



STRONG KIDS NEWS

A family's battle with dystonia: triumphs and tribulations

IN OCTOBER 2007, CASEY BEAGELL NOTICED THAT HER 7-YEAR-OLD DAUGHTER, KAMRI, WAS HAVING TROUBLE KEEPING HER ARM BENT WHEN WRITING. "KAMRI'S ARM KEPT STRAIGHTENING ON ITS OWN," CASEY SAID.

Casey knew exactly what this meant. Casey, her mother Chrys and her sisters Cory and Kelly, have mild forms of dystonia, a neurological disease that can be passed down genetically. Casey already knew a lot about the doctor she was going to see too, since her 14-year-old nephew Riley Segreue had been seeing Jonathan Mink, M.D., Ph.D., professor of neurology and pediatrics at Golisano Children's Hospital at the University of



Rochester Medical Center, for about five years. What Casey didn't know was how quickly the disorder would rob Kamri's ability to walk, eat and even sleep.

Dystonia had manifested itself very subtly in Chrys, Casey, Cory and Kelly. Chrys and Kelly had symptoms akin to carpal tunnel syndrome. However, Casey's nephew Riley's symptoms were much more severe and were getting progressively worse, so Casey knew the potentially debilitating effects the disorder could have on Kamri.

Over time, five of the six children the three sisters had had been diagnosed with dystonia, though Kamri and Riley have had far more disabling conditions than their siblings and cousins. As was the case with Riley, Kamri's condition grew to be very painful with continuous muscle spasms and cramps, but the disorder also progressed at an alarmingly rapid rate. Within six months, Kamri had minimal control over her body.

"Kamri went from having a mild case to not being able to walk, sit, eat or use the bathroom over the course continued on page 4

Kamri Beagell at school. (Site photo provided by Binghamton Press & Sun-Bulletin)



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Dear Friends —

What exactly is the Golisano Children's Hospital at the University of Rochester Medical Center? This may seem like a silly question, coming as it does from the Pediatrician-in-Chief!

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But this issue of our newsletter is a perfect example of why this question is not silly at all.

The University of Rochester School of Medicine and Dentistry and the University of Rochester School of Nursing are components of the University of Rochester Medical Center. The Schools are, in turn, divided into Departments and Centers, some of which are involved in patient care (e.g., Pediatrics) and others of which are not (e.g., Biochemistry). Those that are involved in patient care provide these services in the hospitals, outpatient facilities and laboratories that are also parts of the University of Rochester Medical Center.

Golisano Children's Hospital is one of these hospitals; it provides children's healthcare services, advances the state of such services through research and trains healthcare and related providers within the University of Rochester Medical Center. But the people make up Golisano Children's Hospital come from many Departments (e.g., pediatric orthopedists are from the Department of Orthopedics; pediatric neurologists are from the Department of Neurology; pediatric endocrinologists are from the Department of Pediatrics) and Schools (e.g., pediatric dentists are from the School of Medicine

and Dentistry; pediatric nurse practitioners are from the School of Nursing). And the Ph.D.-trained doctors who work at the Golisano Children's Hospital are researchers, clinical care providers, therapists — you name it!

If you are starting to realize that Golisano Children's Hospital is not "one thing" and cannot exist in just "one place," then you are absolutely right! Most people who say "Golisano Children's Hospital" are thinking of our inpatient wards. And that is a very large and important part of where we do what we do. But because making and keeping children healthy is a very complicated and multifaceted job, we must be whatever and wherever children need us!

In this issue of the newsletter, you will read about just a few of our programs for clinical care, research and education and you will meet neurologists, nephrologists, orthopedists, general pediatricians and lots of our fabulous friends in the community, all working to make the lives of children and their families better! Because of them and all of you, the holidays have a very special meaning for all of us at Golisano Children's Hospital!

All the best for a wonderful holiday season,

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

Pediatricians learn to fight fat at front of lines

WITH AN OBESITY EPIDEMIC SWEEPING THE GLOBE, ROCHESTER'S CERTAINLY NOT BEEN LEFT BEHIND — 30 PERCENT OF MONROE COUNTY KIDS (OVER AGE 2) ARE EITHER OVERWEIGHT OR OBESE, A FIGURE THAT'S COMPARABLE TO NATIONAL AVERAGES.

"This isn't caused by one single factor, but a thousand tiny issues that feed into the problem," said Stephen Cook, M.D. M.P.H., an assistant professor of Pediatrics at URMC's Golisano Children's Hospital, who mapped the county's childhood obesity rates by zip code this past winter. "Kids say that school lunches are gross, so they fill up on chips and candies. Busy families have less time to sit down to nutritious, home-cooked meals. Parents feel uncomfortable letting their kids run around the neighborhoods till dusk, and instead, kids resort to watching TV, surfing the net, and texting constantly. Plus, our society has increased portion sizes and cheap, fast food outlets are open all hours."

While Rochester may be saddled with extra pounds like the rest of nation, what's less typical is the community's sense of shared responsibility when it comes to kids' health — a practice called "community pediatrics." Area daycare experts, health policy pundits, school boards, pediatricians (including Cook), even food suppliers all have pulled together for the Greater Rochester Health Foundation's five-pronged Strategic Plan for the Prevention of Overweight and Obesity. Jointly, they're aiming to dramatically scale back the county's childhood obesity rates over the next decade.

Some task force members are focusing on policy change; others are incorporating developmentally appropriate teaching tools, like nutrition-themed puppet shows, into

daycares. Still others are overhauling school lunches.

"My project is focusing on another front — the pediatrician's office," Cook said.

He estimates that, by working with the 20 largest local practices to step up obesity surveillance and prevention efforts, the project will reach two-thirds of the kids in Rochester. "That'd be a sort of tipping point, and chance to do some really good interventions with families, one-on-one," he said.

But doctors are already burdened with constantly changing best-practice guidelines and busy schedules. It can be overwhelming for them to adopt new approaches to keeping kids on a healthy weight trajectory — techniques such as "motivational interviewing" to more effectively broach issues of weight, nutrition and physical activity, using the correct BMI growth curves (a clinical measure by which healthy weights are assessed), and even administering simple lifestyle surveys during well-child visits.

"The last thing we want to do is demand that pediatricians simply tack more items onto their checklists," Cook said.

Via one-year "learning collaboratives," Cook and Health Foundation collaborators are offering individual practices the chance to seriously rethink their roles in stemming the obesity tide. Core teams (composed of a physician, nurse, office staff member, and even a patient's parent) at each participating practice attend quarterly training workshops and

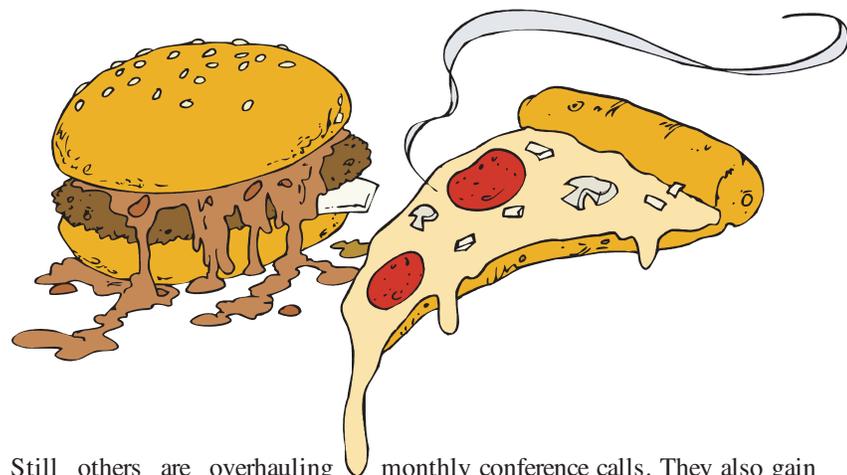
monthly conference calls. They also gain access to a tool-kit of helpful resources, like BMI measurement tools for quick, in-office computing and sample "scripts" for counseling overweight patients. Perhaps most importantly, though, is the built-in networking support: these teams can swap clever ideas of what works and what doesn't with other learning collaborative peers.

"One practice held a canal-side run with their patients," Cook said. "Another shared a trick — setting the office's electronic medical record to remind him to update parents on their kid's 'weight status.' Others advised that discussions about a child's unhealthy weight were more effective when the talk revolved around adopting healthier lifestyle habits, not dropping a certain number of pounds."

And that's the goal, Cook said — shared learning.

"We're figuring out what works. At the end of the year, these learning collaborative participants emerge as the experts; they're veterans who have found practical ways to incorporate new clinical guidelines," he said. "They, in turn, will talk to next year's round of newcomers — allowing us to rely less on outside consultants, because more or less, we've grown our own."

Last year, nine practices completed their cycle in the learning collaborative.



Dystonia

continued from cover

of months,” explained Casey. “Kamri was never comfortable because she couldn’t adjust her body to sit or lie down. We would have to wait for hours at night until her body had spasmed enough to get into a horizontal position where she could lie comfortably enough to go to sleep. When she slept, the spasms completely went away, but the second she woke up, they started all over again.”

Since Casey and her sisters live in Binghamton, which is three hours from Golisano Children’s Hospital, Casey frequently communicated with Mink via email for advice and comfort. “Dr. Mink was absolutely amazing through all of this. There were times I’d email him at 3 a.m. and he would email me back at 5 a.m.,” said Casey. “He had all the answers. I really couldn’t have gotten through this without him.”

The Beagell and Segrue families have DYT1, which is one of 20 specific genetic forms of dystonia that have been identified. Although some forms of dystonia respond well to medications, it often takes very high doses and side effects can cause substantial interference with daily functioning. Another treatment option for some patients is neurosurgical implantation of DBS (deep brain stimulation) electrodes. “Children with certain forms of dystonia, especially the type these kids have, can be dramatically responsive to DBS treatment,” Mink said.

DBS involves inserting wire electrodes into specific targets in the brain. The wires are run under the skin and connect to two pacemaker-like devices that are placed under the skin on both sides of the chest, near the collar bone. A wire connects each device to the brain and sends out pulses, which can correct misfirings in the brain.

Mink recommended DBS for Riley and Kamri as their symptoms worsened. Although Riley’s case hadn’t developed as rapidly as Kamri’s, it was very painful and difficult to deal with. Unlike Kamri, Riley’s mouth and face were never affected by the disorder, but his body flailed, he



Kamri Beagell

couldn’t walk and his head would involuntarily rotate. For two years prior to the DBS surgery, Riley had to use a scooter to get around.

Riley had his surgery at Mount Sinai a month after Kamri was diagnosed, in Nov. 2007. Riley battled a number of infections around the implanted devices and after each one, the family went back to New York City to have the hardware removed and then put back in.

Kamri had her surgery at Mount Sinai in July 2008. She had a few initial issues with the DBS surgery, including an infection a month after her surgery, but she recovered soon afterward.

Mink adjusted the settings on Riley’s and Kamri’s devices on a monthly basis through telemetry, a technology

that involves remotely reading information from the devices without needing to physically remove them from under the skin. Using a magnetic wand, through telemetry, Mink could adjust voltage, the frequency of pulses, how long the pulses lasted and the extent to which the four parts of each side of the brain the wires touched were being stimulated.

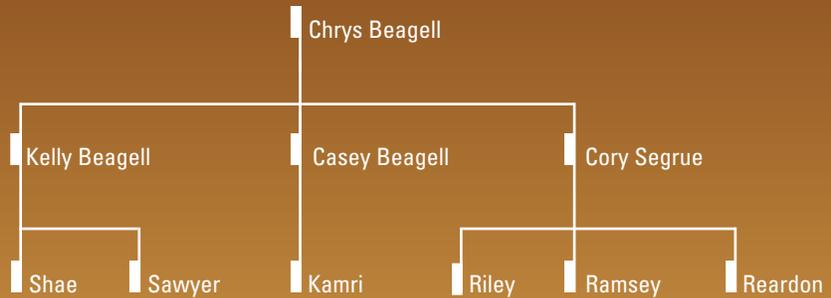
Telemetry requires experience and an extensive understanding of the disorder, both of which Mink has in spades. Mink developed and ran the movement disorder surgery program at Washington University in the mid- to late-1990s, so he had experience with DBS from the time it began being used for essential tremor and Parkinson’s disease. More than a decade later, Mink continues to use

Kamri’s mother said she is 99 percent better. As was the case with Riley, it took a little time to get the settings right, but around March, Kamri started gaining back control over her body.



Riley Segrue

Beagell and Segrue Families



“Children with certain forms of dystonia, especially the type these kids have, can be dramatically responsive to DBS (deep brain stimulation) treatment,”

— Jonathan Mink, M.D., Ph.D.

DBS in a clinical setting for dystonia in children. He also continues to participate in research on the mechanism by which DBS works.

DBS has the potential to produce amazing results, but sometimes the benefit accumulates over a long period of time. “DBS seems to change the plasticity of the brain, without directly interrupting its function,” Mink said.

Four months after Mink most recently made changes to Riley’s settings, Riley’s mother reported that he was still continuing to improve. Riley still has the disorder and has continued to have complications due to infections, but DBS has been effective for him. This year, Riley entered his sophomore year of high school without needing his scooter for the first time in two years.

Kamri’s mother said she is 99 percent better. As was the case with Riley, it took a little time to get the settings right, but around March, Kamri started gaining back control over her body.

“Kamri’s mom would send me cell phone videos of Kamri as she improved.

First it was a video of picking a rock out of the river, then she was going down the slip and slide and now she doesn’t bother sending videos anymore, because there’s really no room for improvement. Kamri is essentially dystonia-free,” Mink said.

Despite the huge road blocks Kamri faced, she never missed school because of her disorder. “She was very determined to be there,” Casey said.

Kamri’s mom is happy to report that as of December 15, Kamri will be completely off her medications, which will improve her ability to excel in school

“It’s almost a blessing that Kamri got so bad so quickly,” said Casey, “because now it’s over and done with.” Mink and the family are hopeful that once Riley’s infection has healed, he won’t need to have the devices removed again and the settings readjusted.

Through it all, the family has had the same pediatric neurologist, a nationally known expert in dystonia, Mink, to turn to with questions and concerns. In addition to Kamri and Riley, three of the

cousins, Ramsey, Reardon and Shae, all go to Mink, who monitors and treats their symptoms. All three have milder cases of dystonia, which have remained under control with small doses of medication.

Kamri just visits Mink two times a year now for check-ups. Casey said the last time Mink saw Kamri, he looked elated by her progress and gave her a huge hug. “Dr. Mink definitely cares about us and about our children,” Casey said.

“There are a lot of things neurologists can treat, but rarely can we make such severe symptoms completely go away, especially in movement disorders,” said Mink. “This really is one of the most rewarding things I’ve ever done in my career as a child neurologist,” Mink said.

Mink continues to remain in close contact with the family. “We’re not supposed to have favorite patients, but Kamri and Riley are right at the top,” said Mink. “Their resiliency and optimism are truly inspiring.”

Where surgery was the standard, casting may be future

Progressive Infantile Scoliosis Responds Well to a Series of Casts: Study

NEW RESEARCH FROM THE UNIVERSITY OF ROCHESTER MEDICAL CENTER (URMC) MAY LEAD DOCTORS TO CHOOSE TO TWEAK AN OLD TECHNOLOGY — CASTING — OVER USING HIGH-TECH IMPLANTABLE DEVICES FOR PROGRESSIVE INFANTILE SCOLIOSIS. CASTING HAS FEWER, AND LESS SERIOUS, POTENTIAL COMPLICATIONS, AND IT REQUIRES NO SURGERY. IN FACT, WITH THE RIGHT TRAINING AND EQUIPMENT, THE SPECIALIZED, SERIES OF CASTS CAN BE DONE AS OUTPATIENT PROCEDURES.

“Best of all, we can cure some children with progressive infantile scoliosis, something we can’t do with surgery and devices,” said James O. Sanders, M.D., chief of Pediatric Orthopaedics at the URMC and author of the research published in this month’s *Journal of Pediatric Orthopedics*. “If we cast these children before their curvatures become severe and before they turn 2, our chances of avoiding surgery and potentially curing them are much better.”

The study followed 55 patients with progressive infantile scoliosis (or early-onset scoliosis) a rare and potentially fatal form of spinal curvature, at Shriners Hospitals for Children in Erie, Pa., Salt Lake City and Chicago. Pediatric orthopaedic specialists used a method of casting, called EDF (for extension, derotation and flexion) that capitalizes on children’s rapid growth to untwist and uncurve their spines over time. The method uses a specialized table and casts with strategically placed holes. Sanders and URMC colleague Paul Rubery, M.D., an orthopaedic surgeon, are two of only a handful of surgeons nationwide who use this specialized method with the goal of curing, not just delaying surgery.

Children are given anesthesia and ventilated during the casting because the pressure on the chest during the procedure can make breathing difficult. The cast may extend over the shoulders like a tank-top and down to the pelvis, but large holes are left open between to relieve pressure on the chest and abdomen while preventing the ribs from rotating. The entire procedure can take less than an hour. Depending on the child’s age and severity of the curvature, the series of casts (removed and refitted every eight to 12 weeks) could be completed in about two years.



“If we cast these children before their curvatures become severe and before they turn 2, our chances of avoiding surgery and potentially curing them are much better.”

Although the casts can be restrictive and cause some trouble with mobility, initially, Sanders said parents are almost always surprised by how quickly their children adapt and how little having a cast changes their lives. Children can’t swim or be immersed in a bath, but they are otherwise unrestricted in their activities.

Current treatments, such as the vertical expandable prosthetic titanium rib (VEPTR), which are attached to the

inside of the ribs and adjusted over time, and growing rods, which are inserted near the spine and lengthened over time, are aimed at delaying spinal fusion. They are not meant to be a cure for the disease, and they present a whole host of potential complications, such as infection, pulling loose and causing stiffness in the chest and back.

“Casting remains the only method which can cure some of these curves,” Sanders said.

But casting doesn’t cure all curvatures and some children may still require growing rods of the VEPTR. Among children in this study a little more than 10 percent saw their curves worsen and they needed surgery. Sanders said his future research will focus on finding the best treatment options for these children, for older children and for those with large curvatures.

Science education at its best: New Visions Health Professions Program

WHILE A GREAT NUMBER OF RESEARCHERS BELIEVE THAT HIGH SCHOOL STUDENT VOLUNTEERS ARE ONLY USEFUL FOR MAKING COPIES, SOUNDARAPANDIAN VIJAYAKUMAR, M.D., ASSISTANT RESEARCH PROFESSOR FOR PEDIATRIC NEPHROLOGY AT GOLISANO CHILDREN'S HOSPITAL AT THE UNIVERSITY OF ROCHESTER MEDICAL CENTER, BELIEVES THAT SOMEONE NEEDS TO SPEND TIME TEACHING THE NEXT GENERATION OF MEDICAL PROFESSIONALS MORE ABOUT THEIR CRAFT.

He invites students into his lab, encouraging them to develop and test hypotheses in hopes that they will come to recognize science as a relevant and worthwhile profession.

"I think that students are capable of a lot more than people think they are," he said. "We need to teach them how to solve real life problems so that they can carry the work that we're doing into the next generation."

Vijayakumar teaches teens how to conduct in-depth experiments to help find a cure for Polycystic Kidney Disease, a disorder that can be fatal to infants. He believes that students learn best when teaching others, so when he works with University of Rochester students through the Strong Children's Research Center summer program, Vijayakumar encourages them to help teach the teens he mentors in the lab. His students learn various techniques and concepts, including how to

isolate protein and DNA from cells and how to quantitate them.

"It's really exciting to work in the lab," said Kelsey Donoghue, one of the students Vijayakumar mentors through the New Visions program at Monroe 2-Orleans BOCES. "I'm learning much more here than I would in a normal high school science class."

Vijayakumar has taken on Donoghue of Gates-Chili and Toby Mahan of Spencerport for a year-long internship offered through the New Visions Health Professions program. The program invites college-bound high school seniors to explore professional career interests like health care through internships that offer high school and college credit. The students spend three hours twice a week helping Vijayakumar with his research.

Vijayakumar also brings teens into his lab as summer volunteers. Jane Walsh, assistant director of Friends of

Strong, started referring high school volunteers to him two years ago, when he responded to a request Friends of Strong issued about summer volunteer openings. Vijayakumar has continued working with one of his summer volunteers, who has built off the research she did in his lab in preparation for a national competition called the Intel Science Talent Search.

"Dr. Vijayakumar is very enthusiastic about mentoring students," said Walsh. She invites other researchers interested in mentoring to contact her, as there are plenty of requests for lab positions from students.

For more information on the New Visions Health Professions program, please visit bit.ly/newvisionsboces2. Students interested in pursuing a volunteer position in a lab are encouraged to contact their guidance office.



"We need to teach [students] how to solve real life problems so that they can carry the work that we're doing into the next generation."

— Soundarapandian Vijayakumar, M.D.



Bike safety event celebrates gift to Kohl's Pedal Patrol



Kohl's Department Store partnered with Golisano Children's Hospital at the University of Rochester Medical Center through the Kohl's Cares for Kids® program to host a special bike safety event for local kids Sept. 27, at the City of Rochester's Harvest Jamboree. The safety event celebrated Kohl's gift of \$66,903 to Injury Free Coalition for Kids of Rochester (IFCKR), based out of the hospital's Emergency Department.

IFCKR members provided kids with free helmets and helmet fittings. Kohl's A-team volunteers then took kids through fun rodeo-style events, where kids could practice safe bike riding between and around traffic safety cones.

Kohl's Pedal Patrol developed out of IFCKR as a program devoted to preventing bike-related injuries among children in the greater Rochester area. For more information on IFCKR, visit <http://bit.ly/injuryfree>.

Young adults visit doctors less as risky behavior peaks



When adolescents graduate to young adulthood, their preventive care tends to fall by the wayside. A recent study has found that young adults are much less likely to use ambulatory or preventive care, even though their mortality rate is more than twice that of adolescents.

"Young adults are generally a healthy population, but many risky behaviors peak in this age bracket and few resources are available for this population," said Robert J. Fortuna, M.D., M.P.H., senior instructor in Pediatrics and Internal Medicine at the University of Rochester Medical Center (URMC).

Fortuna conducted the study with two other URMC researchers, Brett W. Robbins, M.D., associate professor in Pediatrics and Internal Medicine, and Jill S. Halterman, M.D., M.P.H., associate professor in Pediatrics.

The study found that young adults, especially black and Hispanic males, underuse ambulatory medical care and infrequently receive preventive care. Young adults may underuse ambulatory for a number of reasons, including

limited access to care, lack of health insurance and low self-perceived risk, explained the authors.

During young adulthood, the prevalence of substance abuse, sexually transmitted diseases, homicide and motor vehicle crashes all peak. Yet the study's findings show that counseling for young adults, which was rarely offered, typically focused on diet and exercise instead of counseling directed at the greatest threats to their health.

"During a time when many risks peak and unhealthy lifestyle habits form, routine medical care and preventive counseling can improve both immediate and long-term health," said Fortuna.

The study concludes that young adults need to have access to resources that will help them receive appropriate preventive care, especially since they currently underuse ambulatory care services and rarely gets appropriate counseling from health professionals.

22nd Annual Gala

Guests go above and beyond, raising close to \$700,000 for Golisano Children's Hospital



More than 860 guests donned in their finest attire whisked into the Rochester Riverside Convention Center for an unforgettable evening on October 24. Despite concerns over the global economy that continue to linger, Gala attendees went above and beyond any conceivable fundraising goals, raising enough for eight Giraffe Omni-Beds for the neonatal intensive care unit and a record-breaking number of almost \$700,000 net for Golisano Children's Hospital!

Guests were transported from downtown Rochester into a lovely, Tuscan setting as they descended down the escalators and through an elegant, grape-laden trellis at the Convention Center. After cocktail hour, attendees entered the dining room, wrought with golden and maroon majestic hues, where they found their seats and were warmly welcomed by Peter and Allison Formicola, the event's honorary chairs.

Hundreds of silent auction items were available for bidding, ranging from sports memorabilia to wine tasting tours. Live auction items included special butterflies for the hospital created by Paul Knoblauch, a rocking horse created by Mackenzie Childs, an ultimate kid party from Blue Apple Productions and many more enticing packages.

Fever — The Wrath of Polyester wowed the crowd after the live auction with a larger than life retro performance, with pyrotechnics, colorful costumes, and huge images of Sandy Strong shining on the walls. The band rocked the crowd's socks off well into the night. The 22nd annual Gala was truly a night to remember.

- 1 Fever—The Wrath of Polyester complete with fireworks.
- 2 Tom Golisano.
- 3 Mark Siewert raises his paddle.
- 4 Honorary Chairs Allison and Peter Formicola with daughter Rene.

Stay in the loop with our new e-newsletter



Golisano Children's Hospital has developed a fun, new way to provide you with fresh news on a more frequent basis with an electronic newsletter. We invite you to sign up for the e-newsletter to receive updates about what is going on in the hospital, health tips and information about upcoming events.

To sign up, visit

www.facebook.com/GolisanoChildrensHospital and type your email address into the area labeled "email" or visit bit.ly/gchnewsletter.

We're also welcoming ideas for the name of our e-newsletter. Feel free to email: Katie_Sauer@umc.rochester.edu with any ideas.



6th Annual Cycle for Hope

Saturday, February 6, 2010



Cycle for Hope is a six hour spinning marathon taking place at various fitness facilities throughout Monroe and Ontario Counties in New York. The proceeds from this event are divided between Camp Good Days and Special Times and Golisano Children's Hospital.

This is a unique opportunity for everyone to enjoy, whether you are a beginner or an avid spinner. Your time on the bike will help two organizations that enrich the lives of people who are facing some very challenging times in their lives.

To register

Stop into one of the participating clubs to sign up. You can choose your time slot and the amount of time you would like to cycle.

Or, go to www.cycle4hope.org, print out a registration form, fill it out, and bring it to the location in which you want to participate.

Participating clubs:

Flex Gym & Aerobics Center

605 Culver Road, Rochester, NY 14609
585.654.7122

Midtown Athletic Club

200 East Highland Drive
Rochester, NY 14610
585.461.2300 www.midtown.com

Eastside YMCA

1835 Fairport Nine-Mile Point Road
Penfield, NY 14526
585.341.4000

Gold's Gym

855 Publishers Parkway, Webster, NY 14580
585.347.0047 www.goldsgym.com

The Iron Butterfly Health Club

7493 Route 96, Victor, NY 14564
585.924.1540 www.theironbutterfly.com

Canandaigua YMCA

32 North Main St, Canandaigua, NY 14424
585.394.6866 www.canandaigua-ymca.org

Penfield Fitness & Racquet Club

776 Panorama Trail West, Rochester, NY 14625
585.586.7777 www.penfieldfitness.com

Bally Total Fitness

1225 Jefferson Rd., Rochester, NY 14623
585.427.7890

Rochester Athletic Club – Brighton Henrietta

21 Goodway Dr., Rochester, NY 14623
585.424.2222

Rochester Athletic Club – Pittsford

3400 Monroe Ave, Pittsford, NY 14618
585.899.6666

Rochester Athletic Club – Greece Ridge

190 Greece Ridge Center Dr,
Rochester, NY 14626
585.225.8888

Golfers rally to play a round for kids

About 450 players attended the 13th annual Golisano Children's Hospital Golf Classic on Sept. 14, which raised a gross total of \$351,000 for the Children's Hospital. The event was held at three local golf courses: Monroe Golf Club, Ravenwood Golf Club and the Country Club of Rochester.

After an enjoyable day of golf, participants rounded up to commune over a delicious dinner at Monroe Golf Club. Dinner included a touching story from Mike Merriman, a longtime supporter of the Golf Classic who shared his family's experience with Golisano Children's Hospital.

We would like to offer a heartfelt thank you to everyone who came out to support this year's event. We'd especially like to thank our major sponsors:

Presenting Sponsors

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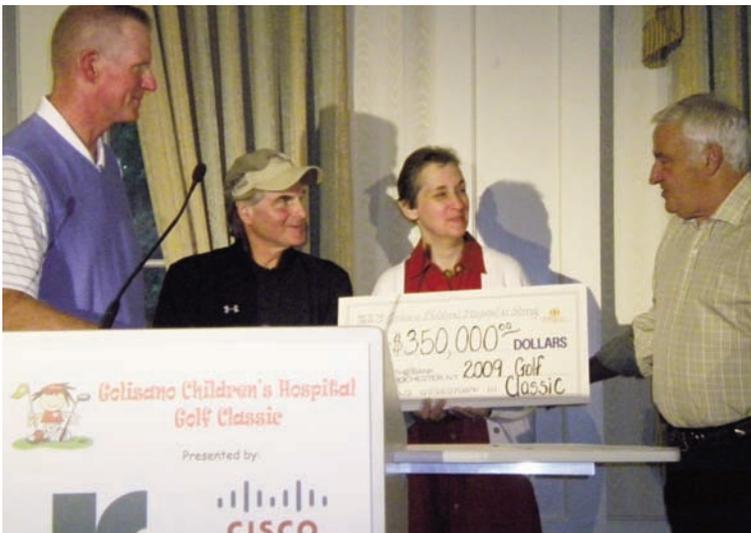




Photo Contest winner has personal connection to hospital

It's no surprise that the sweet face that won the online Sandy and Me Photo Contest in September has a touching reason for bonding with Sandy Strong and Golisano Children's Hospital at the University of Rochester Medical Center.

Natalie Michalek and her twin brother Ryan were born on Thanksgiving Day (Nov. 23) 2006, 11 weeks premature. Ryan was a tiny 1lb. 7 oz. He fought hard, but lost his battle with pneumonia and complications from prematurity when he was 3 weeks old. Natalie was

also tiny, 2 lbs. 7 oz., but after 55 days in the Neonatal Intensive Care Unit (NICU), she came home with her brother Ryan as her personal angel. She turned 3 years old just weeks after winning the Sandy and Me Photo Contest, which m e a n t a gift basket of Sandy toys and a month of being featured on the hospital's giving Web site: www.givetokids.urnc.edu.

Natalie and Ryan's parents, Becky and Jason, have continually supported the hospital, making covers for the NICU's

isolettes and walking in the Stroll for Strong Kids every year. They also come to the hospital's annual memorial service to honor Ryan. They have since moved to Syracuse, but that hasn't stopped them from supporting Golisano Children's Hospital.

"Our family will always do anything to help the NICU, and to have Natalie be a part of the photo contest was wonderful," Becky said.

Light up the holiday season with donations for kids

Golisano Children's Hospital relies on the wonderful donations from the community year-round to comfort the many children treated here. The holiday season is a special time of year, during which Golisano Children's Hospital tries extra hard to make sure kids feel as much at home as possible. We invite individuals and groups who want to help by giving donations to visit the giving site's special page of wish list items at <http://bit.ly/donateitems> for ideas.

If you would like to donate items from Golisano Children's Hospital's wish list, visit <http://bit.ly/gchwishlist> and then call (585) 273-5948 to speak with an Office of Advancement staff member about making a gift.

The Child Life Program promotes play among pediatric patients to feed their emotional and developmental needs. If you would like to donate items from

the Child Life Program's wish list, please follow the steps below:

- Pick a gift from Child Life's wish list at <http://bit.ly/childlife>.
- Make sure to check our safety guidelines: <http://bit.ly/safetoy>
- Make sure "Child Life" is plainly visible on the donation and that you've included contact information.
- Drop off your donation at the Friends of Strong office or the Patient Discharge Area. Visit <http://bit.ly/donateitems> for open hours and more detailed instructions.

We encourage you to take photos of you and/or your group with the donations before you drop them off. Then email them to Katie_sauer@urnc.rochester.edu to have them posted in our Caught Doing Something Good Gallery on Facebook at www.facebook.com/GolisanoChildrensHospital.



Project SEARCH expands into City of Rochester

John Dasfais wants a job. The 21-year-old Spencerport student, who has a developmental disability, wants to earn a paycheck and, hopefully, move out on his own. And he's on the road to doing that through a new program called Project SEARCH at the University of Rochester Medical Center (URMC). Next fall, 12 city students will be able to join him.

Project SEARCH, a national program that helps young adults with developmental disabilities transition to the work world by giving them hands-on experience, started this fall in Rochester for a dozen 18- to 21-year-old students from Monroe 2-Orleans BOCES since the beginning of the school year. It serves as an alternative for students in their last year of high school with the goal of landing a competitive job upon completion. Its successful partnership with The Arc of Monroe County, New York State's Vocational and Educational Services for Individuals With Disabilities (VESID), URMC and BOCES, has inspired the City of Rochester and the Rochester City School District to team up and start a Project SEARCH program for a dozen city residents next September.

Project SEARCH is the first employment program launched out of the Institute for Innovative Transition. The Institute, which was created last year with funding from the B. Thomas Golisano Foundation, aims to improve the quality of life for young adults with developmental disabilities and their families as they transition from



school age to adulthood. The Institute is a collaboration of the Golisano Foundation, Strong Center for Developmental Disabilities, and the Warner School of Education.

"We are very excited to participate in this innovative program in partnership with the City of Rochester and the Arc of Monroe," said Jean-Claude Brizard, Superintendent of the Rochester City School District. "We know that student success doesn't end with high school graduation. It means being prepared for life after high school. Through Project SEARCH, our students will remain engaged in school with a clear vision for the future and the skills to be competitively employed upon graduation."

The City of Rochester will provide

Yauneek Wallace helps patients in her Project SEARCH internship in the Wilmot Cancer Center.

classroom space for the program and, importantly, the internships across a broad range of government departments.

"URMC continues to lead in breaking down barriers with the expertise and passion required to help build a nation fit for all children to thrive," said Jean Howard, Chief of Staff for the City of Rochester. "Our City will support and participate in any 'lessons learned' from Strong during Project SEARCH's first year of operation. We are in motion and preparing for the kick-off of Project SEARCH at the City of Rochester in Fall 2010."

Children's Miracle Network Sponsor

New CMN Sponsor

We'd like to offer a warm thank you to Schwan's, our newest Children's Miracle Network sponsor. Schwan's is offering two special promotions until Thursday, Dec. 31, to benefit customers and Golisano Children's Hospital. For more information, visit <http://bit.ly/schwanspromo>.

Children's Miracle Network is an international non-profit organization dedicated to helping children by raising funds and awareness for 170 children's hospitals throughout North America, including Golisano Children's Hospital at the University of Rochester Medical Center. Each year these non-profit



hospitals treat more than 17 million children afflicted with disease, injuries, and birth defects of every kind.

upcoming events

Nov. 1 – Jan. 1, Holiday Book Drive, Barnes and Noble, 3349 Monroe Ave. Donate books at Barnes and Noble in Pittsford and they'll wind up in Golisano Children's Hospital's waiting areas and playrooms. The books will entertain and educate children as they await procedures and visits to the doctor. Look for the big display in the Pittsford Barnes and Noble to donate. For more information, call (585) 586-6020.

Kards for Kids. Send loved ones a card that comes from the heart and know that you'll be supporting Golisano Children's Hospital. Each package, containing 10 cards, features one of the four designs and costs \$10. Order forms are available at <http://bit.ly/orderkards>.

Dec. 18, 9th annual Rainbow Classic, University of Rochester Palestra. As is tradition, this Pittsford Mendon and Pittsford Sutherland High School basketball game to benefit Golisano Children's Hospital will again raise funds in memory of Katelyn Pasley and Ryan McCluski. The game will start at 6 pm. For more information, call the Pittsford Central School District Athletic Department at (585) 218-1062.

Jan. 26 and Feb. 16, 3rd annual Battle of the Beaks Games, St. John Fisher and Nazareth Colleges. All proceeds from the biggest college basketball competition in the region, will go to the neonatal and pediatric intensive care units of the hospital. The games, which tip off with the women's team at 6 p.m., followed by the men's at 8 p.m., pit the Nazareth Golden Flyers against their rivals,

the St. John Fisher Cardinals. Proceeds from admission, T-shirts, raffles and money from concession sales will also go toward the cause. For more information call Mike Fahy at 389-2838.

Feb. 6, Cycle for Hope, participating clubs. Spin for kids at this sixth annual event, which will benefit Golisano Children's Hospital and Camp Good Days. The six hour marathon will take place simultaneously as folks pedal the day away on stationary cycles from 8 a.m. to 2 p.m. at various gyms and health clubs across Rochester. To see what facilities are participating or to sign up, visit: www.cycle4hope.org or call (585) 273-5948.

faculty awards



Thomas K. McNerny, M.D., F.A.A.P., associate chair for clinical affairs in the Department of Pediatrics and pediatrician at the Panorama Pediatric Group, has been awarded the American Academy of Pediatrics Education Award. The award recognizes a member of the Academy whose educational contributions have had a broad and positive impact on the health and

well-being of children and adolescents. Over the past 38 years, McNerny has precepted numerous medical students and residents, authored or co-authored more than 30 articles, and is editor-in-chief of the AAP Textbook of Pediatric Care and Pediatric Care Online. McNerny accepted his award at the 2009 AAP National Conference and Exhibition which took place Oct. 17 through Oct. 20 in Washington, D.C.

Ruth A. Lawrence, M.D., professor of Pediatrics and Obstetrics and Gynecology at the University of Rochester Medical Center (URMC), has been awarded the 2009 Martha May Eliot Award by the American Public Health Association (APHA) for her tireless



efforts to improve women's and children's health. For nearly six decades, Lawrence's research and clinical work in infant nutrition and clinical toxicology has inspired her colleagues and young people in the field to be advocates for women and children from all walks of life. Lawrence accepted her award at the 137th APHA Annual Meeting and Exposition, which took place Nov. 7, through Nov. 11, in Philadelphia.



Stephen R. Cook, M.D., M.P.H., assistant professor of Pediatrics at URMC's Golisano Children's Hospital, was named one of the Rochester Business Journal's 40 Under 40. The general pediatrician is on the frontlines of the fight against childhood obesity, having authored dozens of studies on the subject and risen to national prominence. Locally, he is an advocate for finding and implementing proven programs to prevent and reverse the epidemic. Cook received the award at a luncheon Nov. 17 at the Rochester Riverside Convention Center.

special thanks

- Penn Yan Homecoming Queen nominees donated \$50 to Golisano Children's Hospital.
- The 15th annual John M. Azzarone Golf Memorial held on June 29 raised \$250 for Golisano Children's Hospital.
- The Raytec Group in Fishers held their 5th annual Carnival of Caring and raised \$2,215 for our region's only children's hospital.
- The University of Rochester graduate students' softball team donated \$273 to the children's hospital.
- Rob Burch, Andy McDermott and their dedicated committee organized the 5th annual Fairport Music and Food Fest — Thank you for delivering great music, great eats and a whopping \$60,000 to our community. We can't wait for next year's festival on August 28.
- Ralph and Megan Angelo requested that guests of their daughter's first birthday bring donations to Golisano Children's Hospital rather than gifts. They ended up raising \$850 for the hospital's play deck.
- Cheshire AV held their 2nd annual golf tournament to benefit the Kirch Center at Golisano Children's Hospital. Through their hard work they raised \$2,774.94. Thanks, Justin and gang.
- The Rochester Chapter of the Buddha Foundation of America held their 12th annual golf tournament and raised \$1,000 for our Child Life Department.
- Kittelberger Florist held their 7th annual golf tournament on August 3, and raised \$3,625 for Golisano Children's Hospital. Thank you Billy Horeth for your support.
- Daniel's Memorial 5K was held this past spring, bringing 150 runners and walkers together to raise \$550 for Golisano Children's Hospital.
- Nancy Eichorn held her annual sale and added a chicken barbecue...needless to say it was a big hit. She raised \$1,051 for Golisano Children's Hospital.

Many thanks all of the generous supporters and event organizers who have made donations to Golisano Children's Hospital. We recognize that economic times are tough and we appreciate every bit of support. Thank you.

Golisano Children's Hospital Development Office Staff

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

Karen Eisenberg
Associate Director of Advancement,
Community Programs and Annual Fund
585-273-1462

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

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

Michele Flow
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

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