



STRONG KIDS NEWS

Golisano Children's Hospital ranks 25th in nation for orthopaedics

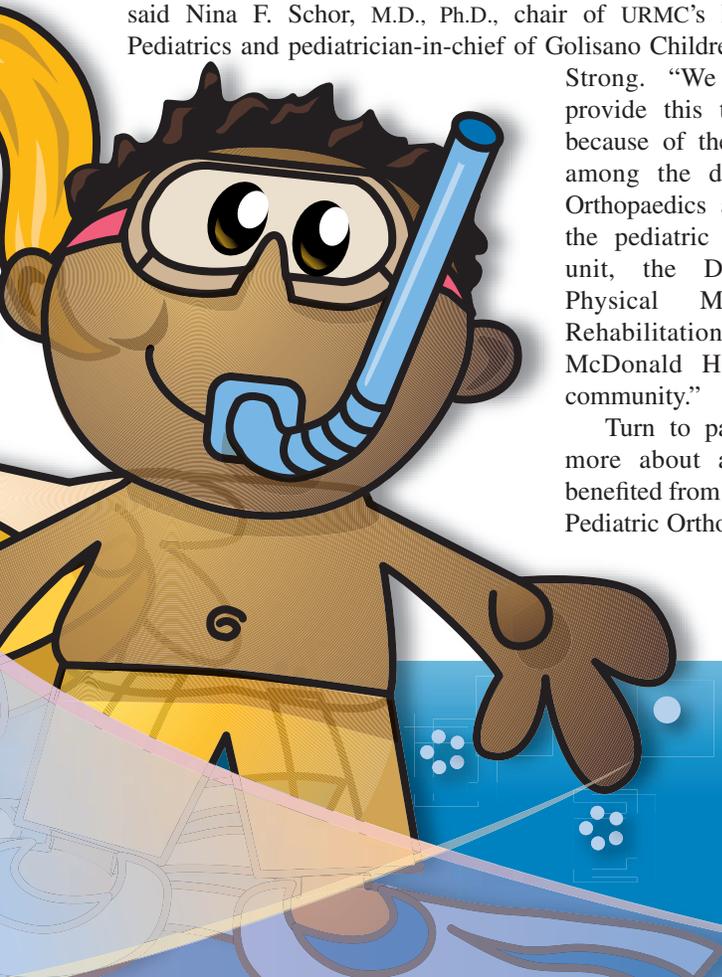
GOLISANO CHILDREN'S HOSPITAL AT THE UNIVERSITY OF ROCHESTER MEDICAL CENTER (URMC) IS THE PLACE TO GO FOR PEDIATRIC ORTHOPAEDICS, ACCORDING TO *U.S. News & World Report*. THE HOSPITAL RANKED 25TH IN PEDIATRIC ORTHOPAEDICS IN THE MAGAZINE'S 2009 EDITION OF AMERICA'S BEST CHILDREN'S HOSPITALS.



URMC has recently focused on expanding orthopaedic services to children. In 2005, the hospital opened a pediatric intensive care unit that made it possible to care for children with the most complicated orthopaedic conditions, and in 2008, it hired a new chief of Pediatric Orthopaedics who specializes in correcting scoliosis and severe spinal deformities.

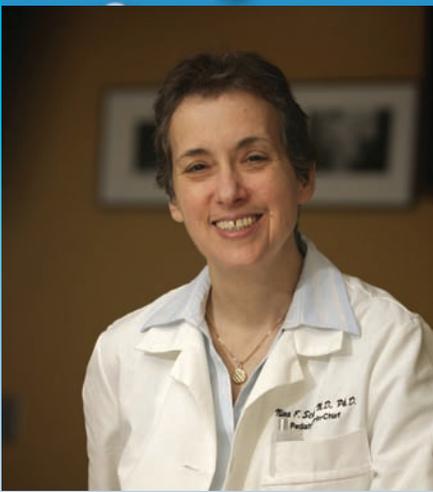
"We are delighted that Golisano Children's Hospital has been recognized nationally for the expert care we are known for regionally," said Nina F. Schor, M.D., Ph.D., chair of URMC's Department of Pediatrics and pediatrician-in-chief of Golisano Children's Hospital at Strong. "We are able to provide this top-notch care because of the collaboration among the departments of Orthopaedics and Pediatrics, the pediatric intensive care unit, the Department of Physical Medicine and Rehabilitation, the Ronald McDonald House and the community."

Turn to page 8 to learn more about a family who benefited from the Division of Pediatric Orthopaedics.



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Dear Friends —

To paraphrase a now-familiar question from the University of Rochester Medical Center TV commercials, “What does it take to be the best of the best?”

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As each year’s *U.S. News & World Report* rankings for children’s hospitals come out, we ask ourselves this question. The answer is housed in a complex algorithm that includes “reputation;” technologies and services; staffing ratios; the total number of inpatient and outpatient visits; and a host of other factors unique to each of the subspecialties evaluated.

The target is a moving one, both because the methodology and evaluated subspecialties change year-to-year and because other children’s hospitals around the country are doing the same thing we are. In so doing, we are moving the bar higher and higher, great for children and families—the only thing that matters!

This year, Golisano Children’s Hospital at the University of Rochester Medical Center is listed by *U.S. News & World Report* as among the top children’s hospitals nationally in the field of pediatric orthopaedics, an honor that earns us the right to proudly display the “America’s Best Children’s Hospitals” logo and garners well-deserved kudos for our pediatric orthopaedists, Drs. James Sanders, Paul Rubery and Gary Tebor and their staff.

You can bet we will be looking in every nook and cranny between now and the next national ranking period for the improvements and public acknowledgments that will push us over the top in other subspecialties. But, as anyone in the business world will tell you, as wonderful as it is to “win,” the important thing for the patients and families and communities we serve is that competition makes us stronger, better—more accessible, more

comprehensive, safer, more convenient and comfortable—for the people who need us most and keep us going right here in Rochester.

So what do we need aside from our own motivation and the public’s vote of confidence to keep getting better and better as the years go on? We are all accustomed to being asked to donate money to defray the costs of building projects and critical pieces of equipment. And these are absolutely necessary. Just look at what we have done together with the Pediatric Intensive Care Unit, Pediatric Cardiac Critical Care Unit, and Pediatric Surgical Suite.

But building buildings and acquiring equipment are not enough. So much of what we, as a leading academic medical center, need is not bricks and mortar. Retaining the best and brightest physicians, researchers, nurses, therapists, social workers, child life specialists in this community; training the next generation of health-care practitioners, educators and scientists; luring the country’s most promising and most accomplished professionals to Rochester—all of this is absolutely critical to our future. And all of it takes sustainable, renewable funding. Want to get to know and help shape a clinical or research program or become a champion of a new program or healthcare professional? Visit givetokids.urmc.edu/

With very best regards to all,


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



New location, new Tuscan theme for 22nd annual Children's Hospital Gala

Spend a fanciful Tuscan night in Rochester for the 22nd annual Children's Hospital Gala on Saturday, Oct. 24, at the Rochester Riverside Convention Center. The new location will take on a touch of Italian refinement with a savory dinner and classic décor overlooking the Genesee River. Later, the Old World atmosphere will break into retro disco as Nik Fever entertains and the atrium is transformed.

The black-tie event begins with a cocktail hour and silent auction at 6 p.m. The live auction and dinner portion of the evening starts at 8 p.m.

The Children's Hospital Gala is the most anticipated elegant affair of the year, but best of all, it is the hospital's largest fundraiser of the year. Physicians,

grateful families, supportive business owners and local dignitaries come together to help the children of the Finger Lakes region while also having a lively, good time.

The honorary chairs for the Gala are the ever-supportive Peter and Allison Formicola and the presenting sponsor is The Cabot Group, a local real estate firm that also sponsored last year's Gala. For more information about this year's event, call Golisano Children's Hospital's Office of Advancement at (585) 273-5948.



New website (givetokids.urmc.edu) New Look!



New giving site celebrates, invites & informs supporters

Golisano Children's Hospital at the University of Rochester Medical Center (URMC) is launching a brand new giving site to make it easier for you to learn more about ways to help our region's only children's hospital.

Now there's more room for us to celebrate our loyal supporters, highlight the many ways you can get involved and connect you with information about our patient care services, research and education and training programs.

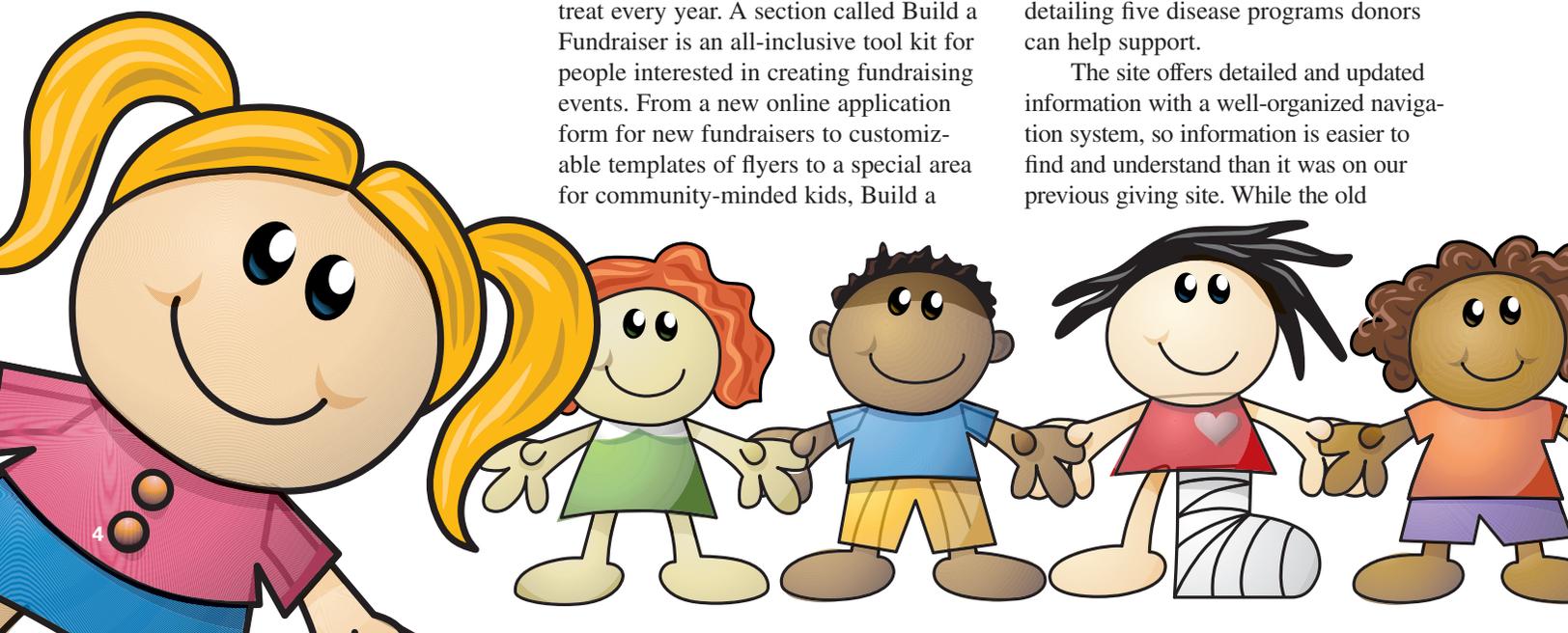
We've created a fun new slide show of community groups and individuals who have been "caught doing something good", a new section to showcase our wonderful Miracle Makers and of course, the incredible stories of our past and present Miracle Kids.

In envisioning this new giving site, we recognized that our vast and diverse community of supporters needed an equally ample assortment of ways to help the more than 70,000 children we treat every year. A section called Build a Fundraiser is an all-inclusive tool kit for people interested in creating fundraising events. From a new online application form for new fundraisers to customizable templates of flyers to a special area for community-minded kids, Build a

Fundraiser makes the process of creating an event fun and easy.

Another section called Give a Gift with Impact provides interested donors with information about various giving opportunities. Visitors can give to improve care, help find cures, help educate or to honor or remember loved ones. They can also learn about how to give through trusts and estates. A Planning for Our Future section supports Give a Gift with Impact by detailing five disease programs donors can help support.

The site offers detailed and updated information with a well-organized navigation system, so information is easier to find and understand than it was on our previous giving site. While the old



Dress up our site with the Sandy and Me photo contest

address, www.gchas.org, will still get you to the site, the new address is givetokids.urmc.edu. Have we mentioned that it's also really pretty?

We're Sporting a Whole New Look

Our new giving site has been completely redesigned to reflect the new look for Golisano Children's Hospital. We've added gorgeous, fresh photos of our patients' faces. New swooshes cut across the page in the same dynamic fashion as URM's look, but with a more kid-friendly color palette of pastels. To celebrate the site's new and improved look, we've given Sandy and her friends an updated look as well. Sandy and her friends pop off the page with a more 3D look that gives them life and depth.

Golisano Children's Hospital's Facebook page

Golisano Children's Hospital's Facebook page (www.facebook.com/golisanochildrenshospital), which boasts more than 1,400 fans and is still growing, has also gotten a makeover. The customized page looks and feels more like the new giving site with more swooshes, pastels and the new Sandy, thanks to a gift-in-kind from Dunn & Rice Design, Inc. With fun colors and designs, the page invites Facebook users to visit the new giving site, see a special album for the 2009 Miracle Kids, give a gift, share stories and follow Sandy Strong on Twitter (@Sandy_Strong). A special DIY Fundraiser tab gives visitors a sneak peek at how to create fundraising events and invites them to check out the giving site for more information.

We built this new giving site for you, our community of supporters. With that in mind, we'd like to invite you to get to know the new Sandy by bringing these characters into your world with a photo contest. Parents are invited to snap a photo of their child(ren) with the new Sandy to enter the Sandy and Me Photo Contest. This is your chance to dress up the new giving site and make it your own!

The winning photos of the Sandy and Me Photo Contest will be featured on the home page of the new Web site at givetokids.urmc.edu, for one month starting at noon Thursday, Oct. 1. The winners will also each receive a gift of items from Sandy's Store.

How to Enter

To enter the Sandy and Me Photo Contest, simply visit the Sandy photo album on Golisano Children's Hospital's Facebook page at www.facebook.com/GolisanoChildrensHospital or email sandy@urmc.rochester.edu to request an image. Print out an image of the new Sandy. Then snap a photo of your child with the image.

How to Submit Your Entry

To submit your photo for consideration, visit <http://tinyurl.com/kssbv>. If you have trouble accessing this link, visit Golisano Children's Hospital's Facebook page, click on the tab "Photos," click on one of the photos under "Fan Photos" and then click "Add a photo." Upload the desired photo. Entries must be received by 11:59 p.m. Monday, Sept. 28. If you are a finalist, you'll receive a private message on Facebook so we can obtain your contact information.

If you are not a Facebook user, email sandy@urmc.rochester.edu and your submission will be posted to our Facebook page. By submitting a photo via email, you are giving permission to post the photo on Facebook and Golisano Children's Hospital's Advancement Web site.

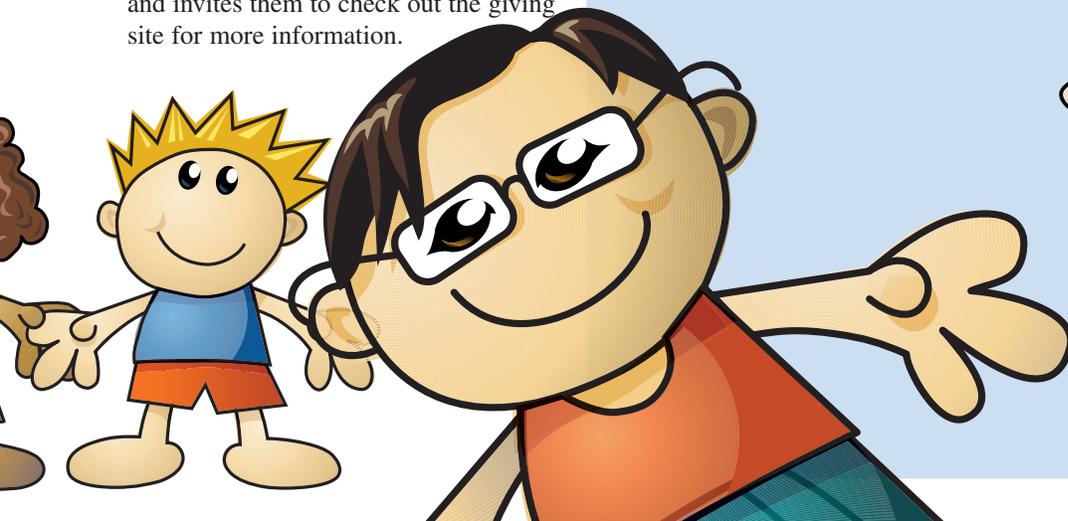
Restrictions

For safety and security reasons, we ask that you only submit photos of children of whom you are the parent or legal guardian. Your submission of the photo is your guarantee that you are the parent or guardian of the kid(s) in the photo. We also ask that you keep in mind that photo submissions are intended to be shared on a kid-friendly site, so please refrain from posting any questionable content.

Judging

Entries will be judged on the basis of creativity, photographic quality and effectiveness in incorporating Sandy into the photo. One of the awards will be determined by the winner of a poll on Facebook. Other categories may include youngest fan of Sandy, most excited fan of Sandy, farthest-away fan of Sandy or most creative use of Sandy in a photo and will be determined by a panel of judges based on the quality and range of submitted entries.

If you have any questions about the contest, please email Katie Sauer at Katie_Sauer@urmc.rochester.edu or call (585) 276-4298.



Dr. Lee joins Pediatric Surgical Team



Golisano Children's Hospital, nestled inside the University of Rochester Medical Center, has a unique atmosphere of a strong emphasis on high quality patient care paired with a focus on research and education. It's that atmosphere that has enabled the hospital to recruit some of the best clinicians and researchers in the country, including Yi-Horng Lee, M.D., a pediatric surgeon.

Lee most recently worked as a general pediatric surgeon at Women's & Children's Hospital in Buffalo and was an assistant professor of Pediatric Surgery at the University of Buffalo. He said the elements that make a good hospital are all present at Golisano Children's Hospital.

"You need to provide great patient service, track results and do research. In addition, you need to provide a high-quality education for future doctors and specialists," Lee said. "There's also a

real synergy between researchers and clinicians here."

Lee, who is working with Walter Pegoli, M.D., chief of pediatric surgery, trained in general surgery at the University of Iowa Hospitals and Clinics, and then spent a year exploring transplant surgery at the University of Pittsburgh Medical Center before entering a pediatric surgery fellowship at the Women & Children's Hospital of Buffalo. His research interests are varied and include necrotizing enterocolitis, pediatric gallbladder disease and appendicitis, and staphylococcal soft tissue abscesses.

Pegoli said Lee is a strong addition to the surgical team.

"We are pleased and proud to have Dr. Lee join us. He is extremely well trained, and has research interests that tie in well with the University's strategic plan," Pegoli said.

New board member Gail Riggs is committed to caring



Gail Riggs's first experience with Golisano Children's Hospital at the University of Rochester Medical Center was when her twins, Abigail and John, were admitted to the neonatal intensive care unit (NICU) as preemies. They were just there to grow, explained Riggs, M.S.W, Ph.D., but in the NICU, Riggs saw many other babies who needed much more serious medical treatment.

She and her husband, Patrick Riggs, M.D., chief of Vascular Surgery at Rochester General Hospital, moved to Rochester from New Orleans in 1993 to do fellowships at the University of Rochester. Riggs came to do a fellowship in behavioral medicine and her husband had a fellowship in vascular surgery.

They planned on moving back South when they were finished, but fell in love with Rochester for its beautiful

lakes and its family-centered community. "Once we had children, our love for this community just magnified," said Riggs. "We wanted to give back because the community had given us so much."

The Riggs' children, now 7, serve as a source of inspiration for giving back. In 2005, the Riggs funded the Riggs Special Care Nursery in the NICU to help the more than 1,200 babies that visit the NICU annually. They continue to be very supportive of the very special unit and other areas of the children's hospital, as well as the Rochester community.

Riggs has also created a company named after her daughter called the Abigail Riggs Collection, which has been hugely successful in selling handbags locally and nationally and benefits non-profit organizations including Golisano Children's Hospital.

Telemedicine expansion gives parents more options



“We hope this gives the many, many parents struggling to balance family and work responsibilities a more convenient, less time-consuming and less expensive way to get their children the care they need” — K. McConnochie, MD, MPH

Parents who need after-hours healthcare for their children don't need to turn to the Emergency Department (ED) for common childhood illnesses, such as ear infections and sore throats. The Health-e-Access Telemedicine Program, based at Golisano Children's Hospital at the University of Rochester Medical Center, has expanded its hours to include every weekday evening and Saturday morning at locations within some of the most impoverished neighborhoods in Rochester. That makes it not only possible but also very convenient for children to visit the doctor and avoid a costly trip to the ED.

The program allows information to be transmitted from a specialized camera that provides diagnostic-quality images of the ear drum, throat, eyes and skin. In addition, an electronic stethoscope captures lung and heart sounds and video-conferencing allows face-to-face communication. Doctors, hopefully at the child's own pediatric or family medicine practice, then make a diagnosis and prescribe treatments.

“Parents often take their children to the Emergency Department because they can't miss work to take their children to the doctor's office the next day,” said Kenneth McConnochie, M.D., M.P.H., the program's director and a professor

of Pediatrics at Golisano Children's Hospital. “We hope this gives the many, many parents struggling to balance family and work responsibilities a more convenient, less time-consuming and less expensive way to get their children the care they need.”

The program seeks to connect patients with their own providers, and several city pediatric and family medicine practices have already signed on to the expanded hours. Parents should call their own practice to arrange the after-hours telemedicine visit. The hours are 4 to 8 p.m. Monday through Friday, and 9 a.m. to 1 p.m. Saturdays. Locations vary based on patient needs and staffing. If parents run into trouble arranging the

visit, they can page Health-e-Access staff at (585) 220-2890 for help.

Health-e-Access has almost eight years of experience and more than 7,000 visits in child care programs and elementary schools. It has demonstrated that most illnesses prompting office and ED department visits can be well-managed through telemedicine. For the more than 3,000 children with telemedicine access from child care or schools, actual reduction in emergency visits has been 22 percent. The program also has shown that providers obtain diagnostic-quality information by telemedicine that is as good as or better than information obtained in person.

The program has more than halved sick-leave absences among children and helped parents avoid taking significant amounts of time off to care for their sick children.

McConnochie was a founder shareholder of Tel-e-Atrics, Inc., which supplies hardware, support services, and the FDA-registered software that powers Health-e-Access, and may receive future compensation from the company.



A doctor and family joins forces to fix two sisters' legs



MARLENE LADUKE KNEW THERE WAS A NEW DOCTOR IN TOWN EVEN BEFORE A RECOMMENDATION WAS MADE. JAMES O. SANDERS, M.D., PROFESSOR OF PEDIATRIC ORTHOPAEDICS AT THE UNIVERSITY OF ROCHESTER MEDICAL CENTER'S GOLISANO CHILDREN'S HOSPITAL ARRIVED TWO YEARS AGO, AMIDST QUITE A BUZZ.

As an administrative assistant at the pediatric residency program, Marlene had heard all about Sanders from the pediatric residents in her program, who excitedly talked about his reputation for being a very knowledgeable teacher to both parents and patients.

“Dr. Sanders is very big on teaching parents about their child’s condition and what possibilities there are for treatment. He wants to make sure you understand at whatever level of medical knowledge you have,” said Marlene.

The family’s first meeting with Sanders was surprising, to say the least. As a complete fluke, the whole family came to the first appointment Marlene had set up for Juliana, now 2 years old. Sanders took one look at Marlene’s husband Chad and the two girls, Josie and Juliana, and kindly said he thought he knew what condition they might have. Before the first x-ray or any genetic testing, Sanders was, and remains, quite confident that Josie, Juliana and their father had bowed legs, meaning the femur and tibia curved outward, and a form of skeletal dysplasia called multiple epiphyseal dysplasia (MED). MED is characterized by malformed knees, feet, and hands, scoliosis, and joint pain that is usually in the hips or knees.

Since there is no cure for MED and

“Dr. Sanders is very big on teaching parents about their child’s condition and what possibilities there are for treatment. He wants to make sure you understand at whatever level of medical knowledge you have”– M. LaDuke

treatment earlier on produces more positive results, Sanders suggested treating Josie right away. Sanders put KFO (knee-foot orthosis) braces on last summer, when Josie was 18 months old. He explained that younger children's bowed legs tend to be more easily correctable because their bones are still very pliant. Since Josie was a bit older than the optimal age to begin this kind of treatment, Sanders recommended that she wear the KFO braces 24 hours a day. They were only to come off for bathing. Because Sanders had taken the time to work through the family's questions and concerns, the LaDuke family understood exactly why Josie needed the treatment she did.

After three or four months, Josie's legs were still bowed outwards and her bones had not moved at all. Sanders suggested another course of treatment—Taylor Spatial Frames, external fixators used to correct bone deformities. On Oct. 7, 2008, Sanders put on the two rings that went around each of Josie's legs and six vertical struts that could be adjusted to slowly move her bones. The rings connect to bones in the leg by wires or half pins. Chad and Marlene adjusted these according to calculated numbers Sanders gave them, so that little by little, the bones in Josie's legs moved inward and her legs became less bowed.

Josie's deformities were corrected in three to four weeks, as is typically the case with the frames, and the braces were left on to allow her bones to heal. Unfortunately, while Josie's bones were healing, she developed an infection so on Dec. 22, the frames were removed and replaced with full-leg casts. When Sanders checked her legs two weeks later, he found that Josie's right leg had healed but her left leg had not.

After two more months with a long-leg cast on Josie's left leg, x-rays revealed that the bones had still not healed. In early March, Sanders decided to do a bone marrow aspirate, a procedure in which bone marrow is extracted from the hip and injected into the break site to help with healing. Sanders then put a custom brace on Josie's left leg so it could continue to heal.

In mid-March, Sanders found that Josie had a vitamin D deficiency, which may have contributed to the delay in healing of her left leg. Sanders recommended vitamin D supplements to strengthen her bones.

Treating the child, not the disease

As every parent knows, all children are different. From that first appointment, Sanders recognized that Juliana's treatment might be different than Josie's. Sanders decided to give the family a

less expensive option for Juliana's braces, since he didn't want to bill them unnecessary expenses, explained Marlene. However, Juliana would not tolerate her first set of braces.

Juliana started out wearing A-frame braces at night but the 18 month old found them to be very restrictive and difficult to sleep in. She was not able to sleep more than four hours a night. Due to the discomfort, Sanders fitted Juliana with KFO braces to be worn at night.

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Below: Juliana (left) and Josie (right) sit together at an appointment with Sanders.



Partnerships, grant bring first Project SEARCH here

Program Helps Young Adults with Developmental Disabilities Transition to Work World

A partnership among several local agencies has allowed Rochester to start its first Project SEARCH, a program that helps young adults with developmental disabilities transition to the work world by giving them hands-on experience. Coordinated by the Institute for Innovative Transition at Strong Center for Developmental Disabilities, which is funded by a grant from the Golisano Foundation, the program begins in August with the help of Monroe 2-Orleans BOCES and The Arc of Monroe County and will be based at the University of Rochester's Golisano Children's Hospital.

A New York State Developmental Disabilities Planning Council (DDPC) \$100,000 grant will fund the first Project SEARCH program in Rochester and, with support from the Golisano Foundation, two additional Project SEARCH programs in Monroe County that are scheduled to launch fall 2010.

Project SEARCH is a national program that started in Cincinnati as a one-year high school transition program, providing training and education for 18- to 21-year-olds with developmental disabilities. It serves as an alternative for students in their last year of high school with the goal of landing a competitive job upon completion.

"This is such a unique program in that it's a business model that allows individuals with developmental disabilities to develop job skills that lead to competitive employment," said Susan Hetherington, M.S., director of Project SEARCH at Golisano Children's Hospital who holds joint appointments at the University of Rochester's Warner School of Education and the University of Rochester Medical Center's Department of Pediatrics, where she is an assistant professor of clinical pediatrics and education. "Gaining these employable skills is incredibly important to helping these young adults become more independent."

Five days a week, 10 to 12 area school district students enrolled in the



"This is such a unique program in that it's a business model that allows individuals with developmental disabilities to develop job skills that lead to competitive employment" – S. Hetherington, M.S.

Monroe 2-Orleans BOCES will report to Golisano Children's Hospital where they will learn job readiness skills in the classroom for two hours. They will spend the rest of the day developing those skills in an unpaid internship alongside a job coach provided by The Arc of Monroe County (or The Arc). The students will rotate through three internships during their year in the program. The internship opportunities include greeting families when they arrive at the hospital, asking parents if they need anything in the waiting rooms, doing office work in divisions of the hospital and cleaning and maintaining isolettes in the neonatal intensive care unit.

The partnerships among BOCES, The Arc and Golisano Children's Hospital are integral to the program's creation and survival. Monroe 2-Orleans BOCES will identify potential students to apply for

the program. Golisano Children's Hospital will provide the space for classroom instruction and the internship opportunities. Job coaching provided by The Arc will lead the young adults down the path toward eventual employment, the ultimate goal of the program.

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.

Miracle Weekend ends strong with record numbers

It was a record-breaking year for the Stroll for Strong Kids. Not only did we surpass our previous record for number of participants with 3,000 walkers, but we also raised more funds for Golisano Children's Hospital than ever before, with a grand total of \$310,549.

Four of the 2009 Miracle Kids and their families attended the Stroll. ❶ Cory Milburn led the walk, sporting a special t-shirt that designated him as captain of the Cruzin' for Cory team. True to the team name, Cory cruised through the walk in a toy car with a poster on the back, detailing the odds Cory had beaten and exclaiming, "I'm a Miracle Kid!" Cory was among the top individual fundraisers, raising \$3,230. His team of supporters, Cruzin' for Cory, was among the top teams as well, donating \$9,222 to Golisano Children's Hospital.

❷ Brooklynn Spencer's team, Troopin' it for Brooklynn, also helped lead the Stroll, proudly wearing specially made t-shirts with a photo of Brooklynn on them. Brooklynn's team raised \$1,060 and had all sorts of supporters, including one of Brooklynn's doctors who raced in the new 5K Run. Taylor Randall and her family also came out for the Stroll for Strong Kids. The Randall and Spencer families had to travel more than an hour and a half to attend both the Stroll and telethon.

❸ Tea Papke's Team Tea consisted of family, friends and coaches and raised \$1,968 for the hospital — nearly \$1,500 of which was raised by Tea herself. The weekend's honorary members were joined by University of Rochester President Joel Seligman, Monroe County Sheriff Patrick O'Flynn, M&T Bank's regional president Dan Burns (the event's presenting sponsor) and the 2009 chair of the Stroll Tim Fournier.

This year's unprecedented totals came as no surprise because several new and exciting traditions started at the 2009 Stroll. A new 5K Run was headed up by the Stroll's founder Don McNelly. The Stroll also moved from Genesee Valley Park to a new location on the Wilson Quad at the University of Rochester.

❹ The 26th annual Children's Miracle Network (CMN) Telethon, hosted by 10NBC, celebrated the more than \$4.1 million raised over the course of the year for Golisano Children's Hospital at the University of Rochester Medical Center. The telethon, presented by Perkins Restaurants, shared the compelling stories of all that the 2009 Miracle Kids had experienced and how far they'd come.

During the event, Miracle Kids and their families reunited with doctors who had been so integral to their treatment. Miracle Kids from previous years and other patients and families also returned to recount their trials, tribulations and triumphs for viewers. CMN sponsors, community groups and individuals touched by the hospital also joined in to share their reasons for giving to the hospital.

We'd like to thank the thousands of participants, volunteers and supporters who helped make Miracle Weekend a success. Your charisma, compassion and commitment to helping the many children served here was truly phenomenal.



Interactive technology introduced for asthma care

When children are admitted to Golisano Children's Hospital, they and their parents often have a lot of health-related questions. The GetWellNetwork® PatientLife System®, an interactive bedside patient education and entertainment system, available for families in the pediatric hospital at the University of Rochester Medical Center, provides parents with 24/7 access to information about their child's condition. A new informational package on asthma has recently been added to the GetWellNetwork system, which allows patients admitted to the hospital for asthma-related issues to learn more about their condition and how to prevent future flare-ups.

"This addition to the GetWellNetwork system is huge since 10 percent of admissions to the hospital are asthma-related," said Elizabeth Lattimore, administrative director for clinical services at Golisano Children's

Hospital. "We want to streamline nursing efficiency and increase patient satisfaction with this system. We also want to provide patients and caregivers with relevant disease-specific health information throughout their stay and follow-up instructions to help them manage their disease after discharge and avoid further admissions."

Physicians and nurses are taking steps to make sure patients know about this readily available, individualized health information. Michael S. Leonard, M.D., chief quality and safety officer for children's services and pediatric hospitalist at Golisano Children's Hospital, is helping to familiarize physicians with the system so they can order educational videos, just as they order x-rays, labs and medications.

Physicians prescribe a set of videos to asthmatic patients and nurses complete the order by sending videos directly to the patient's bedside,

according to Jan Schriefer, M.B.A., Dr. P.H., assistant professor at Golisano Children's Hospital. The prescribed videos can answer general questions like "What is Asthma?" and detail more specific issues like possible triggers for asthma and how to self-monitor asthma care treatment. The asthma suite, created by KidsHealth, also offers testimonials from children and teens living with asthma and parents whose children have asthma. Nurses have received training in how to start follow-up conversations.

"The information in these videos helps get families and nurses on the same page when they talk because families have learned important background information," said Terri J. Scharfe-Pretino, senior clinical nurse specialist at Golisano Children's Hospital.

Patients and families have immediate access to reliable information, which helps ease feelings of anxiety. The system also offers an alternate way for patients to learn about their condition in a way that is easy for kids and adolescents to understand. Trying to absorb all the information nurses and doctors offer when they speak with patients and their parents can also be overwhelming, so the system offers a way for parents to revisit important information regarding their child's health condition. Prescribed videos on the system vary based on condition and range from basic hand hygiene to information about tracheotomies.

The asthma suite is just one part of an entire "edutainment" system, which is currently available to 88 patient beds at Golisano Children's Hospital. Patients can communicate with the outside world with the GetWellNetwork system by using a wireless keyboard to access emails and Web sites on the television screen monitors in their hospital rooms. The system also provides 60 current on-demand movies, which are updated quarterly. For more information on ways to support the GetWellNetwork system, visit givetokids.urmc.edu.



upcoming events

Aug. 29, Fairport Music and Food Fest, Lift Bridge Lane, Fairport. This summer favorite has grown exponentially over the past four years due to its popularity and ever-growing cohort of volunteers and attendees. Event organizers have been named winners of the 2009 Miracle Maker Award for Outstanding Commitment by a Community Group. The event runs from noon to dark. Adult tickets cost \$10 in advance or \$15 at the door. Kids ages 12 and under get in free. Proceeds benefit the Golisano Children's Hospital at the University of Rochester Medical Center. For more information, go to www.fairportmusicfest.com.

Sept. 14, 13th annual Golf Classic, Monroe Country Club, Ravenwood Golf Club and Country Club of Rochester. The Golf Classic, which garners hundreds of participants and takes place across three golf courses, is thought to be the biggest annual golf tournament in the Rochester area. Lunch and

registration begin at 11 a.m. and the shotgun start kicks the competition off right at 12:15 p.m. Dinner at the Monroe Golf Club will follow the day of golf. For more information, call (585) 273-5948 or visit givetokids.urmc.edu.

Oct. 10, Genesee Valley Hunt Race Meet, Nations Road, Geneseo. This traditional outdoor event is perfect for families, who will enjoy live music, Horses & Hounds on Parade and much more. Kids will love the free pony rides and horse-drawn hay rides. Proceeds go in part to Golisano Children's Hospital. The event will take place 10 a.m. to 4 p.m. Tickets can be purchased for \$8 in advance and for \$10 at the door. Children under 12 get in free. To order tickets or find out more information, go to www.geneseevalleyhunt.org.

Oct. 10-17, 13th annual Cruise for a Cause, Norway. Get on board the Norwegian Pearl

to help our region's children. Rates start as low as \$579 per person. For every cabin booked, \$25 is donated to Golisano Children's Hospital. For more information, please call 1-888-461-2628 ext. 276 or visit www.cruiseforacause.org.

Oct. 24, 22nd annual Golisano Children's Hospital Gala, Rochester Riverside Convention Center. For more than two decades, this black-tie fundraiser has been one of Rochester's most elegant events of the year. The gala garners hundreds of guests for a silent and live auction and decadent food and libation. Attendees know they'll get their money's worth with a new surprise every year and the promise that all the money raised goes towards helping sick and injured children. The cocktail hour starts at 6 p.m. and dinner is served at 8 p.m. If you'd like to volunteer, donate gifts-in-kind or purchase tickets for this stellar event, please call at (585) 273-5948.

community spotlight

2nd Annual Roc City Rib Fest

Turned Up the Heat

In its second year, Roc City Rib Fest took on a new date, a new location and a whole new set of credentials. The fest relocated to Ontario Beach Park and held a two-day event on Saturday and Sunday, May 23 and 24, during Memorial Day weekend.

Before competitors were even pulling out their tongs, the 2009 festival had been certified by Gov. David Paterson as a New York State Championship barbeque contest and declared the first Kansas City Barbeque Society-sanctioned barbeque competition in Rochester history.

Event organizers knew how to drum up interest in the revamped event. Big billboards, radio show interviews and an impressive Facebook page following (with nearly 650 fans) got people revved up for ribs well before the event took place.

It also didn't hurt that the event was one of the few in the area scheduled to take place on a holiday weekend when people were looking for things to do at home. Many families opted to take a "staycation" rather than travel during Memorial Day weekend.



Event-goers found the Rib Fest to be a tasty, family-friendly outdoor event, where they could enjoy the weekend's beautiful weather without leaving Monroe County.

The fest was a huge success, raising more than \$8,000 for Golisano Children's Hospital at the University of Rochester Medical Center.

Next year's event will again take place on Memorial Day weekend, but will last four days rather than two. The 3rd annual Rib Fest will run from Friday, May 21, to Monday, May 24, 2010. Friday night's event will be open to adults only, while Saturday, Sunday and Monday will welcome families with kid-friendly events.

To see photos of the 2009 event, visit www.roccityribfest.com.



Children's Miracle Network Sponsors

Kiwanis Clubs made a quarter mile of quarters at local malls

On April 4, not one, but two Kiwanis groups garnered community support for Golisano Children's Hospital by creating a quarter mile of quarters at area malls. For its fourth year in a row, the Finger Lakes division of the Kiwanis Club held the special fundraising event at Eastview Mall. Their goal was to collect 4,000 quarters for Golisano Children's Hospital; enough quarters to make up a quarter of a mile.

This year, the Genesee Kiwanis Club joined in on the fun by collecting quarters for their own quarter mile at Marketplace Mall. The groups stayed at the mall all day and collected \$9,000 total for the region's only children's hospital.

Wal-Mart wrapped up its Miracle Month of May

Our 14 local Wal-Mart and Sam's Club stores are committed to helping our region's children. Every year, the stores devote six weeks, from the beginning of May to the middle of June, to raising funds for Golisano Children's Hospital. Through the hard work of employees and generosity of Wal-Mart and Sam's Club customers, the stores raised \$55,818 over the course of the six-week period.

WAL★MART



Tops Friendly Markets posted a friendly face

Our Miracle Maker Award-winning Children's Miracle Network (CMN) sponsor this year, Tops Friendly Markets, finished their CMN balloon promotion at the end of May. Employees sold \$1 paper balloons to raise funds for Golisano Children's Hospital. This year's balloons were specially designed to remind customers what it's really all about: the kids. The balloons featured the face of 2008 Miracle Kid Anders Swanson.



special thanks

Special thanks to these and all generous groups that support Golisano Children's Hospital. If you are interested in hosting a fundraiser please go to givetokids.urmc.edu and complete the Community Fundraising Application Form or call 585-273-5948.

- The Screaming Beavers Hockey Club held their 8th Annual Golf Tournament on June 20 and raised \$1,381.
- The Senior Leadership Seminar students at Fairport High School sold bagels to classmates, faculty and staff, raising \$450.
- Lisa's Hallmark held a Webkinz Party at Marketplace Mall and raised \$45 for our region's only children's hospital.
- EZ Bottle & Can Return donated a portion of their business profits to the children's hospital in the amount of \$81.
- Roc City Rib Fest — THANK YOU for delivering great eats and a whopping \$8,198 to our community. Way to go organizers, Brian and Todd!
- Martha Brown Middle School in Fairport—you ROCK! For the 5th year these fine young students held a fundraiser to benefit kids. The Walk-a-thon raised a staggering \$17,000!
- 7-year-old Alexander Umiker held his annual lemonade stand and raised \$45! What's better than kids helping kids?
- Avon Middle School held a car wash this spring and raised \$302. Go Braves!
- The Honeoye Falls Lima Interact Club held a Boys Pageant in memory of a classmate. This annual event got rave reviews and generated \$2,320.
- Mrs. Siragusa's senior English class at Brockport High School organized a walk and raised \$1,545.
- The Health Education Department at Gates Chili High School raised \$33 to raise awareness for Leukemia.
- The annual Greek Festival generously donated \$1,000 again this year. Thank you!
- The ROC City Roller Derby held a "bout" this spring and raised \$875.
- Teri Madonna, a student at Mercy High School, organized and directed the play "Bernarda Alba" and raised funds in the amount of \$805 for the eating disorders division at Golisano Children's Hospital.
- Heather VanDeMark held a Mother's Day Flower Sale in memory of her daughter, Julia Marie, and raised \$1,800!
- The Browns Backers football club donated the balance of their members' dues—\$175.
- The Photo City Browns Backers donated \$200 to the NICU. Go Browns!
- The Rochester Red Wings guest bartended at the Distillery in Greece and donated \$150 from the night.
- Webster Thomas and Willink middle schools held a Jar Wars during spirit week and collected \$1,362 in memory of Noah Passero. Thank you!
- Chris Johnson's classroom at Cosgrove Middle School held a production of "Charlie & the Chocolate Factory" and raised \$143.
- The Pittsburgh Steelers Fan Club raises money all season long for Golisano Children's Hospital. For the 2008–09 season they donated \$1,800. Go Steelers!
- Martial Arts America held a kick-a-thon to raise money for kids. Through the thousands of kicks they raised \$4,438. Wow!
- The Father's Day Memorial Scholarship Fund donated \$1,000 to the hospital in memory of Jesse Guido.
- The annual SMILE spaghetti dinner organized by Nazareth students and staff raised \$2,500 for the Craniofacial and Cleft program.
- The "Girls Rock Club"—4th graders at East Rochester Elementary School—collected money and donated \$34.
- Thank you Wayne Central High School for holding a fundraiser and donating \$226!
- Last Man Standing—the infamous football club—donated \$3,000 for nursing education.
- B&L Wholesale held the 14th annual B&L Golf Tournament and raised \$114,000 to help purchase a machine that will help pediatric cardiac patients.

Two sisters' legs

continued from page 9

After nine long months, Sanders found no change in her condition.

In April 2009, Sanders sat down with the LaDuke family to discuss the best way to treat Juliana. Juliana had a more defined case of bowed legs, walking on the sides of her feet instead of flat-footed. She was also much more verbal about her pain than Josie had been, who was more apt to “plow through anything,” according to her mother.

Together, Sanders and the family discussed their options. Taylor Spatial Frames worked for Josie, but Juliana was a different child with a different tolerance level than her older sister, and Sanders recognized this as much as Juliana’s parents did.

“Really, when it comes down to it, Dr. Sanders treats the child, not the disease. He can’t alter every single variable, but he absolutely tailors his treatment of each patient based on their own distinct personalities,” said Marlene.

Sanders suggested that he could do the majority of the correction in the operating room when he put the frames on, rather than asking the family to

adjust the braces a little bit every day, as they done had with Josie. After discussing some possibilities for treatment, Sanders told the family to take as much time as they needed to think about their options.

The LaDukes ultimately decided to have Sanders go ahead and do the majority of the correction on the day of surgery. They scheduled the four-and-a-half hour surgery for May 19. Added together, the girls had seen Sanders more than 30 times over the past year — sometimes with multiple visits in the same week. Once Juliana’s braces come off, the family is hopeful that appointments with Sanders will be limited to just a couple times a year until puberty. The girls will have to be monitored more closely as they mature through puberty, as growth plates move a lot during that time period, and there is 20 percent chance the girls’ legs will need to be corrected again.

Looking towards the future

It is still not clear exactly what genetic disorder the LaDuke toddlers have. While Sanders treats the girls, Chin-To Fong, M.D. associate professor of

Pediatrics Genetics Department at Golisano Children’s Hospital, works on identifying their exact diagnoses.

As Juliana went into surgery in May, her father went to the Radiology Department at Strong for a full skeletal survey ordered by Fong. Fong then sent the genetics information, along with the skeletal survey, to a registry in California, where a genetic analysis will determine definitively whether Chad, and consequently his daughters as well, have MED.

“The girls’ operations were inevitable: now it’s just a question of putting a name on their disorder,” said Marlene. Very specific research is taking place in the field of genetics, so knowing exactly what the girls have can help if the family decides to follow or take part in any research studies. While there is not a cure, the LaDukes are hopeful that in 25 to 30 years, when the girls are ready to have children, there may be a way to alter the gene mutation. “We are hopeful that science will catch up with them,” their mother said.

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