

STRONG KIDS NEWS



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

FEATURED STORIES:

From wheelchair
to basketball

3

Casting improves joints

5

The Sibling Watch program

8

Plastic surgery heals leg

9

Gala sets record

12



Helping kids feel like kids

When children have to spend time in the hospital, nothing is normal. Their bed isn't their normal bed. Their food isn't their normal food. Their mood and how they feel isn't normal.

That's why Golisano Children's Hospital at Strong's Child Life Program is so important. Playing games on the play deck, blowing bubbles in a play room and watching movies in their patient rooms are essential activities — for a time, they offer the children a chance to feel normal again. But the job of the Child Life Department is much more than even that. It's incredibly varied.

"Our job is to make sure children and families are comfortable and can

understand and manage the stressful situation they're in when a child is in the hospital," said Wendy Lane, a child life specialist and coordinator of the hospital-wide program. "Sometimes that means playing; sometimes that means showing a child what a medical procedure will be like on a doll; sometimes that means helping a family say goodbye."

Child Life Specialists and other child life staff work with patients in the inpatient areas (including the Pediatric Intensive Care Unit where the most critical patients stay), the Emergency Department, the surgical suite, the outpatient clinic and the infusion areas. They work with patients who have come

Continued on page 13





Dear Friends —

What exciting times we live in! Most of the human genome has been sequenced; the molecular bases of disorders like cystic fibrosis, muscular dystrophy, and polycystic kidney disease have been determined; stem cells from adult tissues may hold the promise of a cure for disease of people of all ages.

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Within this veritable explosion of technical capability and biomedical knowledge, one unifying truth has come to light: many of the molecular species responsible for common adult diseases play a critical role in normal growth and development. What this means is no surprise to any card-carrying pediatrician—the seeds for healthy adulthood must be sown during childhood. While children are most certainly not just “little adults,” adults are just as certainly the cumulative product of processes that begin in childhood and adolescence. This is what makes the increasing incidence of, for example, obesity, heart disease, and diabetes at younger and younger ages so frightening.

At every level, we at Golisano Children’s Hospital at Strong and our partners in the community and region and at the University of Rochester approach childhood healthcare from this prospective. In our offices and clinics and on the Hospital wards, we all serve as educators as well as physicians, giving proactive and anticipatory guidance to families and children, making prevention of disease and maintenance of health our first priority. As you will read in this issue of our newsletter, this family education process all starts before birth and, in the Neonatal Intensive Care Unit, includes attention not just to parents, but to siblings, as well. In our laboratories, we apply concepts learned from the study of Alzheimer’s and Parkinson’s disease to

the therapy of childhood nervous system cancers and apply what we learn about immune system embryonic development to the conquest of adult diseases like lupus and lymphoma. Our research, you will read, is basic, clinical, and “translational” (bridging-the-gap) biomedical and social science. In the classroom, we train medical students, residents, and fellows to access and acquire new knowledge, not just to memorize today’s facts, because what is state-of-the-art today may be obsolete tomorrow.

What is absolutely certain in all of this is that we could not do any of this alone. We depend on and remain ever grateful for the support of the Greater Rochester community in all of our efforts. Having recently moved to Rochester, I can tell you that what you have and what we have together are virtually unique—a perfect synergy among the community, the Hospital, and the University and Medical Center. What better role model could there be for our children as they forge ahead into adulthood? You joined us on Liftbridge Lane at the Fairport Music and Food Festival and you encouraged your children to enter our coloring and kid-naming contests. There can be nothing more exciting than the confluence of purpose and dedication to the health and well-being of our region’s—indeed, our world’s—children. As I begin my life in Rochester, I look forward to working with each and every one of you towards our common, critical goal—healthy children, adolescents, and adults.

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

Hospital's neurology division offers hope

Less than 18 months ago, Matthew Sorano was in a wheelchair—months from being confined to a bed—and he struggled to speak, lost 20 pounds, drooled and fell asleep at 6 p.m. every day. None of the specialists the family saw in Albany, Boston and Vermont could tell them what was wrong. In fact, more than one suggested Matthew's trouble swallowing, fatigue and loss of mobility were the result of a psychological problem.

Matthew's parents, Judy and Steven of Fort Edward near Saratoga Springs, N.Y., struggled for three years to get their middle son, now 13, the care he needed. One local physician, Shawn Jorgensen, M.D., a physical medicine and rehabilitation specialist, volunteered to take Matthew on as a patient and to be his advocate in the medical world.

Jorgensen found specialists closer to home and encouraged the family to keep searching for a treatment, but it wasn't until they were referred to Jonathan Mink, M.D., Ph.D., a pediatric neurologist and national expert in movement disorders at Golisano Children's Hospital at Strong, that they found the hope they needed.

"The first thing he said to us was, 'You've come to the right place. I may not be able to give you a definitive diagnosis, but I can help Matthew,'" Judy recalled Mink saying to them. Suddenly hope was back.

Mink immediately saw signs of Parkinson's disease, a chronic and progressive disorder of the nervous system that causes tremors, slow movements, muscular stiffness and poor balance. Parkinson's rarely strikes anyone under 40, let alone under 20, but Mink said Matthew had all the classic symptoms. Mink prescribed a small dose of an adult medication for Parkinson's.

"Within a week, we knew that it was helping. Since then, it's been

simply fine-tuning," Judy said. "Now, he's walking, he's talking, he's eating food, he's riding his bike again. It's amazing the difference in just a year."

In addition to training in Pediatric Neurology, Mink did formal fellowship training in movement disorders in which he saw both children and adults with movement problems. There are few experts on pediatric movement disorders in the country, and Golisano Children's Hospital is fortunate to have one of them in Mink. He also directed the Deep Brain Stimulation program for Parkinson Disease at Washington University, so he saw many patients with Parkinson's disease before meeting Matthew.

Prior to seeing Mink, Matthew hardly attended school anymore. Now, he goes for five hours a day. He can finish his own homework, rather than having to tell his mother what to write.

"It is very rewarding to be able to make such a dramatic difference in the life of someone like Matthew," Mink said. "We rarely have the opportunity to provide treatment that gets kids out of wheelchairs and allows them to play

basketball again. Things are by no means perfect for him and we have not provided him with a cure. However, we were able to improve his quality of life substantially."

Not all the patients of the Pediatric Neurology Division at Golisano Children's Hospital have rare diseases. A wide variety of conditions are diagnosed and treated, but the most common are seizures and headaches.

Elaine Gersz, 11, of Brighton began experiencing severe headaches about two years ago. Because she also has bad allergies, her family and her pediatrician, Correne Wirt, M.D., first pursued the possibility that the headaches were reactions to an allergen.

When all possibilities were exhausted, and one headache lasted two weeks and included a day-long visit to the emergency department, Wirt referred Elaine to Golisano Children's Hospital at Strong's Pediatric Neurology Division. There, Elaine, her mother, Marsha Raines, and her father, Steven Gersz, met Allison King, M.D., and Lauren Zwetsch, N.P., and Elaine was

Continued on page 14



Left:
Matthew
Sorano went
from wheel-
chair to
walking under
Dr. Jonathan
Mink's care.



Above: Elaine Gersz's migraine
headaches used to control her;
now, she controls them.

Announcing our contest winners!



4 and under Teagin Brandes, 4 years old, Wellsville



5 to 8 years old Alexis Baker, 8, Rochester



9 to 12 years old Amy Aldwinckle, 12, Geneva

Thanks to all who submitted to our contests this September—we're proud to unveil the winners!

Kid's Coloring Contest

Kids' Coloring Contest, sponsored by ESL Federal Credit Union awarded \$500 savings bonds to first-place winners in each of three age categories: 4 and younger, 5 to 8 and 9 to 12. Winning submissions are pictured above and at left.

Name Sandy's Friends Contest

Local artist John Kuchera first designed Sandy Strong back in the '70s. Before long, we realized she was pretty lonely and fixed that by creating some friends to keep her company. Unfortunately, we were so excited to give Sandy new friends that we forgot to name them!

Thanks to Steven Campione Jr., 9, of East Rochester and Olivia Spence, 4, of Fairport, the waiting is over. Below are the newly named friends. We made sure to send them home with some goodies, too—an iPod nano, a one-year family membership to the Strong National Museum of Play and a doll of the friend they named, created by local artist Shanna Murray, who creates boutique children's clothing and toys centered on character development (visit www.twotrees.etsy.com).

To see more contest winners and entries, visit www.gchas.org.



◀ **Anna Wellagain**
"It gives hope and meaning to why we go to the hospital."
Olivia Spence, 4



◀ **Michael Miracle**
"My brother's named Michael—he's autistic, and has come a long way. It's a miracle!" Steven Campione Jr., 9

Casting helps treat kids with joint complications

Arthritis usually conjures up pictures of the elderly with twisted and unbendable joints, but those complications are not isolated to the elderly. Children, even as young as 5 years old, can end up with wrists so inflamed and painful that they lose mobility, and sometimes even the most advanced medication, occupational therapy and high-tech splinting doesn't work.

That's when occupational therapist Dana Emery, O.T.R./L., pulls out low-tech plaster and casts the joint. "This isn't what casting was meant for, but it has been working well for patients who haven't responded to other treatments," said Emery, who works with Golisano Children's Hospital at Strong's pediatric rheumatology and immunology clinic through a partnership with the upstate New York chapter of the Arthritis Foundation. "It's difficult for some of our young patients to keep splints on enough to make a difference in the range of motion; this way, they can't even think about taking it off."

Young patients with chronic diseases such as arthritis and lupus often experience intense pain in their wrists. To compensate they curl their hands in, particularly when asleep. Over time, that can shorten the tendons and ligaments on the inside of the wrist, making it difficult to extend their wrists past the straight (or neutral) position. Most often, patients will take medication and perform exercises to combat the problem. But that doesn't always work. The next step is to splint the joint with a removable custom-made brace. That can also be unsuccessful, especially if patients take off the splints too often.

"That's when we consider casting. It isn't the best choice for all our patients, but when all else fails, it's wonderful to have the option," Emery said.

Emery initially worked with chief occupational therapist Kathy Stoklosa, M.P.A., O.T.R./L., who, citing medical literature, suggested casting the patients.

Since early this summer casts have been used on three pediatric patients. Emery puts the casts on the first day aiming for five to 10 degrees past where the child can hold her wrist on her own. On the seventh day, the cast is removed. A new cast is put on, again at five to 10 degrees past where the child can hold her wrist on her own. The final aim is for 70 degrees past the straightened joint, and so far, the casts have been successful.

The success has led Emery and the rest of the team to consider other diseases they see in the clinic, such as scleroderma, an autoimmune disease that hardens the skin and often other tissues such as blood vessels. Samantha Fisher, 13, of Irondequoit, received her first cast Sept. 29. Her range of motion has been impacted mainly in her right arm; she is only able to hang from the monkey bars with her left arm.

Lori Fisher, Sam's mother, agreed to the casting regime, despite it not

being a common practice for patients with scleroderma.

"It's not invasive. It's not medicine. It's not surgery," Fisher said when explaining why she was quick to agree.

Plus, the pair had big plans to decorate the casts each week until Sam has regained as much motion as possible.

"We're fortunate to have an innovative occupational therapist in our clinic, and we're encouraged by the results of the casting treatment so far," said David M. Siegel, M.D., M.P.H., chief of pediatric rheumatology and immunology at Golisano Children's Hospital at Strong. "Without the support of the upstate chapter of the Arthritis Foundation, which provides a grant to pay for Dana's time in the pediatric rheumatology clinic, patients wouldn't have immediate and free access to the kind of care she provides."

For more information on arthritis, visit www.arthritis.org.

Dana Emery casts Sam Fisher's elbow to help the teen regain flexibility she has lost to scleroderma.



Penicillin, Amoxicillin losing effectiveness against Strep, newer antibiotics recommended

Children who receive penicillin to treat a strep throat infection are two to three times more likely to relapse than those who receive cephalosporin, a newer antibiotic. Amoxicillin fairs only slightly better than penicillin with a failure rate of 24 percent.

"A strep infection can be very painful for children and worrisome for parents whose kids can run high fevers," said Janet Casey, M.D., a pediatrician at Elmwood Pediatric Group and a clinical associate professor of Pediatrics at Golisano Children's Hospital. "Relapses mean more pain and more missed school for the children, and for parents, it can mean missing more work and more pay."

Casey, one of many community pediatricians engaged in research at the University of Rochester Medical Center, is the author of a study on the effectiveness of some often-used antibiotics on Group A beta-hemolytic streptococcal tonsillopharyngitis, or strep throat, that was presented at the Interscience Conference on Antimicrobial Agents and Chemotherapy in San Francisco at the end of September. The study, which was co-authored with Michael Pichichero, M.D., a professor of Microbiology and Immunology at the University and a pediatrician at Elmwood Pediatric Group, will be published in *Clinical Pediatrics*.

Strep throat infections are common among children between 2 and 18 years



old. Symptoms include sore throat, fever, headache, abdominal pain, vomiting and swollen tonsils and glands. More than 1,000 children with positive rapid strep tests or positive cultures participated in the study between September 2004 and June 2005. Of those who took penicillin, 36 percent relapsed, 24 percent with amoxicillin relapsed and 13 percent relapsed with cephalexin. Antibiotics should be used only in patients with a positive rapid strep test or culture. Antibiotic treatment of sore throats without a positive strep culture needs to be avoided because it results in overuse of antibiotics and the potential development of antibiotic

resistance.

"The treatment of strep throat needs to be tailored for the patient. First generation or older cephalosporins have a smaller failure rate for a first-time infection; however, for a patient with recurrence or multiple infections in a season, a second or third generation cephalosporin or Augmentin is probably better," Casey said. "These antibiotics can be costlier, but when parents factor the potential cost for another office visit, cost of another antibiotic, cost of more lost work, day care or school, it becomes much less a factor."

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Summer golf events a giant success

Expanding the annual Children's Hospital Golf Classic to four courses this year was a complete success, raising \$225,000 and bringing together almost 500 players!

It was such a wonderful Golisano Children's Hospital at Strong event that no one thing could be considered the highlight: "The absolutely perfect day with respect to weather, the wonderful turnout, the fact that we achieved our goal of expanding the tournament to four golf courses and the featured presentation that evening that reminded us all why we were there," said Mike Goonan, chair of the event, board member and chief financial officer of the University of Rochester Medical Center.

The popularity of the annual tournament, held Sept. 11, inspired organizers to add a fourth course to the event this year — Monroe Golf Club, Irondequoit Country Club, Ravenwood Golf Club and Greystone Golf Club —



Photos provided by Mark Muench.

so they would not have to tell a single golfer hoping to help the hospital that there isn't enough room.

The Golf Classic wasn't the only golf event to benefit the hospital:

- B&L Wholesale Golf Tournament, June 28 raised \$100,000.
- Otter Lodge Golf Tournament, July 18, raised more than \$5,000.
- WNY Optics/Photonics Golf

Tournament, July 20, raised \$9,000.

- Guido's Pasta Villa's Annual Golf Outing, July 30, raised \$3,600.
- Tim Milgate Charity Golf Tournament, Aug. 7, raised \$18,600.
- Kaufmann Golf Tournament, Aug. 28, raised funds for the Pediatric Surgical Suite.
- Frank Dianic Golf Tournament, Sept. 15, raised more than \$4,000.

Fairport Music and Food Festival doubly good

What a celebration! Villagers savored one of summer's final weekends, enjoying scrumptious eats and musical treats to the benefit of Golisano Children's Hospital at Strong.

The festival featured:

- Three stages, 20 different entertainment acts (bands including: blues, jazz, rock, disco and pop — not to mention, children's entertainers).
- 24 food vendors, offering a fusion of Fairport favorites: pizza, wings, fried bologna, lobster foccacia, greens and beans, tacos and more.
- Free children's activities.
- 100 stellar event-day volunteers.
- 7,000 attendees, who together raised \$30,000 for donation to Golisano Children's Hospital — more than double last year's total (\$13,700)!

For more photos from the event, visit:
www.gchas.org/news/FMFF.cfm



Photos provided by Dave Barrone.





Photo by Megan Dailor.

Giovanna Johnson of Rochester visits her daughter, Kanea Nixon, in the Neonatal Intensive Care Unit.

Sibling Watch program helps NICU families

An early delivery or a sick newborn captures a lot of attention, in most cases causing well-meaning family, friends and neighbors to flock. But when a child's stay in the Neonatal Intensive Care Unit (NICU) becomes extensive, the support sometimes dwindles off and child care issues surface.

"Parents just can't be in two places at once. Those with older children are split between much-needed bonding time with their NICU son or daughter and finding someone to watch the other kids," said Chris Tryon, NICU child life specialist at Golisano Children's Hospital at Strong.

And, since children must be 3 years old or older, pass a health screening check at each visit, and have their immunizations on record with the hospital in order to visit the unit, it's quite a bit of work to make sure they're healthy enough to bring inside. Even after siblings are allowed in, the NICU may be overwhelming. They may also start to resent their young siblings for monopolizing their parent's attention and disrupting the family's life.

Tryon and colleague Lori Snyder, a social worker who focuses on NICU families, watched parents and older siblings struggle long enough — why not establish a "sibling watch" program that offers in-hospital childcare services to NICU families and gives older

siblings needed attention?

"Lots of people have seen news stories and wanted to get involved — people that, before the program, had no idea that a NICU was even here," Tryon said. "But as soon as they did, they wanted to help."

Tryon and Snyder, after a year of planning, finalized details and figured out a way to staff a summer-long pilot program. With the help of Jane Walsh from the Friends of Strong volunteer organization, they targeted junior volunteers who, though interested in the NICU, were not quite old enough to work with the sick and premature infants.

Sibling Watch launched on June 28 and ran through the end of August. The

service offered care through advanced sign-up on Monday and Wednesday afternoons and used a gated-off section of the Family Waiting Area adjacent to the NICU.

Kids ranged from 18 months to 10 years olds. The program followed strict daycare guidelines (especially heeding the 1-to-5 staff-to-child ratio) and implemented a parental paging system for emergencies and an ID band and sticker system to make sure the right kids are sent home with the right parents. The junior volunteers, who had toured the NICU as part of their training, benefited from having a first-hand grasp of how delicate, high-tech and volatile the NICU atmosphere could be. Because of it, they appreciated their role in the hospital's support network and were happy to have some relaxing playtime with NICU siblings — paying them attention and sharing an afternoon of sculpting Play-Doh, pushing around Hot Wheels, or plopping down with the kids to share a good book.

Brittney Stanley, 17, of Holley, was one of those volunteers who enjoyed her Wednesday afternoon Sibling Watch post. Now a high school senior, she said she hopes the experience will lend some sparkle to her resume, when she applies to Utah State University this fall with plans to major in child psychology.

Continued on page 14



Lori Snyder and Chris Tryon are the brains behind the NICU sibling program.

Whole again: Putting the pieces back together

Robin Finch, mother of four, used to be an unflappable senior typist in an emergency room in Buffalo. She had developed an incredible way of keeping her cool, even while checking in people in the most tragic of conditions. She had to.

Little did she imagine, back then, that one day the roles would reverse and she would be the frenzied, frantic parent, checking in one of her sons and hoping for a relief, comfort, a miracle, anything.

Last September her youngest son, Bayley, only 5 years old and a day shy of kindergarten, left his mother's side while they were waiting to cross Angell Road.

"I had my arm out, in front of him, to check traffic. When I turned my head back, I saw him being hit," Finch said. "I kept thinking, 'that's not my son,' hoping it wasn't happening."

Finch shouted to her oldest child to call for help, and then immediately ran to check on Bayley. He was lying in the road. Conscious, but in shock, he couldn't feel anything.

"I'll never forget his little voice asking 'am I still alive, Mommy?'"

Finch said. "He had an open leg fracture, muscle hanging by its skin, wounds on his left ankle where you could see the bone. It wasn't until I saw him wiggle his toes that I had a first little wind of hope."

Bayley was brought to Erie County Medical Center by Star Flight. He was regaining sensation. Bayley was stabilized in Buffalo, but there was still uncertainty. Would infection set in; would the leg heal, would Bayley need an amputation?

To answer those questions, the Finches were transferred to Golisano Children's Hospital at Strong, where pediatric plastic surgeon John Giroto, M.D., also director of the Cleft and Craniofacial Anomalies Center and the Pediatric Plastic Surgery Team, took the case. Bayley needed the coordinated, team care of many specialists, and Giroto outlined a comprehensive treatment plan—and backup plans—and presented them to the Finch family.

Giroto would supervise Bayley's multiple surgeries, many of which were conducted just to stabilize his wounds. Jonathan Gross, M.D., M.P.H., was



Dr. Giroto

recruited from Strong Memorial Hospital to work on the orthopaedic end, plating and fixing the broken bones.

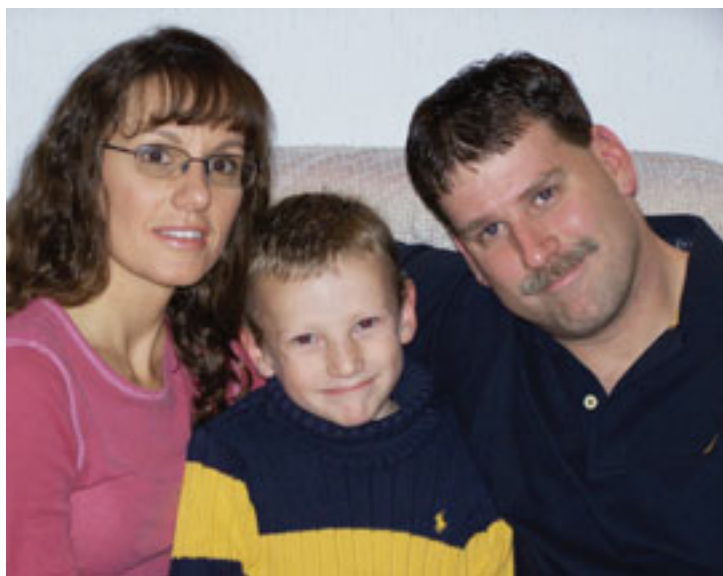
But, since Bayley had lost significant amounts of muscle, tendons and soft tissue, the toughest part still remained—how would they close Bayley's wounds, and make him whole again?

With the support of Howard Langstein, M.D., a gifted microsurgeon and chief of Strong's Division of Plastic and Reconstructive Surgery, Giroto's team transferred muscle and skin from Bayley's abdomen to his leg—a grueling, all-day surgery that proved an absolute success. In the days that followed, Giroto transferred additional skin grafts from Bayley's left thigh to cover wounds on his left knee and left ankle.

The concerted effort paid off. Thanks to Giroto and a team of specialists—along with the help of an in-hospital tutor who kept him up to speed in his studies and a faithful father who took six weeks off work to stay nearby—today Bayley is an energetic first grader who plays in gym class with no restrictions, rides his skateboard and works hard to do his little brother duty of tagging along, keeping up.

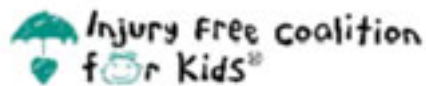
But somehow, Finch said, even all of that stunning progress—Bayley's ability to keep on track with his education, to regain a normal level of mobility—

Continued on page 14



Bayley Finch with his parents, Robin and Shaun.

As winter forces us indoors, beware of falling furniture, other hidden home dangers



Child-proofing devices abound: cabinet locks, door knob covers, faucet scald protectors, outlet covers and, of course, safety gates.

But even with all of these safeguards in place, other subtle yet serious dangers still lurk in the home—they're seemingly innocent items, like bookshelves, dressers, armoires and TVs, that tip over much easier and more often than most parents expect.

In fact, the U.S. Consumer Product Safety Commission (CPSC) estimates that between 8,000 and 10,000 people nationwide pay a visit to their local emergency room every year for injuries related to furniture tip-overs. The majority of those victims are kids, and on average, six are killed. The CPSC announced in September that the number of TV tip-over fatalities alone—which are just a part of all furniture-related tip-over cases—had already reached 10, twice the expected yearly average.

"As parents, we admire our children's curiosity, their spirit of adventure," said Lynn Cimpello, M.D. and co-director of the Injury Free Coalition for Kids Rochester at Golisano Children's Hospital at Strong. "But unchecked, their exploratory nature can pose big risks. When kids bump into and try to climb up or onto television stands, dressers, bookcases and other pieces of furniture, accidents happen. The furniture just isn't built to withstand that kind of weight or play."

The consequences can be deadly, but there's a ray of hope: they're preventable. Proposed national legislation, if passed, would require that all future furniture items at risk for tip-over bear warning labels and be sold with anchoring devices. In the meantime,



Drs. Anne Brayer and Lynn Cimpello are co-directors of Injury Free Coalition for Kids Rochester.

there are immediate measures you can take to protect children in your home:

- Secure all top-heavy or unstable furniture with anchoring equipment, such as brackets, screws, toggles, or industrial-grade Velcro.
- Tie loose cords up and keep them away from kids, who are apt to trip over or yank on them.
- Make sure the base is strong enough to support the television set, and that the set is placed as far to the back of the stand as it will go.
- Store heavy items in lower shelves and drawers.
- Don't give kids a reason to climb; avoid keeping the remote control, a favorite toy or other tempting items on top of furniture.

"It takes such a small sliver of time for an accident to happen, but we see injuries from falling objects all the time," said Anne Brayer, M.D., who co-directs Rochester's Injury Free program with Cimpello. "Parents must

take caution and secure televisions, bookstands, everything with the slightest potential to tip."

Help Keep Kids Injury Free

The Injury Free Coalition for Kids Rochester is a child injury prevention program based at Golisano Children's Hospital at Strong, where it draws on rich experience of co-directors Anne Brayer, M.D., and Lynn Cimpello, M.D., who both practice pediatric emergency medicine.

Stationed in Monroe County, where unintentional injury is the leading cause of death in children less than 18 years old, Injury Free Rochester welcomes your support. To find out how you can make Rochester a safer place to grow up, visit www.injuryfree.org, or call Karen Knauf, program coordinator, at (585)275-9748.

Pediatric community celebrates former chair

The evening of Sept. 9 started with heartfelt speeches and ended with a musical tribute from Rochester pediatricians — a fitting celebration of Elizabeth “Lissa” McAnarney, M.D., the sixth chair of the University of Rochester Medical Center’s Department of Pediatrics. Her time as chair and pediatrician-in-chief of Golisano Children’s Hospital at Strong ended as she handed the baton to Nina Schor, M.D., Ph.D., who became the seventh chair Sept. 1.

The dinner, held in the Rochester Riverside Convention Center Lilac Ballroom, was attended by about 350 people, a who’s who of the pediatric and philanthropic communities. The evening’s speakers ranged from University President Joel Seligman and Medical Center CEO Bradford C. Berk, M.D., Ph.D., to hospital namesake and Paychex founder Tom Golisano and Michael Weitzman, M.D., former associate chair of Pediatrics here and now chair of Pediatrics at New York University.

Of course, there was no shortage of fun, with a group of Golisano Children’s Hospital pediatricians led by Craig Mullen, M.D., Ph.D., chief of pediatric hematology/oncology, serenading McAnarney with “Mona Lisa” (reworked into “Mama Lissa”) and “In My Life.” Another group from Rochester General Hospital, Captain Dave and the Northsiders, led by David Siegel, M.D., M.P.H., chief of Pediatrics at RGH, dressed in stage costumes and sang a reworked version of “Rhythm of



the Rain.”

“We’ll miss you but we know you’re not going too far. In fact, you’re only down the hall. You’ve earned some time to think and write, and savor life. We want you to just have a ball,” Seigel sang, with other pediatricians backing him up.

After the performances, faculty and staff presented McAnarney with several thoughtful gifts, including a memory book and artwork by patients. And, to honor McAnarney’s 13 years of dedicated service as chair, Howie Jacobson, chair of Golisano Children’s Hospital’s board, announced that one of hospital mascot Sandy’s friends would be named Lissa. As he presented her with Paul Knoblauch’s artistic rendering of the

little redhead, he noted that one of McAnarney’s greatest accomplishments — a unified pediatric community — was demonstrated earlier in the night.

“You won’t find another event in Rochester in which RGH and Strong would share a stage,” he said.



Left: Tom Golisano, hospital namesake, enjoys the pediatricians’ performances.

Right: Howie Jacobson, chair of the hospital’s board, announces that Sandy Strong’s red-haired friend is now “Little Lissa.”



Annual Children's Hospital Gala raises \$460,000

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A record 960 guests attended 19th annual Golisano Children's Hospital at Strong's Gala Oct. 21, and the hospital netted a record \$460,000 in donations. Guests were treated to an expanded event, which sprawled across two hangars at USAirports on Scottsville Road for the first time this year.

Gala guests were able to better mingle during the silent auction portion of the evening because an entire hangar was devoted to it. In addition to the wonderful items up for bid in the silent auction, guests also had the opportunity to purchase items in the hospital's wish list area. This area featured everything from CD players and activity tables to help provide entertainment for our patients to high tech equipment to help provide the best care to our children.

Mark and Marcia Siewert, good friends and supporters of the children's hospital, served as honorary chairs. Mark Siewert is a dedicated board member who serves on the major gifts and corporate committees. The couple donated to both the new surgical suite, naming the kite-lined entrance hallway after their son Mark Daniel, and to the Pediatric Intensive Care Unit, naming the family waiting room.

Howie Jacobson, chair of the children's hospital board, once again served as the live auctioneer during the dinner portion of the evening. There was plenty of activity as guests tried to outbid each other for items such as a spectacular Hearts on Fire diamond ring donated by Cornell's Jewelers, a party for 100 at Richardson's, a Tops Market shopping spree, the ultimate spa experience donated by Del Monte Spa and Lodge—just to name a few. Another highlight of the live auction was bidding for the butterflies made by Rochester artist Paul Knoblauch. The butterflies will be displayed in the children's hospital. At the completion of the auction, guests enjoyed an evening of dancing to music by Nik and the Nice Guys.

The gala is the hospital's premier event of the year and the largest single fundraiser. ESL Federal Credit Union served as the gala's presenting sponsor for the fourth year. Their contribution along with the hundreds of sponsors, live and silent auction donors and guests, helped create a spectacular and very successful evening. Next year's gala will be held on Oct. 20, 2007.



CMN News



TOPS Markets increased their giving this year, wowing us with a check worth more than \$27,000 to help ill and injured kids here at Golisano Children's Hospital. The money was raised during their two-week fundraising campaign, selling orange and yellow CMN balloons and holding various fundraisers at their 19 locations (including one MARTIN'S Super Food Store).

TOPS joined as a CMN partner last year and their enthusiasm has set a fine example. Beyond paper balloon sales, TOPS has extended support as a major sponsor in the 2006 Radiothon in February, and this October were proud sponsors of the 19th annual Gala (they also made additional donations to the Gala's silent and live auctions).



Above: TOPS "never stops" helping raise healthy children. Left to right: Dan VanAuker, store manager, Jefferson Road TOPS; Todd Nettnin, store manager, Mt. Read Boulevard TOPS; Jack Kelleher, Director of Operations and Merchandising.

Child life staff

Continued from cover

here for a whole spectrum of reasons, ranging from a simple check-up to chemotherapy treatments to recovery after a car accident.

They teach patients and families about upcoming medical procedures, such as what it will be like when they receive a bone marrow transplant, and they arrange for special activities on the play deck to keep kids feeling like kids. They also help adolescents, who are navigating the tricky line between childhood and adulthood, find ways to deal with their illnesses and occupy their active minds.

It's that loving care and attention to developmental needs that inspired a recent donation to the program from Rolla and Kirsten Huff. The couple recently toured the hospital and were inspired by the behind-the-scenes work done by the Child Life staff.

"Children being comfortable and feeling secure in their environment is hugely important to getting over their illnesses," Rolla Huff said.

Kirsten Huff said the business world has taught them both that shrinking

budgets can affect programs like this. "We can't let that happen."

The Huffs, who are parents, decided they wanted to ensure the program's future, so they did something a little more creative than the average donor—they endowed a gift. Endowing a gift



allows money to be released annually which makes the program more stable than a one-time gift does because the program can count on receiving money into perpetuity.

Nina Schor, M.D., Ph.D., pediatrician-in-chief, has placed a priority on growing endowments within the hospital and the Department of Pediatrics and hopes the Huffs' gift will inspire more.

"There are many benefits for donors in endowing a gift, especially if the endowment is earmarked for a program, whether clinical, research, or combined in nature," Schor said. "It's a very personal gift because the donor can have an ongoing relationship with the program or person they are endowing and gain inside insight into the development of new services, medical and scientific knowledge, treatments and preventive strategies."

Endowment donors, like the Huffs, can assure that good work goes on into perpetuity.

For more information on endowing a program or chair, please call (585) 273-5948.

Neurology

Continued from page 3

diagnosed with migraines.

“(Zwetsch) carefully listened to Elaine’s history,” Raines said. “She listened to us. She developed a rapport with Elaine.”

King and Zwetsch designed a comprehensive approach for Elaine’s headaches. The family read a recommended book, changed Elaine’s diet and began a new medication. Raines said King and Zwetsch have been very accessible, and Elaine has mirrored her strength on the basketball court with her strength in navigating newly forbidden foods and managing migraines when they begin.

“It’s amazing how a child who was 10 and 11 years old was really an integral part of her treatment plan,” Raines said. “It’s also important to remember that when a child says she has a headache, it can be just as severe as when an adult says they have a headache.”

Whole again

Continued from page 9

wouldn’t have been enough. Something still would have bothered her.

“For the longest time, all I thought about was his perfect body on the day he was born. As a mother, I couldn’t stop wanting that back,” she said.

A counselor at the children’s hospital helped Finch free herself from some of that blame.

“They asked me, ‘if you’d known, wouldn’t you have done everything in your power to prevent it?’” Finch said. “Of course, my answer was yes, I certainly would have, to which the counselor came back with, ‘And since there was no way you could have known, it can’t possibly be your fault.’”

That made sense, helping her with some of that guilt, Finch said. But the wounds, though improving, were still ghastly reminders, and somehow, they had a cruel way of digging back up all that hurt.

Anticipating this, Giroto and his team committed to follow-up surgeries to continue erasing the scars. The surgeries continue, even today.

“Healing really happens in two arenas—the physical and the emotional, but they’re incredibly inter-

twined.” He says, “That’s why we work so passionately to help put the pieces back together so kids and families can go on to live the best quality of life possible, feeling and looking whole again. For Bayley, we wanted him to be able to head off to school with plenty of confidence.”

Today, a few surgeries later, Bayley’s leg bears only a small scar—and with time, and more surgery, the visible reminders of the accident will fade further, becoming even less noticeable.

Hopefully, so will the memories.

“We tell him there’s nothing to feel awkward about—and it’s really true. It really is looking healthier each time,” Finch said.

This summer, Bayley was able to wear shorts without embarrassment.

“For a boy who was shy before the accident, that’s no small triumph,” Finch said. “And while we like to say the surgery is all about helping Bayley, giving him confidence, making him whole, it’s really more than that. It’s helped all of us. The scars, the memories—they’re all vanishing together. We’re all becoming whole again.”

Sibling watch program

Continued from page 8

“The afternoons zipped by,” Stanley said. “The parents were grateful, and the siblings felt special.” She and other volunteers were impressed with the program’s organization and felt a keen awareness of the fact that they were helping in not one, but two ways: easing the stressors of seeking child care and dispelling the old “boring hospital” stereotype that might have soured into sibling resentment.

During its three-month pilot, the program served one-third of NICU families; some parents commented that because of it, their older children, for

the first time, actually enjoyed having to head to the hospital.

Given the success of the Sibling Watch program pilot, Tryon and Snyder are exploring ways to expand it with new volunteers and extended service hours. You can get involved, too; just read below to find out how.

Did you know?

The 52-bed Regional Neonatal Intensive Care Unit is the only one of its kind in the Finger Lakes Region. It’s a highly specialized, nationally recognized center providing the highest level of care available to 1,200 sick or premature newborns every year!

Get Involved

Help a NICU Family: “An Evening of Wine and Wishes”

Join us 7 to 10 p.m on Saturday, March 24, at the Memorial Art Gallery for an evening devoted exclusively to the tiniest patients at Golisano Children’s Hospital at Strong. The wine-tasting event will provide a chance to meet and mingle with Neonatal Intensive Care Unit staff, reflect and celebrate the progress the NICU has made over time, and most importantly, learn of future needs, wishes and how you can play a key part in granting them. For more information on the event, contact Betsy Findlay at (585) 273-5933 or Karen Eisenberg at (585) 273-1462.

Special Thanks

Many thanks to all of these groups and the countless others that continue to support our region's only children's hospital!

- When Carrabba's Italian Grill opened in Henrietta Oct. 30 in a grand celebration, the restaurant generously gave the hospital 50 percent of its sales, \$3,658.
- Pittsford Dance Studio students put on a creative ballet rendition of Bram Stoker's "Dracula" love story Oct. 28 to benefit Golisano Children's Hospital at Strong. They raised \$1,800.
- Graham Lodge and Patrick Booher celebrated their 10th year helping us Cruise for a Cause Oct. 15 to 22. The tropical excursion benefits Golisano Children's Hospital and provides a wonderful opportunity for relaxing fun.
- Evergreen Car Wash gave all customers a free car wash on Oct. 20, and collected donations for the hospital. They raised \$1,000.
- South Beach Salon held a cut-a-thon for the hospital, donating 100 percent of its sales Oct. 14 & 15 to help sick and injured kids. They raised \$118.
- Genesee Valley Hunt Races raised funds for the hospital during its day-long horse racing and family fun Oct. 14 in Geneseo.
- The masterminds behind Comics for Kids did it again this year, holding a laugh-filled evening of comedy on Oct. 13 that also benefited the Hematology/Oncology program at Golisano Children's Hospital at Strong. They raised more than \$13,000.
- Bellini's Italian Eatery made its debut in the Rochester community, by celebrating the grand opening of its Victor location Oct. 10 & 11 with all proceeds from the opening benefiting Golisano Children's Hospital at Strong. They raised \$4,581.
- Flower day was again a success Sept. 29, raising \$1,987. Many businesses around the Rochester area bought carnations to benefit the hospital. Thank you!
- The Penfield Challenge 5K Sept. 24 raised \$600 for Golisano Children's Hospital at Strong. Many thanks to organizers and runners.
- Paul Tessoni & Ron Billitier held their annual golf outing on Sept. 22 and raised \$3,775 for Golisano Children's Hospital! Many thanks for their tireless planning and to their many sponsors.
- The Rochester Yacht Club held the annual Rochester Regatta on Sept. 20 and raised \$2,000 for Golisano Children's Hospital.
- The 6th annual Frank Dianic Memorial Golf Tournament held on Sept. 15 raised more than \$4,000 for the hospital's cancer research through its four-man scramble at LeRoy Country Club and 50/50 raffle.
- The Frank Vito Memorial Pasta Dinner Sept. 10 celebrated Frank's legacy by raising \$3,700 at The Diplomat Party House.
- Gary LaPietra, SUNY Brockport Men's Soccer Coach, once again organized the annual soccer tournament to benefit the Neonatal Intensive Care Unit. They battled the torrential downpour on Sept. 2 & 3.
- Ed Kaufmann held his annual golf classic on Aug. 28 at Greystone and raised funds for our region's only children's hospital.
- The B&B Horse Trials were held Aug. 27 and, again, raised \$1,228 to support Golisano Children's Hospital.
- The Fairport Music & Food Festival Aug. 26 provided music and fantastic Fairport food to late-summer festival goers. This awesome annual event raised more than \$30,000 for patients at Golisano Children's Hospital at Strong.
- The 10th annual Golisano Children's Hospital Golf Classic Sept. 11 expanded to four golf courses and raised \$225,000. Thank you for continuing to make this event a growing success.
- The Irondequoit Senior Softball League held their annual tournament on August 13 and raised \$1,400 for Golisano Children's Hospital.
- The 7th annual Tim Milgate Charity Golf Tournament held August 7 at the Deerfield Country Club celebrated Tim's memory and made a difference for children at Golisano Children's Hospital at Strong. The golf outing raised \$18,620 for the Pediatric Intensive Care Unit.
- The Carnival of Caring Aug. 12 to 18 brought together employees from Raytec, Gorbelt and Retrotech in Victor for daily entertainment and to help children at Golisano Children's Hospital at Strong. They raised \$6,428.

- Mommies for Miracles held Dancin' in the Streets Aug. 19 at Nathaniel's Pub with funky local vendors and four of the area's hottest bands to benefit Golisano Children's Hospital at Strong. They raised \$1,000 for the Child Life program.
- The 2nd annual Flying H Ranch Rodeo July 29 & 30 raised \$1,467 for the hospital while entertaining crowds with bareback bronco riding and calf roping.
- Guido's Pasta Villa's annual Golf Outing July 30 at Victor Hills Golf Course raised \$3,600 for Golisano Children's Hospital at Strong.

Upcoming events

Dec. 15, 6th annual Rainbow Classic University of Rochester's Palestra on the River Campus. The Pittsford Mendon vs. Pittsford Sutherland High School basketball game to benefit Golisano Children's Hospital. Funds are raised in memory of Katelyn Pasley and Ryan McCluski, and go to support the Pediatric Intensive Care Unit. For information on tickets or the game, call Pittsford Central School District Athletic Department at (585) 218-1062.

Dec. 17, Nutcracker on Ice ESL Sports Centre. Tickets are \$8 for adults and \$5 for children. For more information, call the ESL Sports Centre at (585) 424-4625.

Feb. 3, Cycle for Hope 2 This event takes place at several gyms and health clubs across Rochester from 9 a.m. to 3 p.m. It benefits Golisano Children's Hospital at Strong and Camp Good Days and Special Times. For more information, call (585) 273-5948.

Feb. 5, Paul Tessoni's 5th annual Ski Invitational Bristol Mountain Ski Resort. For more information, call Linda Dirksen at (585) 273-5939.



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