STRONG KIDS Control Control

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

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When she was nine months old, Kaitlin Welsher's little belly turned big and hard—almost like she was pregnant.

Her mother, Kellie Girvin, thought it was probably just something out of which her daughter would grow, but to be careful, she brought Kaitlin to the doctor, expecting to hear that she was worrying too much and should go home, and that her little girl would be just fine.

Instead, the doctor referred Kaitlin for more testing.

"That referral was very scary for us." Girvin said.

An ultrasound, CT scan and liver biopsy together soon confirmed something even scarier than the initial need for a referral — Kaitlin had Andersen's disease, a rare condition that caused her small liver to store glycogen, rather than metabolize it.

"That's why her tummy was so big," Girvin said.

Kaitlin would need a new liver, and soon.

Immediately Girvin, who had been aware of the option of live-donor liver procedures, knew that she wanted to be considered as a donor. The wait for live-donor surgery is shorter than the wait for a cadaveric organ, she said, plus there's a lessened chance of complications down the road.

And naturally, as a mother, she was willing to give anything for her *Continued on page 14*





Dear Friends -

Someone recently pointed out to me that, in mid-December,

I had completed my first hundred days as Pediatrician-inChief of Rochester's Golisano Children's Hospital at Strong.

Part of me thought my colleague silly for pointing this out.

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After all, the only other people of whom I have heard analogous things said have been Presidents of the United States! But another part of me realized from this remark how critically important it is that one frequently take stock of what one has accomplished in the context of one's short- and long-term goals. One hundred days is surely not long enough to have made a lasting contribution. But it is an excellent weigh station at which to assess whether or not we are together headed in the right direction and whether or not our velocity is sufficient to keep pace with our ever-changing universe.

In the few months that I have had the honor and pleasure of leading Rochester's Golisano Children's Hospital, of working with its faculty, staff, Board, community, and partners at Strong, URMC, and the University of Rochester, so many wonderful things have happened. We have celebrated and contributed at our most successful Gala ever. We have performed 23 percent more inpatient evaluations and conducted 7 percent more outpatient visits between July and December 2006 than we did between July and December 2005. We have garnered more mentored research support for our new, young physicianscientists than ever before. We have made the children of our region healthier and their parents more aware of threats to their children's health. And we have done it all in an era of fiscal austerity, record-breaking clinical demand both in number and complexity of patients, retrenchment of the Federal

government vis-à-vis its commitment to research funding, and in a physical plant most of which is in excess of three decades old. They don't call us "Strong" for nothing!

But sustaining this level of achievement will not be easy. Recruiting and retaining the mentors for our young physician-scientists (like Dr. Cook, about whom you will read in this issue) requires endowed professorships; there is no other mechanism for compensating faculty for mentoring, program building, visionary leadership. Serving our patients in the best way we know how requires state-of-the-art inpatient and outpatient facilities (like those of the pediatric surgical suite and PICU used by Dr. Alfieris, our transplant team, and their respective patients, thanks to your dedication and generosity) for every service we provide. And we cannot sustain programs that link our academic expertise to the environment in which we sit—programs like Pediatric Links to the Community, the Vaccine Surveillance Network, and our newer initiatives in prevention of obesity, asthma, childhood stroke, complications of high blood pressure, and prematurity —without underwriting from generous corporate and individual donors.

I may have completed only one hundred days or so here in Rochester. And I have no designs on the Presidency. But you have already taught me that, with your help, anything is possible. Together we must dream big, aim high, and build for the bright, proud future. Our children deserve nothing less.

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

Children's belly fat increases since 1990s

It's no secret that America's children are getting fatter, but what we didn't know until recently is that children's bellies are expanding. That means fat around their organs is increasing and that's also increasing their likelihood of developing diabetes and heart disease.

Abdominal obesity increased more than 65 percent among boys and almost 70 percent among girls between 1988 and 2004. The finding of growing girth is significant because abdominal obesity has emerged as a better predictor of cardiovascular disease and type 2 diabetes risk than the more commonly used Body Mass Index, a weight to height ratio that can sometimes be misleading.

As the first nationally representative study to document the increase in children's belly fat, the study in *Pediatrics* paints a bleak picture for these children who have a higher risk of heart disease, adult-onset diabetes and metabolic syndrome. The good news is that, for children and adolescents, the health effects are often reversible through improved lifestyle and weight loss.

"Kids, teens and adults who have early stages of atherosclerosis in their arteries can have a healthy cardiovascular system again," said Stephen Cook, M.D., an assistant professor of Pediatrics at the University of Rochester Medical Center's Golisano Children's Hospital at Strong and an author of the study about childhood abdominal obesity. "Older adults who have plaque build up have a much harder battle, especially if the plaque has calcified."

Measuring waist circumference is not a "vital sign" normally taken in a visit to the doctor. A BMI is commonly calculated at a well visit, but there are limitations to those measurements. A very muscular person may register a high BMI score, even if he is very healthy and has an average waist circumference. On the flip side, a sedentary child may not register a very high BMI score, but if he carries a lot of fat around his middle, he may be at a higher risk for health problems than other children with the same BMI score. Cook said there is no gold standard yet for how waist circumference should be measured and no consensus yet on the cut-off point for abdominal obesity. However, he added, the study should be a warning for physicians and parents to limit sedentary activities, such as TV

and computer time, and to teach and model healthy eating and exercise behaviors; childhood obesity is a serious and growing problem—perhaps even more than people already believe.

According to data from the National Health and Nutrition Examination Survey (NHANES) between 1999 and 2004, the percentage of 6- to 11 year-old children with high BMI scores rose about 25 percent (15.1 percent in 1999–2000 to 18.8 percent in 2003–04). But the increase in abdominal obesity of the same group over the same period was even more dramatic, more than 35 percent (14.2 percent in 1999–2000 to 19.2 percent in 2003–04).

"Those increases only grow more alarming as you tease out specific age groups over longer periods of time," Cook said. "For example, between the 1988–1994 data and the 1999–2004 data, the largest relative increase in the prevalence of abdominal obesity occurred among 2- to 5-year old boys—84 percent—and 18- to 19-year-old girls—126 percent."



Stephen Cook, M.D., said there is no gold standard yet for measuring waist circumference, but our children's growing bellies should be a concern.



From my eyes: a teen's perspective

Bethany Marsh, 17, reflects on two years of fighting Acute Lymphoblastic Leukemia.

Two years ago I started to feel different. My step was slower and every day became harder to handle. I went to my doctor several times. She thought it was just the flu. I went back to the doctor, this time with crushing bone pain that ibuprofen and Tylenol wouldn't touch. I became weaker and weaker as they tried to figure out what was wrong. By the end of the day, the doctors in the small local hospital where I had been taken told me they suspected I had leukemia. That night I was hooked up to a morphine pump to help make me more comfortable. My family was very scared. I don't think I would have been so frightened if I hadn't seen my mom crying.

The next day, after I was settled into my new room at Golisano Children's Hospital at Strong, my primary oncologist, Dr. David Korones, came in to tell me that I had cancer. I asked if it was curable, and he said yes, it was. I told him that I would eat cat poop if it would help me to get

Little did I know what I was about to go through and how much my life was about to change. better, and that it was time to get started!

When I first lost my hair I'll admit that I was devastated, but that lasted about a day. After that it became fun having no hair. Everyone thought that I was so cute. When my mom cut it she said, "Tweety! My baby!" (She always thought that I had looked like Tweety Bird when I was little because of my big eyes, long eyelashes, and the one or two strands of hair on my head.) I have experienced a number of serious complications and side effects to medications over

the past two years, including an allergic reaction to a chemotherapy drug, chemical hepatitis, the formation of three large blood clots in my heart, kidney stones, gastritis, seven compression fractures in my spine which confined me to a wheelchair for a couple of months, and necrosis and bursitis of the hip (significant tissue damage). I gained 40 pounds through steroid and drug treatment, and lost 50 pounds after throwing up almost nonstop for three straight months.

Even during my worst times though, I have truly seen cancer as a blessing. The most important reason I believe this to be true is that I have met so many wonderful people. The nurses, doctors, and social workers who spend their days in this hospital are a special breed of people and are simply amazing. They treat me like I'm capable of thinking logically, and they expect me to ask questions and make suggestions about my own treatment. They want to know what I'm thinking and feeling, and because they have seen so many other kids going through the same treatment as me, they were able to encourage me and give me hope and strength to believe I could come out the other side strong and well. Coming to this hospital has made me realize how many wonderful people there are out Another reason I feel cancer has been a blessing is that I have developed relationships with my

family that I might not have otherwise. I never knew that a mother's touch could be healing until I got there who are devoted to helping others. cancer. My sister, even though she is five years younger than me, at times takes care of me as though she were the big sister. And my Dad always seems to keep the humor going when I need it. I've learned so much these past two years. I've learned that my family, love, and reaching out to others are the most important things to me. Without them there is no true happiness. Cancer has helped me grow up into the person I've always wanted to be, decide what I believe in, and determine what I want out of life. I've learned how much the world takes for granted too. Simple things like taking a shower, brushing my teeth and walking up the stairs are amazing luxuries and require a lot more strength than you think. Every day I wake up I am thankful that I'm alive!



Bethany (center) smiles with her nurses at a Teens Living with Cancer Banquet.





Network monitors new vaccines, infection rates

Years of research and testing go into producing vaccines and getting them approved by the Food and Drug Administration. Thousands of patients participate and millions of dollars are invested in ensuring the vaccine is effective and safe before the vaccine arrives in pediatric and family physician offices. But who checks on vaccines after they are routinely administered to hundreds of thousands of children?

The New Vaccine Surveillance Network, which is based in Rochester, Nashville and Cincinnati, began surveillance for several vaccine-preventable (or potentially vaccine-preventable) childhood infectious diseases in 2000 with funding from the Centers for Disease Control and Prevention. Over the six years the network has been in existence, physicians and laboratories have monitored the rates of viral infections caused by influenza, respiratory syncytial virus, parainfluenza and rotavirus in children seeking care in emergency rooms, children's hospitals, doctors' offices, and clinics in the three participating cities.

The goal is to be able to show whether newly available vaccines are effective in reducing the incidence of infections from those viruses, but the surveillance can also point out the need for new recommendations, as well as the occurrence of unrecognized problems with a vaccine. (Preventive vaccines for some of the viruses mentioned above don't yet exist, but the data being collected will help decide whether such vaccines are needed and how best to use them.)

This network is the only pediatric one of its kind, and no similar network to monitor adult infections exists.

"It is amazing that big, careful studies, using both clinical and microbiologic data — rather than either one alone — have not been able to be performed before for these infectious diseases," said Geoffrey Weinberg, M.D., pediatric infectious disease expert with Golisano

Children's Hospital at Strong. "With our Network we can now analyze the exact impact of a new vaccine on infection rates by population. And we can give these accurate data—quickly—to the CDC, so that decisions to modify pediatric vaccine usage may be made in a timely way."

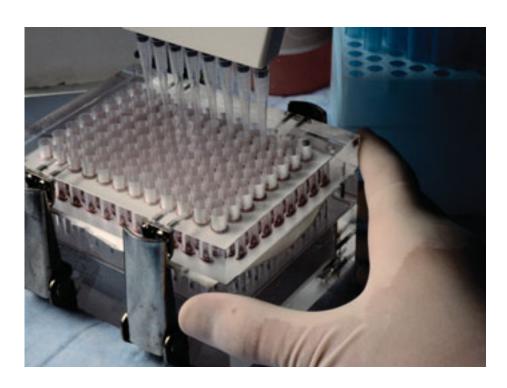
As an example, because of this behind-the-scenes work of Rochester physicians and laboratory technicians, the CDC and the American Academy of Pediatrics decided to modify routine pediatric flu vaccine recommendations in 2006 to include 2- to 5-year olds. The recommendations were made after the Network provided data that undiagnosed influenza infections in children up to 5 years of age were common, and responsible for many more Emergency Department, clinic and office visits than previously recognized.

Peter Szilagyi, M.D., M.P.H., Chief of Ambulatory Pediatrics at Golisano Children's Hospital, and Caroline Hall, M.D., professor of Pediatrics and Medicine, coordinate the testing and analyzing along with Weinberg, but key to the success of the network is the local community.

"The unified system of pediatric care in Rochester pretty much puts all pediatricians on the same team, and makes Rochester an ideal place to do this kind of research and monitoring," Weinberg said. "And just as important are the parents who allow us to gather the information we need for these studies."

The new rotavirus vaccine, which was approved in 2006, will be intensely watched by the network, especially because the first approved vaccine for rotavirus (a different product) was unsuccessful because questions arose about its safety. The network has been studying infection rates among young children since 2005 so it can compare the rates now to those after the new rotavirus vaccine has been widely administered. It will also monitor whether there are any issues with the vaccine's safety.

To find out how you can support vaccine research at Golisano Children's Hospital at Strong, call (585) 273-5948.



Clues to why some babies are premature may lie in genes

Almost 500,000 babies are born too early in the U.S. every year, putting them at risk for lifelong disabilities such as chronic lung disease and developmental delay. Although there has been an increase in multiple births, those early births are only a piece of the 30 percent increase in premature births since the early 1980s.

Golisano Children's Hospital at Strong is part of a five-year National Institutes of Health study of possible genetic links to prematurity. Four centers are participating, including the University of Iowa, the University of Pittsburgh in Pennsylvania and Wake Forest University in North Carolina.

Chin-To Fong, M.D., chief of pediatric genetics at the University of Rochester Medical Center's Golisano Children's Hospital, is leading the effort locally with the help of Ronnie Guillet, M.D., Ph.D., neonatologist at Golisano Children's Hospital, and Eva Pressman, M.D., director of Maternal Fetal Medicine and Obstetrics, University of Rochester Medical Center, Strong Memorial Hospital.

"Imagine knowing that you're more likely to give birth early through a simple blood test. We may be able to better prevent early births or better prepare for them," Fong said.

Women found to be at risk would receive increased surveillance, such as more frequent prenatal visits, pelvic examinations and ultrasounds to evaluate cervical length, Pressman said. "They may also receive certain pharmaceutical therapies if further studies demonstrate the benefit of therapy."

Delaying delivery for even a few days can dramatically improve the outcome for extremely low birth-weight infants, said Guillet, who is also the nursery director at Highland Hospital. "Survival increases significantly between 23 and 26 weeks and continues to increase, though at a more gradual rate, from 26 weeks to term."



Physicians and their patients could be alerted to be more in tune with the early signs of labor, and patients would be referred to the appropriate hospital. In case specialized care is needed, the baby would already be in a hospital where perinatologists, neonatologists, specially trained staff and equipment are available to stabilize and care for the infant

Fong's team and his counterparts in the other centers are recruiting 200 families of premature babies per year for a total of 1,000 families in a five-year period to participate in the study.

"Imagine knowing that you're more likely to give birth early through a simple blood test."

Locally, this will be done at Golisano Children's Hospital and Highland Hospital.

Family members (including grandparents) enrolled in the study will complete surveys and provide genetic samples (ie. blood or saliva) with the help of study coordinators Lauren Smith, M.S., and Amy Mayhew, M.P.H. Families with a baby born prematurely during the study timeframe who have another family member who was born preterm may provide the most interesting information for the project. The higher the incidence of prematurity in a family, the more likely it is that a genetic link can be identified.

"Right now we don't know if it's the mother or child who is affected or if it's a combination of the two that triggers the premature birth," Fong said. "This research could help us learn who is at highest risk and why, and potentially make a huge impact on the long-term health of these children."

For more information on this study or on services provided by Golisano Children's Hospital's Division of Pediatric Genetics, call (585) 275-5857.

Miracle Makers award winners

Community shines, thanks to its stars

Each year, countless individuals, businesses and organizations champion the needs of Golisano Children's Hospital at Strong. In an effort to spotlight some of our most devoted supporters, we have a biannual tradition of choosing "Miracle Makers" who have made creative and passionate strides for children here.

This year, we'd like to congratulate our Miracle Makers and the so many other people, businesses and organizations who are always willing to help. Your generosity continues to make a difference every day—whether it's providing art supplies for the activity room where kids receive weekly treatments, gathering friends for a fundraiser outing, or purchasing life-saving medical equipment from our wish list. It all counts; our success stories are proof!

See the Miracles You've Helped Us Make!

Plan to tune in to News 10NBC on June 1 and 2 for our 24th annual telethon, and you'll hear stories of strength and courage that chronicle the journeys of this year's Miracle Kids and their families (we'll introduce you to them in our Spring newsletter!)

This year's Miracle Makers

- J.T. Mauro Company, honored for Outstanding Commitment by a Corporation.
- Wally Straight, honored for Outstanding Commitment by an Individual.
- Bob Jacobson, honored for Outstanding Commitment by a Board Member.
- Paul Tessoni, honored for Outstanding Commitment by a Community Group.
- Erik Iglewski, honored for Outstanding Commitment by a Health Care Provider.
- RE/MAX First and RE/MAX 1st Commercial, honored for Outstanding Commitment by a National Corporate Sponsor.
- Deb Moyer, honored for Outstanding Commitment by a Volunteer.

The DRIVE for Miracles 8th annual Radiothon moves to summer

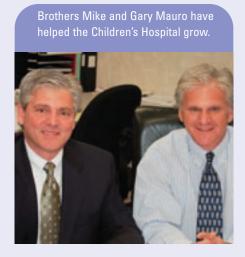
Our radiothon, usually held in February, has moved to June 21 to 24, 2007. Tune into The Drive 100.5 (formerly MIX 100.5) to help kids when they need it most. Proceeds will benefit Rochester's only children's hospital. Keep up to date by checking <code>www.gchas.org</code>. To share the story of your child's brave moments at Golisano Children's Hospital, e-mail Betsy Findlay at <code>bfindlay@admin.rochester.edu</code>.

J.T. Mauro Company Outstanding Commitment by a Corporation

J.T. Mauro Company, majority owned by brothers Gary and Michael Mauro, is a mechanical contracting company with a tradition of taking a vested interest in its clients.

For Golisano Children's Hospital at Strong, that means J.T. Mauro steps beyond its expected role in providing complete mechanical systems for the PICU/PCICU and the William and Mildred Levine Pediatric Surgical Suite projects; they also support the hospital by sponsoring metal fish and butterfly sculptures that adorn the walls leading to the new units, funding a PICU nurse's station, sponsoring the annual Gala and golf tournaments, and providing the Miracle Makers' Luncheon since its inception. It is due time they attended this luncheon as an award winner!

Michael Mauro says the company's commitment to the University is deeply rooted, starting with its support of the research campaigns and continuing



through the current needs of the cancer center and the patient units today. The special attraction to the children's hospital, he says, began while working on the new Emergency Department's pediatric component.

"Dr. Elizabeth McAnarney, then chair, told us that this was only possible because of the support of people like us," Michael Mauro said. "It was in that moment that we realized the power to make a difference was trusted to people just like us, as well as others in our community."

Since then, he and Gary have enjoyed the privilege of watching first-hand as the hospital evolves and of seeing the direct impact of the community's support—J.T. Mauro's included.



Bob Jacobson

Outstanding Commitment by a Board Member

In 1995, Bob Jacobson was part of a committee at B&L Wholesale Supply whose members wanted to start a corporate golf tournament that would be both recreational and purposeful. To do that, the group turned to Golisano Children's Hospital at Strong as a possible beneficiary of their proceeds. The tournament grew, taking on a life and personality of its own as customers and suppliers sponsored holes. It has been an annual tradition ever since.

Jacobson joined the board more than 10 years ago, further cultivating the relationship between the company and the hospital, which was making (and today continues to make) holiday donations in honor of its preferred customers, in lieu of sending them a more conventional gift, such as a fruit basket or bottle of wine. These customers are adamant about the idea that these gifts are impacting kids who need it more than

they do, and they take pride in knowing that together they are just shy of raising nearly \$500,000 for the children here. Not surprisingly, this too has become an unbreakable tradition.

Jacobson, proud grandfather of five, attends events and board meetings faithfully and is much to credit for a flourishing school and community fundraising program (the committee he chairs). He says the most moving part of being involved in work for the children's hospital has been pledging B&L's support of building the William and Mildred Levine Pediatric Surgical Suite on the tails of just finishing a corporate commitment to the PICU/PCICU.

For Jacobson, this marked a seamless move from supporting growth in one sector of the hospital to another; he had seen first-hand how important it was to treat kids in a separate, more childfriendly space. We are indebted to him



for his eager support as we took on this challenge.

Astonishingly, Jacobson describes this involvement as a privilege, not a duty. "I get more out of it than I give, it seems," he said. "It's a great source of joy for me."

Wally Straight

When Wally Straight lost one of his 13 grandchildren before the child's fifth birthday, he was changed forever. He says he still remembers hearing the little voice on the phone pleading "Grandpa, help me."

Fueled by those words, Straight, a greeter at Newark Wal-mart, took action to help other ailing children. He has already collected more than \$148,000 for Golisano Children's Hospital, one dollar at a time since 2002, when he began using his position to ask customers to consider helping.

Straight credits much of his fundraising success to the supportive community; he says that some frequent customers keep a \$1 bill—or a \$5 bill—in their pockets on shopping errands just in case he is working.

Outstanding Commitment by an Individual

Beyond simply inviting incoming customers to donate, Straight has risen to more drastic charity challenges—like donning a painter's suit and offering those who donate a chance to splatter him with hot dog toppings (like relish, ketchup and mustard!), or dancing on the store counter with customers who donated \$20 or more. Once, he even wore a ladies garter over his pants; people really played along, slipping cash beneath it!

Straight is one of our many devoted hospital supporters who, touched by grief, find the courage to reach into their own hardship and discover what lies at the core: a beautiful challenge. He is a sterling example of how one person's passion can inspire an entire community to make a difference for children.







Eric Iglewski

Outstanding Commitment by a Health Care Provider

Eric Iglewski, pediatric social worker for Hematology and Oncology at Golisano Children's Hospital at Strong for five years, says his job boils down to being "an authentic, compassionate presence" for patients and their families.

Having a consistent relationship from the start, for as long as families need it, reminds them that, in Eric, they have an ally here at Golisano Children's Hospital who is ready to be a resourcebroker, to help bring closure and build memories, or to just listen when they need it.

Iglewski says that families with children facing life-threatening diseases too often suffer great reduction in their quality of life; an important part of his role is to make sure they take care of themselves, that they find reasons to celebrate and things to relish.

"One of the best parts of the job is watching kids' wishes get granted—

whether it's swimming with the dolphins in Hawaii or meeting Michael Jordan or setting off on a shopping spree free-for-all," Iglewski said. "Watching the parents as they watch their children, that is rewarding, too."

But Iglewski does more than listen—outside the job's hours, he keeps championing kids by heading up the social work department's Stroll for Strong Kids team, and by going on the annual radiothon and telethon to help give listeners and viewers a glimpse of what it's like to work with the kids and families here.

"I am surrounded by superheroes, and people need to know that," he said. "Day in and day out, I watch parents shine, cope and find ways to enjoy the moment. I see kids that refuse to wallow in self-pity, and instead, move on; they keep living, enjoying the gifts they have."



We thank and congratulate Eric for his fine work, standing (or strolling!) strong for children, teens and families here. He is part of the team that makes this hospital the kind of place where healing is a holistic, family affair.

Paul Tessoni Outstanding Commitment by a Community Group

Five years ago, Paul Tessoni, a faithful friend to Golisano Children's Hospital, decided to hold the first ever annual ski invitational at Bristol Mountain to benefit the hospital. He raised \$11,700, astounding us all. His enthusiasm snowballed and he also hosted a golf tournament later that year. Again we received a gift to help the children, this time for more than \$2,500.

Tessoni prefers to keep his gatherings small and intimate, usually by limiting the number of guests. This has been his secret to creating an environment where attendees can really network and form friendships, meanwhile keeping a small enough troop that he can still manage to cook for them all. This is his second secret to success: Tessoni lures his participants back with savory memories of baconwrapped scallops, jumbo shrimp and beef tenderloin, a feast that has been dubbed "Paul's Picnic."

Golisano Children's Hospital at Strong is grateful for Paul and his faithful picnickers who, over the past five years, have helped him to raise more than \$132,727 to help kids here in their moments of need. We are thrilled to have you as an advocate, supporter, and friend; we are inspired by your creativity, realizing each charity endeavor as an opportunity for forming rich memories and celebrating friendship.

(left to right) Richard Pifer, Paul Tessoni, Bill Goodrich, and Larry Decker.



RE/MAX First and RE/MAX 1st Commercial

Outstanding Commitment by a National Corporate Sponsor

Without the backing of local businesses, Golisano Children's Hospital at Strong would be without one of its most powerful allies. One of those faithful supporters is local RE/MAX First and RE/MAX 1st Commercial, led by principal broker, Tom Schnorr.

On an international scope, RE/MAX is proud partner of Children's Miracle Network (CMN), a non-profit coalition dedicated to helping children by raising funds and awareness for 170 non-profit children's hospitals throughout North America, thanks to the generosity of corporate CMN sponsors, like RE/MAX.

And, since the striking hallmark of CMN is that all funds raised by these sponsors stay to work locally, directly benefiting the CMN hospital in the community in which they are raised,

Rochester's RE/MAX First and RE/MAX 1st Commercial together presented us in excess of \$16,000—and that was in 2005 alone.

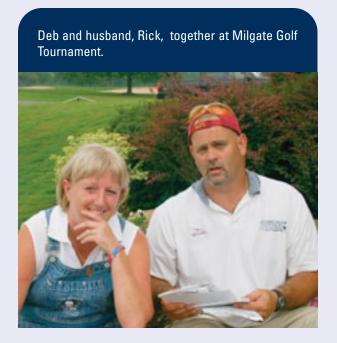
Part of this is made possible by individual RE/MAX agents, who get involved by generously contributing a donation for each real estate transaction made through The Miracle Home Program; Schnorr also has been leading a company campaign for Golisano Children's Hospital at Strong and we are floored that he has tripled returns above his initial commitment. Additionally, his team has named a room in the new PICU/PCICU and consistently provides sponsorships to our annual Gala and Stroll fundraisers.

We are grateful to RE/MAX for their ongoing commitment to the health of all



children growing up in this community. Their philanthropy is a model for all.

Deb Moyer Outstanding Commitment by a Volunteer



Volunteers usually work behind the scenes, quietly filling in gaps and never seeking thanks or due recognition. Deb Moyer, loyal supporter of Golisano Children's Hospital for the last six years, grieved the tragic loss of her brother, Tim, in a healthy way, by focusing her energies on something positive.

That "something" has been the coordination, planning and implementation of the annual Tim Milgate Charity Golf Outing, which benefits the hospital, raising more than \$71,000 to date. Three years ago, also in Tim's memory, she agreed to raise \$40,000 over the course of four years for the Blood Gas Room in the new Pediatric Intensive Care Unit. She reached her goal in three—a testament to Moyer's tireless work ethic, seeking out sponsors, silent auction raffle items, and even choosing inspirational kids each year whose friendship reminds her why this work is so important.

Moyer and her family are stalwart advocates of this children's hospital, speaking out whenever they have the chance to remind Rochester and the surrounding region what a jewel they have in their own backyard. Truthfully, we think we have a jewel ourselves—in Deb.

Doctor Spotlight: George Alfieris, M.D.

Raising the bar: Surgeon's desire to reach higher may be tied to his sport

George Alfieris, M.D., performs 300 heart surgeries a year, often on newborns who are only hours old.

"There's not a case that's not lifethreatening," he said. "You're working with a human heart."

And he's right. The role of the average pediatric cardiac surgeon is demanding to say the least, with surgeries lasting between four and 10 hours at a time. And since Alfieris focuses on newborns and infants—8 of every 1,000 of whom are born with some sort of structural flaw in their heart—their delicacy poses an even greater challenge.

Many wonder, what primes someone for a career so taxing, so technical, and so marked by high stakes? In Alfieris' case, it may have been his sport.

A pole-vaulter back in the eighth grade in his New Jersey high school, Alfieris remembers his coach first discovering his aptitude for precise technique one afternoon at track practice.

Impressed with young Alfieris' agility and sprinting, the coach handed him a pole and steered him in the direction of the vault.

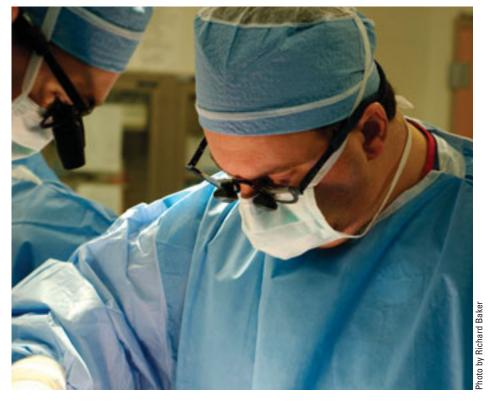
"It was made of metal back then, not fiberglass," he laughed. But the sport, procedural and demanding, fit him perfectly.

"I thrived under pressure, actually performing better when the bar was set high, when the meets counted most. The vault was always the last event to wrap up in the track meet, and often, those points hung in the balance."

Others might crumble under that stress, but "being needed to help beat the competition only bettered my game," Alfieris said.

That steel determination, paired with athleticism, would win him county and regional championships. And his best jump of 14-feet was high enough to bring scholarship offers dangling from universities like Cornell and Rutgers.

College, however, wasn't to be about jumping, he said. He had plans to major



in physiology, and laid his pole aside to focus on his studies. It wasn't until the summer after his first year of graduate school, during work with a National Institutes of Health cardiac research lab in Bethesda, that his mentor, like his coach, also recognized his impeccable hand-eye coordination—no doubt honed by five years of vaulting. The mentor encouraged him to keep at it.

Alfieris, who as a kid had a heart murmur himself, did just that. He embarked on a career in cardiothoracic surgery and, thanks to the vault which had trained him to produce precision in the midst of pressure, he was able to approach this as another serious venture—one with big pay-offs, high standards and undeniable risk. His career blossomed.

"As a vaulter I never thought of the possibility of getting hurt. You couldn't," he said. "And much of that has translated to my work today. You can't contemplate the risk. You acknowledge it, face it, and you rely on your practice. You decide to never back away from a healthy challenge."

Both the vault and cardiac surgery are unforgiving, meticulous endeavors that demand rehearsal, resilience and a strong sense of self-survival.

"All my endeavors are serious, and the stakes are always high," said Alfieris, who also flies a piper Aztec twin-engine plane for a hobby. "At the end of the day, what keeps you coming is the relentless pursuit of perfection, as they say. It's this idea of raising the bar." Still, that's not the best part of his job.

"Being able to give a child back to their parents and a future back to a child is the ultimate win. It's a privilege to do that sort of work in this community, to be able to bless families like that almost every day."



Caught doing good!

Our community bands together to help kids

Genesee Valley Hunt Races Make Strides for Children's Hospital

(Below, left to right) Howie Jacobson, Austin Wadsworth, Stephanie Von Bacho, Janice Barrett and Sterlin Harris stand as a \$2,000 check is presented to Golisano Children's Hospital. The funds were raised this fall on race day, which celebrated a 78-year tradition of horse racing, canine events and family fun, in a valley back-lit by autumn's orange and gold. Though rainy, the festivities carried on without a hitch.

"Nutcracker on Ice Holiday Show" Grows

(Below right) Giant rats and sugar plum fairies laced up their skates, not their ballet slippers, for the Sunday, Dec. 17 "Nutcracker on Ice Holiday Show" at ESL Sports Centre. In true holiday spirit, a portion of the profits – more than \$3,000 – benefited Golisano Children's Hospital at Strong. The show's attendance more than doubled this year, with more than 650 attendees, up from last year's 300. An open-skate with the cast afterward raised additional funds for the children's hospital.

6th annual Rainbow Classic Astounds Us Again

(Bottom, left) The annual Pittsford Mendon – Pittsford Sutherland basketball competition has become a children's hospital fundraising staple. This year's Rainbow Classic tournament proved strong again, raising an astounding \$20,500! The money will

continue to pay off a pledge for the patient room in the new PICU named in memory of Katelyn Pasley and Ryan McCluski; both received care here at Golisano Children's Hospital.

Cycle for Hope Spins up a Storm

(Bottom right) Andy Nye and area spinners trekked out to gyms all over Rochester on Saturday, Feb. 3, to participate in Cycle for Hope, a six-hour spinning fundraiser that raised \$19,000 for co-beneficiaries Golisano Children's Hospital at Strong and Camp Good Days/Special Times. (Victor's Iron Butterfly even had kid-sized equipment available, allowing the smallest of spinners to work-out!)















CMN News: "Young Children: Priority One"

"Young Children: Priority One" is the Kiwanian initiative that places continual focus on the needs of kids—including pediatric trauma, safety and infant health.

It's also the reason our local divisions, composed of 32 clubs, made a commitment three years ago to increase their fundraising efforts and name a room in the Pediatric Intensive Care

Unit/Pediatric Cardiac Intensive Care

Since then, their support has more than doubled, including grassroots efforts from golf tournaments to pancake breakfasts to their most recent accomplishment: laying out a quartermile stretch of quarters. Their overall support reaches nearly \$30,000!

Here at Golisano Children's
Hospital at Strong, we wish warm and
grateful congratulations to the Finger
Lakes and Genesee Division Kiwanis
Clubs for so many successes in their
never-tiring efforts for our region's most
valuable resource—our children!



registration forms will be available on-line at www.gchas.org



Phot Func

Amanda Padgham Photography

Schedule a session in May to have your child photographed by Amanda Padgham, a brilliant natural light photographer service, and 10 percent of the proceeds from all prints you order will benefit Golisano Children's Hospital at Strong.

Booking encouraged by April 1 to ensure best availability; call Amanda at (585) 764-2341. To learn more, visit www.amandapadghamphotography.com.

A match in Rochester

Continued from cover daughter. That sort of sacrifice came with the territory.

Girvin spoke about this opportunity with Adel Bozorgzadeh, M.D., director of solid organ transplantation at Golisano Children's Hospital at Strong. He strongly agreed, and arranged for testing the many willing family and friends, including Kaitlin's father, Jeremy Welsher, who all hoped to be suitable matches.

Girvin didn't hear back with results for two weeks, and was growing anxious waiting for the phone to ring. When she could bear it no longer, she called, only to hear the most wonderful news.

"My blood type matched Kaitlin's," she said. "I told them that I was ready, at which point they told me that the surgery would happen only five days later, that there was no time to waste."

The news was dizzying, with the surgery coming even earlier than Girvin expected. But she knew there was no choice. Girvin began packing, alternately baby clothes and her clothes, anything either of them might need

while recovering, and meanwhile assuring her other daughter, 11, to not worry, that things would turn out all right.

"In my heart though, I was nervous too. I wanted to be near Kaitlin, to watch over her, but that wasn't possible given that I would be in surgery too."

A few mornings later, Girvin arrived with young Kaitlin and packed bags, ready for simultaneous surgeries; surgeons would remove part of Girvin's liver and give it to Kaitlin. Both halves, they said, would again grow to nearly full-size in six to eight weeks—a miracle singular to the liver and no other organ in the body.

The procedure went remarkably well, though Kaitlin's part of the surgery revealed the gravity of the situation that would shake them all; this was all happening not a moment too soon.

"When they went to remove her old liver, they realized it was three times the size it should have been," Girvin said. "Two more months, and she would have been too sick even for the surgery."

Absorbing that reality, Girvin rested in the hospital for a week, sore but

thankful; Kaitlin stayed longer, for a month, under the watchful attention of the pediatric ICU team, and her father.

"She's a trooper," Girvin said.
"Kaitlin was groggy, initially, but
perked up within two days, wanting to
move and play as much as you can
while connected to tubes and monitors."

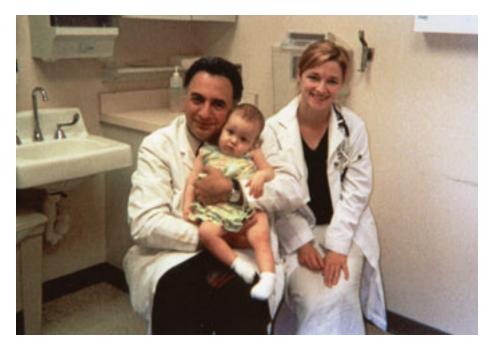
That was a glimpse of hope, though. And within only a month of being home, Kaitlin had progressed even further. She was nosier than ever, lit by new curiosity and vigor as she explored absolutely everything.

"She was walking alone, using a cup and a spoon by herself, getting bigger and smarter all the time," Girvin said. "Every day it's something new."

Now, just shy of her second birthday, Kaitlin is especially fascinated by discovering shapes and learning to place them in the right holes — with her faithful beanbag doggy in tow, of course.

"Everything was beautiful at the hospital," Girvin said. "We're so lucky to have her, we're so lucky."





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 and raised \$3,658.
- Pavilion Central Schools held a teachers vs. students basketball game to benefit Golisano Children's Hospital on Nov. 3. The FUNdraiser raised \$1,453 for our region's only children's hospital.
- Bon Ton held Community Day on Nov. 11 and sold coupon books to customers. The sales raised \$692 for Golisano Children's Hospital.
- Many businesses and individuals in the Greater Rochester Community supported Golisano Children's Hospital by purchasing "Kards for Kids" – holiday cards designed by patients. The card sales raised \$1,800.
- Kudos to Exxon Mobil for making a donation of \$1,000 to Golisano Children's Hospital in

- honor of its employees. The employees were injury-free for the last quarter of 2006.
- Teachers at Winslow Elementary in Rush Henrietta made a donation of \$375 for "Friday Relaxed Day."
- Hilton High School's Class of 2010 held a bake sale and raised \$140 for Golisano Children's Hospital.
- In honor of Mary Grace Hanrahan's birthday her family donated \$500 to Golisano Children's Hospital.
- The Goddard School's grand opening yielded a donation of \$100 to our region's only Children's Hospital.
- Jay Advertising sent in a check on behalf of Saints & Sinners in the amount of \$2,500!
- The Crane School held the McCare night at McDonalds and raised \$66.20.
- John Paradiso held the 2nd Annual December

- to Remember on Dec. 2. He raised \$1,670 and collected many toys for the patients.
- The 5th Annual Rainbow Classic was held on Dec. 15. The Pittsford Sutherland vs.
 Pittsford Mendon Basketball games are held annually to remember classmates Katelyn Pasley and Ryan McCluski. This year's event raised \$20,500.
- The ESL Sports Centre held the Nutcracker on Ice and raised more than \$3,000 for Golisano Children's Hospital.
- Shear Ego Salon & Spas held a holiday collection to purchase items off our wish list. They raised \$660 from the employees! Thank you Gene Cardamone and the many stylists, technicians and staff.

Upcoming Events

March 16–17, 34th annual Brockport Dance Marathon, Brockport High School. Students and faculty will dance the night away, hoping to raise thousands for Leukemia research at Golisano Children's Hospital! For more information contact Ann Hamlin at (585) 637-3240.

March 25, 2nd annual Sabres and Amerks Alumni Hockey Game at the Blue Cross Arena, 1 Memorial Square, Rochester. Cheer on your favorite hockey player alumni as they challenge each other for Golisano Children's Hospital. Doors open at 3 p.m. For more information, call Linda Dirksen at (585) 273-5939.

March 31, WITR Children's Hospital Charity Concert at the Ritz Sports Zone in RIT Student Alumni Union, 1 Lomb Memorial Dr., Rochester. Come out to hear 89.7 WITR, RIT's student-managed radio station, as it broadcasts its first charity concert. The show begins at 9 p.m. and will feature the bands Scissors for Lefty, Boyskout and The Noise on Vinyl. Admission is \$2 for all ages.

For more information, please write to witrmusic@gmail.com.

April 20, 5th annual Talent for Tots and Teens Talent Show, 300 East River Road, Rochester. Watch some of Rochester's talented youngsters compete for top honors at this talent show. For more information or to purchase tickets, contact Ida Wheeler at (585) 273-5907 or IWheeler@Alumni.Rochester.edu.

April 29, NICU Wall of Miracles,

Flaum Atrium at the University of Rochester Medical Center. NICU parents and grandparents, here's your chance to purchase and decorate a tile in honor of your special NICU patient! Tiles will be installed as a tribute wall outside the NICU and are available now for reservation by calling (585) 273-5948. For more information, visit www.gchas.org.

May 6, 3rd Annual Girls Day Out. To be held at the Rochester Riverside Convention Center. Enjoy a day of pampering, complete with mini-makeovers, music and more! For more information, call Betsy Findlay at (585) 273-5933 or Karen Eisenberg at (585) 273-1462.

May 10, 6th Annual Chiavetta's Chicken Barbeque, University of Rochester Medical Center. Starting May 1, reserve your ticket for a half chicken, two salads, roll, butter and cookie before they sell out — it's just \$7.95!

To purchase, call Karen Bisbo (585) 275-6367, or stop by room 4-2536. For more information, call Linda Dirksen at (585) 273-5939.

May 21, Golfing for Kids, presented by Walmart and Sam's Club, Fox Valley Golf Club and Transit Valley Club, Lancaster and East Amherst. The 18-hole competition will feature Golisano Children's Hospital at Strong as one of two beneficiaries.

Registration is at 9 a.m.; shotgun start at 10 a.m. For more information on registration (by May 1), sponsorship or underwriting opportunities, call Betsy Findlay at (585) 273-5933 or Angela Pullen at (585) 273-5937.

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