esteem has been boosted dramatically, especially since he participated in the equestrian event at the Special Olympics. He hasn't been inter-

ested in athletics, but the therapeutic horseback riding has helped Paul improve his core strength, balance and flexibility. As Harley moves forward, back and side to side, Paul has to make adjustments, which encourage his muscles to relax, open up and stretch. His verbal skills, sense of responsibility and level of trust are all much stronger as well.

"The benefits for our participants have turned out to be much broader in scope than we had anticipated," said Jonathan Friedlander, president and CEO of the EquiCenter.

The center has much to be proud of as it celebrates its fifth anniversary and co-founders Jonathan and Stacy Friedlander

have high aspirations for what the future holds for nationally accredited nonprofit therapeutic equestrian center. In 2004, the couple founded the EquiCenter to provide highly beneficial therapeutic programs to children and adults with physical and emotional challenges, such as cerebral palsy, muscular dystrophy, epilepsy, visual impairments, autism and traumatic brain injuries.

Therapeutic riding instructors, who are nationally certified by the North American Riding for the Handicapped Association, work with doctors, therapists, parents and riders like Paul to develop individualized intervention plans specific to each child's needs. The center



Jonathan Friedlander

“Equestrian therapy is a wonderful and unique service, which enhances the well-being of children in our community,”

— Elizabeth R. McAnarney, M.D.



Stacy Friedlander

has quickly become a resource for many other populations as well, including at-risk youth, veterans and senior citizens.

Golisano Children’s Hospital is one of the EquiCenter’s biggest allies in the center’s quest to grow and expand its community outreach. Faculty members from Golisano Children’s Hospital sit on the EquiCenters health advisory board, including Elizabeth McAnarney, M.D., Golisano Children’s Hospital’s former pediatrician-in-chief, Stephen Sulkes, M.D., director of the Strong Center for Developmental Disabilities and Richard Kreipe, M.D., associate professor of Adolescent Medicine at Golisano Children’s Hospital.

“Equestrian therapy is a wonderful

and unique service, which enhances the well-being of children in our community,” said McAnarney, “Thanks to Golisano Children’s Hospital’s working relationship with the EquiCenter, we’re continuing to find new ways children can benefit from this type of therapy.”

The partners have several projects in the works, including Strong Strides. The program will provide equine-assisted therapy to children recovering from cancer and their families, to help them cope with the emotional tolls the disease can take. In addition to helping families, Strong Strides, which is funded by the Pediatric Links with the Community Grant Program and the Community Ped-

iatrics Advisory Council, will also provide an opportunity to gather data on the benefits of equestrian therapy. The data will help provide evidence to support the benefits patients and families already see.

Paul’s mom Beth, a cancer survivor, hopes to volunteer in the Strong Strides program to share her story with families and provide them with emotional support. “When I look at this program and what it does, I feel so blessed that it’s here and I want to help,” said Beth. “It makes you want to pay it forward.”

For info.: <http://www.equicenterny.org/>. To see a video about our partnership, visit www.youtube.com/Give2GCH.



HOLIDAY WISH LIST

Help kids feel like kids this holiday season



Children stay at Golisano Children's Hospital at the University of Rochester Medical Center anywhere from a day to months at a time. The hospital makes sure that kids still feel like they're kids with items like kid-friendly literature, age-appropriate toys and arts and crafts. If you'd like to make a gift this holiday season, please visit www.givetokids.urmc.edu and click the Sandy Strong button titled, "Make a Gift."

To find out how to donate items to Golisano Children's Hospital, visit our "Donate Items" page online at <http://bit.ly/DonateItems>. Golisano Children's Hospital's 2010 Wish List includes small and big ticket items, ranging from crayons to defibrillators, to give donors options as to how they'd like to help.

Golisano Children's Hospital's dedicated team of Child Life specialists has two wish lists: one online gift registry from the hospital's Children's Miracle Network sponsor, Walmart, and another set of items listed online. The Child Life Department is there to ensure that children's emotional and developmental needs are being treated along with their medical needs. To see what items are on Child Life's lists, visit <http://bit.ly/ChildLifeWishList>.

Because our patients are acutely ill, it is not possible to deliver gifts/directly to the children. You're welcome to drop off or ship donations. Once you've reviewed the list of items requested at <http://bit.ly/DonateItems>, please be sure to review safety guidelines and drop-off and shipping procedures.

Please send photos of Community groups and individuals who donate items to sandy@urmc.rochester.edu, with a description of who you are, what you're giving and why you decided to give. We'll celebrate your donation on our Caught Doing Something Good Facebook album. Please contact Michael Fahy at Michael.fahy@rochester.edu or (585) 276-5176 with any questions.



▲ The DeWitt Road Student Council collected toys for children at Golisano Children's Hospital in honor of Tessa, the Student Council secretary, and other students at DeWitt who have been treated at the hospital. Tessa has spent more than 100 days at Golisano Children's Hospital over the past two and a half years.

The Kids Miracle Makers Club donated special audio/visual equipment and a check for \$224.91 to Golisano Children's Hospital. Club members raised funds for the equipment and donation with proceeds from their Balloon Bonanza Project.



Community Spotlight

Making Something Remarkable — The Tim Milgate Golf Fundraiser

The annual Tim Milgate Golf Fundraiser is grounded in hope. Deb Milgate-Moyer and her family have chosen to turn a tragic situation into something remarkable. In 1995, Tim Milgate was murdered in his home by a culprit who has yet to be identified. For more than a decade, the Milgate and Moyer families have honored the memory of Tim Milgate by holding an annual golf event, which has raised tens of thousands of dollars annually for children treated at Golisano Children's Hospital. The event has raised more than \$250,000 for local charities, including more than \$135,000 for the children's hospital. Funds raised have helped with renovations for the Pediatric Treatment Center, which re-opened in the summer of 2008 and provides a sunlit playroom and large, private rooms for families who come to the hospital for outpatient treatment.

Each year, Milgate-Moyer chooses an "Inspiration Child" to recognize and hold the tournament in honor of. She works with families to figure out what they need and then reached out to community sponsors to find ways to donate to families. Gifts in the past have ranged from handicap-accessible ramps to help children get around to vacation trips for much-needed rest and relaxation for families. We are so appreciative of the family's dedicated and spirited endeavor to make a positive impact in the Finger Lakes community. Thank you so much for all that you do.



A History Rooted in Giving — Brockport Dance Marathon

The Brockport Dance Marathon has continued to grow and prosper over nearly four decades thanks to strong leadership, an enthusiastic student body and a committed community of supporters. To date, the event has raised a remarkable \$225,000 for Pediatric Hematology and Oncology Division at Golisano Children's Hospital at the University of Rochester Medical Center.

Curt and AnnMarie Hamlin have been organizing the dance marathon from the event's onset. Students at Brockport High School start preparing for the annual event well before they get their dancing shoes on in March. They reach out to family members and friends for sponsorships. A committed band of students behind the event, ready and willing to pull an all-nighter of dancing out of the goodness of their hearts, have enabled the event to retain its high average of about \$15,000 in donations raised year after year. Golisano Children's Hospital is so grateful to the members of the Brockport community who carry on this noble cause to help children battling and coping with cancer. The students' passionate commitment to their peers is truly an inspiration to us all. To find out more about the 2011 event, which will run from 8 p.m. March 18, to 8 a.m. March 19, please visit www.givetokids.urmc.edu.



14 Annual Golf Classic leads to an optimistic course



A little wet weather didn't dampen the spirits of the hundreds of golfers who participated in the 14th annual Golisano Children's Hospital Golf Classic. The annual classic spans far and wide and this year's event on Sept. 13 was no exception, with more than 470 golfers across three golf courses: Country Club of Rochester, Ravenwood Country Club, Monroe County Club.

Avid and novice golfers alike came out to support children treated at Golisano Children's Hospital at the University of Rochester Medical Center. The day-long event ended with a riveting speech from a family who knew the benefits of having a stellar hospital close to home all too well.

David and Michelle Tillapaugh have four daughters and a very special son, Connor, now 14, who was diagnosed with a rare disorder called X-linked adrenoleukodystrophy. The family told attendees that, thanks to an expert diagnosis from Jonathan Mink, D.C., chief of Child Neurology at Golisano Children's Hospital, and a timely bone marrow transplant from Craig Mullen, M.D., Golisano Children's Hospital's chief of Pediatric Hematology and Oncology, Connor is alive and well today. To read more about Connor, visit <http://bit.ly/ConnorsStory>.

The event was a big hit and thanks to generous sponsors and donors, the 2010 Golf Classic raised an astounding \$267,000 for Golisano Children's Hospital. Special thanks to our major sponsors of this year's tournament:

Presenting Sponsors

LeChase Construction
Deloitte and Touche

Platinum Sponsors

Cisco/Fingerlakes Technologies Group
IBM
Ikon Office Solutions
Med Assets
Navitech
Network Appliance

Save the date for the 2011 Golf Classic: Monday, Sept. 12, 2011

To learn more about Golisano Children's Hospital's Golf Classic, other hospital events and stories about patients who have sought care here, visit www.givetokids.urmc.edu.



Children's Miracle Network spotlight



Thanks to Tops Friendly Markets, Shirley Visconte doesn't have to worry about buying groceries for an entire year. Patient Bryce Czekanski pulled her ticket to win \$5,200 worth of groceries from Tops, amounting to \$100 every week. Tops raised \$36,000 for Golisano Children's Hospital through the Tops Grocery Giveaway promotion, as well as \$45,000 through Children's Miracle Network (CMN) balloon sales in June. Thank you so much to our strong supporters at Tops Friendly Markets.

Special thanks to Kinney Drugs. Between March 14 and May 23, local stores in Canandaigua and Lyons gave patrons the opportunity to contribute to Golisano Children's Hospital at the University of Rochester Medical Center and raised \$4,000.

The annual Credit Union Cherry Blossom Ten Mile Run, held in Washington, DC, brings credit union participants from across America to join together. More than

15,000 runners participated and raised nearly \$860,000 for children's hospitals affiliated with Children's Miracle Network across America. Locally, Pittsford Federal Credit Unions and Summit Federal Credit Unions participated to provide \$8,300 for Golisano Children's Hospital.

The Potter's House Christian Fellowship Church held a fundraiser in the parking lot of the Henrietta Walmart and brought in \$200 for Golisano Children's Hospital.

The Penfield-Perinton Kiwanis Club raised \$2,000 for during their annual golf tournament, held this past summer.

Hospital supporters went casual for kids on Sept. 15, donning jeans for the second annual Miracle Jeans Day. Local businesses and organizations donated \$12,820 to Golisano Children's Hospital for the annual event. Thank you to all who participated.

Upcoming Events

Nov. 26 – Jan. 4

Nights of Shimmering Lights

Wayne County Fairgrounds, 250 West Jackson St. in Palmyra. A light and sound show that shines more than 200,000 lights brightly for the holiday season will donate a portion of admission proceeds to Golisano Children's Hospital. Print the gift card at <http://bit.ly/nightsoflights> and bring it to one of the shows between 5 and 9 p.m., Sunday through Thursday, and \$2 will go towards helping our region's children. Visit www.nightsofshimmeringlights.com for more info.

Dec. 17

Rainbow Classic

University of Rochester Palestra Stadium. This annual rivalry between Pittsford high schools has done a world of good for patients at Golisano Children's Hospital. Pittsford Mendon and Pittsford Sutherland High Schools will duke it out beginning with a women's game at 6 p.m. and a men's game following at 8 p.m. For more information, please call the Pittsford Central School District Athletic Department at (585) 218-1062.

Jan. 18 and Feb. 15

Battle of the Beaks

St. John Fisher and Nazareth Colleges. The battle between the "beaked" school teams is back on this year. The first games between the women's and men's teams will begin at 6 p.m. Jan. 18, at St. John Fisher College with the second starting at 6 p.m. Feb. 15, at Nazareth. The games will have t-shirts for sale, a prize raffle and a walk of fame with photos of student athletes who have been touched by Golisano Children's Hospital. Tickets are \$5 and can be reserved ahead of time by contacting Becky Fahy at (585) 389-2735 or rfahy6@zimbra.naz.edu.

Feb., date TBD

Winter Walk for Strong Kids

St. John Fisher College. Get kids out and moving this winter with this second annual fundraiser for Golisano Children's Hospital. Following a short walk, families can partake in games and fun winter-themed activities. Organizers are asking for a \$10 donation to participate and \$25 for a commemorative t-shirt. For more information, please contact

Jennifer Granger at (585) 385-8315 or jgranger@sjfc.edu.

Feb. 5

Cycle for Hope

Participating clubs around the Rochester area. Spin for good at the annual Cycle for Hope event, which benefits Golisano Children's Hospital and Camp Good Days. To participate in the 6-hour spin-a-thon, which will run 8 a.m. to 2 p.m., please visit www.campgooddays.org/CFH/CFHmain.htm or call (585) 273-5948.

Feb. 10-12

100.5 FM Drive for Miracles Radiothon

Strong Memorial lobby and Eastview Mall. Tune in for miraculous stories of hope and strength during this annual radiothon, which raises funds for Golisano Children's Hospital. For more information on volunteer opportunities during the Radiothon, visit www.giveto.kids.urmc.edu or call Betsy Findlay at (585) 273-5933.

Show some Valentine's love at this year's Radiothon

Valentine's Day isn't just about romantic dinners, chocolates and bouquets. It's also for showing love for Golisano Children's Hospital through the Drive for Miracle Radiothon.

This year's 11th annual radiothon is scheduled to take place 5:30 a.m. to 7 p.m. Thursday, Feb. 10, and Friday, Feb. 11, at the Strong Memorial Hospital lobby and 8 a.m. to 7 p.m. Saturday, Feb. 12, at Eastview Mall. Listeners need only turn the radio dial to 100.5 FM The Drive during those hours to hear updates from patients and families you know and new tales from families sharing their stories for the first time.

Find out how Anders Swanson, who suffered from a rare brain tumor, is doing today. Listen as the parents of Cory Milburn, a little boy born 15 weeks premature, talk about their passion for giving back to Golisano Children's Hospital. Mark your calendars to tune in for these incredible stories and more at the annual radiothon.

There are many ways you can help:

♥ **Sign up to be a Change Ranger.** Why not make your planned gift a little bit bigger by asking friends and family members to join in with a group donation? Change Rangers are hospital supporters who gather donations on behalf of



Golisano Children's Hospital at the University of Rochester Medical Center. Visit www.givetokids.urmc.edu to learn more about what it takes to be a Change Ranger.

♥ **Call (585) 241-KIDS to make a gift.** Pick up the phone and make a gift to help kids in the Finger Lakes region. Volunteers will be answering calls at this phone number, which will only be open during radiothon hours.

♥ **Sign up to volunteer.** If you'd like to be one of those hospital advocates picking up the phone and taking donations, call (585) 273-5948 and ask how you can help.

♥ **Make a gift online.** Visit: www.givetokids.urmc.edu to donate to

Golisano Children's Hospital.

♥ **Text "STRONG" to 85944** to make a \$10 donation.

For more information on the upcoming radiothon, call Golisano Children's Hospital's Office of Advancement at (585) 273-5948 or visit www.givetokids.urmc.edu. We welcome you to stay connected and learn about what's going on at the hospital by signing up for our e-newsletter at <http://bit.ly/GCHsignup>, checking out our Facebook page at www.facebook.com/GolisanoChildrensHospital, watching videos on our YouTube channel at www.youtube.com/Give2GCH or following our Twitter account, www.twitter.com/sandy_strong.



Children with high blood pressure more likely to have learning disabilities

Children who have hypertension are much more likely to have learning disabilities than children with normal blood pressure, according to a new University of Rochester Medical Center (URMC) study published today in the journal, *Pediatrics*. In fact, when variables such as socio-economic levels are evened out, children with hypertension were four times more likely to have cognitive problems.

“This study also found that children with hypertension are more likely to have ADHD (attention deficit hyperactivity disorder),” said Heather R. Adams, Ph.D., an assistant professor of Neurology and Pediatrics at URMC, and an author of the study.

“Although retrospective, this work adds to the growing evidence of an association between hypertension and cognitive function. With 4 percent of children now estimated to have hypertension, the need to understand this potential connection is incredibly important.”

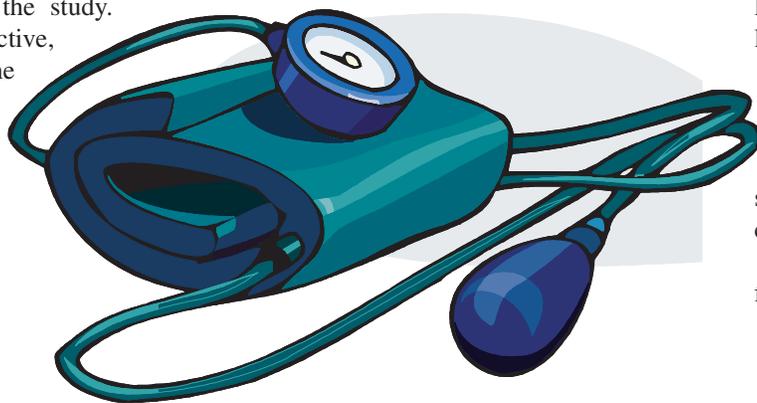
Among the study’s 201 patients, all of whom had been referred to a pediatric hypertension clinic at URMC’s Golisano Children’s Hospital, 101 actually had hypertension, or sustained high blood pressure, determined by 24-hour ambulatory monitoring or monitoring by a school nurse or at home. Overall, 18 percent of the children had learning disabilities, well above the general population’s rate of 5 percent. But the percentage among those without hypertension was closer to 9 percent, and among those with hypertension, the rate jumped to 28 percent. All of the children were between 10- and 18-years-old, and the children’s learning disability and ADHD diagnoses were reported by parents.

This study is part of a series of hypertension studies by Golisano Children’s Hospital researchers, led by Principal Investigator Marc Lande, M.D., a pediatric nephrologist, but it was the first that included children with ADHD. Previous studies excluded them because ADHD medications can increase blood pressure. Researchers included them this time because, although it is possible that some of the children’s hypertension was caused by medications, it is also possible that the higher rate of ADHD among children with hypertension is a reflection of

neurocognitive problems caused by hypertension. Twenty percent of the children with hypertension had ADHD whereas only 7 percent of those without hypertension had ADHD among the study participants. And even when ADHD was factored out of the analyses, there was still a higher rate of learning disabilities in the hypertensive, compared to the non-hypertensive group of children.

“With each study, we’re getting closer to understanding the relationship between hypertension and cognitive function in children,” Lande said. “And this study underscores the need for us to continue to tease out the potential risk children with hypertension have for learning difficulties at a time when learning is so important. It may be too early to definitively link hypertension and learning disabilities, but it isn’t too early for us, as clinicians, to ensure our pediatric patients with hypertension are getting properly screened for cognitive issues.”

The study was funded by a grant from the National Institutes of Health.



“With each study, we’re getting closer to understanding the relationship between hypertension and cognitive function in children. And this study underscores the need for us to continue to tease out the potential risk children with hypertension have for learning disabilities at a time when learning is so important.” — Marc Lande, M.D.

“Parents are the experts about their own children. In order for us to provide the best possible care, we need to all be on the same page.” — Michael S. Leonard, M.D.

A team of Dr. Leonard, hospital staff and the Morrell family, discusses the care plan for Zachary.



Family-Centered Care

continued from cover

for us to provide the best possible care, we need to all be on the same page.”

Kate Ostrander, R.N., a nurse and discharge coordinator, said that family participation is key, not only to the care team, but also to the child’s long-term success, especially when it comes time to go home.

“Everything goes smoother when parents are on the team and everyone is on the same page,” Ostrander said. “Families can go home sooner and with more confidence in caring for their child.”

Ostrander said the nursing staff encourages families to get involved with the care and feeding of their children, whenever medically appropriate. For example, nurses will train families on how to feed their child through a gastronomy-tube (“g-tube”), so they can feel more involved in the care but also so they can ask questions and feel comfortable doing it before they go home.

In the neonatal intensive care unit (NICU), staff started incorporating the family-centered care philosophy into practices several years ago. Changes have included allowing families to stay during rounding and participate in the conversation about their baby’s care.

Patrick Hopkins, N.P., a nurse practi-

tioner in the NICU, said that parents are essential to the care of their children, especially in the NICU, and family-centered care recognizes that.

“Ultimately, (family-centered care) will be good for the babies, for the parents and for the staff,” Hopkins said.

Historically, when families arrived to visit their babies, NICU staff called back to the nurse caring for the baby before the family scrubbed up and headed back. In the spirit of family-centered care, the NICU is trying out no call-backs to see if families prefer that. Hopkins said the trial has had its ups and downs because sometimes families arrive during procedures and they have no warning, but more often, families appreciate being able to take part in their child’s care. Hopkins recounted an instance when a mother arrived just as

the team was starting a medical procedure on her baby. They gave her the choice to either stay or come back when they were finished.

“Mom stayed and held the baby’s hand,” Hopkins said. “The baby was not at any risk, and, in fact, the baby was probably more comfortable. Research is showing parents can provide extra comfort.”

Hopkins said the hospital has made significant improvements in its adherence to the philosophy and is working on more, including making the entrance to the NICU more welcoming and changing the signs to eliminate the word “visitor” (because parents are welcome in the hospital anytime and are not visitors to their own children).

“Family centered care is a journey, not a destination,” Hopkins said.



The Santiago family

special thanks

- The sixth annual Fairport Music and Food Festival was a huge success raising \$93,000. Thank you so much to the festival's amazing event organizers, volunteers and participants.
- The 21st annual Ten Ugly Men Festival supported a number of charities this summer, including Golisano Children's Hospital. Your donation of \$9,000 is greatly appreciated.
- Thank you to the Budda Foundation of America for their recent donation of \$1,100 in October following their annual golf tournament.
- Nancy Eichorn donated \$1,438 from proceeds from her annual garage and bake sales, and chicken barbecue, which featured live music for the first time. Thanks, Nancy.
- The 3rd annual Masters of Magic performance generated \$1,540 from their event. Thank you to everyone involved!
- We appreciate the Aquinas Institute's recent contribution of \$187 after money was collected in home rooms throughout the school. Thank you all.
- The band Hard Logic selected Golisano Children's Hospital as their charity of choice for a \$250 donation after they played at the Rochester Home Builder's Association Homearama event. Thanks to both groups.
- Our appreciation goes out to The Raytec Group for an incredible donation of \$4,557.87 from their 6th annual Carnival of Caring.
- Mrs. Kornfeld's elementary class at the Pinebrook School in Rochester donated \$40 from a card sale they held. Thanks to all the students and teachers that participated!
- We want to thank the Golden Treasures Talent Show for donating \$546 following their event.
- Thanks so much to the Orleans BizKids program, who donated \$31.13 from their two lemonade stands.
- The Kool-Aid Stand and Bake Sale put on by Kristine Cerami & Co. generated \$148 in proceeds, which were all donated to Golisano Children's Hospital. Thanks everyone.
- We offer thanks to the Kids Miracle Making Club, which donated \$224.91 and audio-visual equipment from the Golisano Children's Hospital Wish List this October. Thank you all so much.
- Finally, thank you to the Country Way Corn Maze team, who donated \$266.50 from their maze proceeds to the hospital. We appreciate all your efforts.

Many thanks to these and all generous supporters and event organizers that benefit Golisano Children's Hospital!

If you are interested in hosting a fundraiser please contact Michael Fahy at: michael.fahy@rochester.edu or (585) 276-5176.



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

Scott Rasmussen
Assistant Vice President for Advancement
585-273-5932

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

Karen Lynch
Associate Director of Advancement
585-273-1462

Michael Fahy
Assistant Director of Community Fundraising
585-276-5176

Jennifer Paolucci
Program Assistant, Special Events and
Children's Miracle Network
585-273-5936

Michele Wild
Gift Processor
585-273-5931

Heather Hare
Assistant Director, Public Relations and Communications
585-273-2840

Katie Sauer
Public Relations Assistant
585-276-4298

Mitch Christensen
Public Relations Graphic Design
585-276-5248



Find us on facebook

www.facebook.com/GolisanoChildrensHospital

givetokids.urmc.edu



UNIVERSITY of
ROCHESTER
MEDICAL CENTER

MEDICINE *of* THE HIGHEST ORDER

GOLISANO

CHILDREN'S HOSPITAL

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

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

