

STRONG KIDS NEWS



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

FEATURED STORIES:

Donors endow
professorships

4

Straight from a NICU mom

6

Telemedicine expands

8

Metabolic syndrome in kids

9

CMN News: balloons away!

13



Head-strong baby girl

(with the help of Golisano Children's Hospital and her helmet)

Autumn Jones, not yet six months old, sits in her mother's arms, swatting playfully at a musical Winnie the Pooh honey pot. With cherub cheeks and curious, darting eyes, she seems like any other contented baby—except for a barely-there pink scar that zigzags ear-to-ear like a headband.

The scar, fading fast with each passing month, tells a story the little girl will never remember, thanks to doctors at Golisano Children's Hospital's Cleft

and Craniofacial Center, who practice the most innovative techniques in surgery.

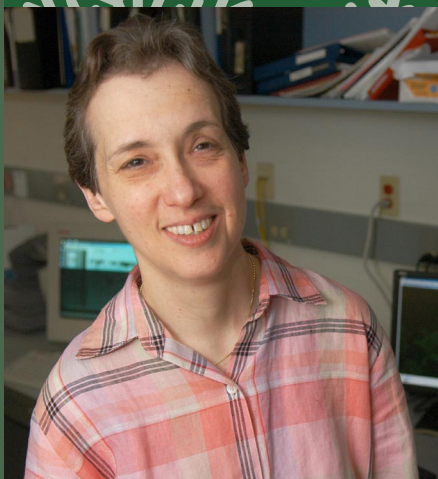
Something wrong

At her 2-week check up at English Road Pediatrics, Autumn's pediatrician, Benny Vitullo, M.D., sensed something might be wrong.

"He said that Autumn's head was egg-shaped, with a ridge jutting out across the back," remembers her mom,

Continued on page 3





Dear Friends —

When you think of what we as individual parents do for our children and families and what GCHaS does for the children and families of this region and beyond, things seem to be divisible into two components: what we do in “the here and now” and what we do for the future.

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This issue of our newsletter shows in several different arenas our dedication to ensuring the best for now and for the future.

Take the national epidemic of childhood obesity, for example. If we are to fight this plague effectively, we must treat and educate children and families who are currently struggling with this condition and develop and implement interventions that prevent childhood obesity in the future. That's why GCHaS has, not only a group of pediatricians and pediatric subspecialists dedicated to providing state-of-the-art treatment for childhood obesity and its side effects, but also a game plan for development of a comprehensive obesity prevention center in the future.

Similarly, our fundraising efforts are aimed both at the present and at the future. Events like the Wine and Wishes evening and the dozens of wonderful community celebrations and activities provide critically needed funding for the equipment, supplies and personnel that allow us to provide care for thousands of children each year. They literally raise the funds that provide incubators and warming tables for our NICU, private rooms for our treatment center

and computer access to our inpatients. Endowment funds, including those directed at faculty chairs and those aimed at particular programs, are an investment in the future of GCHaS, of upstate NY, of our children's children's children. They provide an incentive for the best of the best to work and live here and the ability to move forward and provide new and improved therapies and services even when federal and private grant and insurance funds are not plentiful. They allow us to dream of better healthcare tomorrow even while we are providing state-of-the-art healthcare today.

What does it take to provide the best possible care today and ensure that the future holds even better care tomorrow? It takes all of us and our unending dedication to both the here and now and the future.

With heartfelt thanks from our families to yours,

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

Head-strong

Continued from cover

Catrina Jones.

Vitullo ordered a 3-D CT scan to be taken when Autumn was two months old. Immediately following, she and her parents, for the first time, would meet to discuss the results with John Giroto, M.D., FACS, FAAP, director of the Pediatric Cleft and Craniofacial Center at Golisano Children's Hospital at Strong, and pediatric neurosurgeon, Howard Silberstein, M.D.

A baby's skull bones, the doctors explained, usually "float," attached only by small fibers called sutures. By remaining unfused, they're able to weather some of life's earliest hurdles—such as passing through the birth canal, and growing rapidly, along with the brain, during infancy.

But on the back of Autumn's head, one of the sutures had already fused—a condition called craniosynostosis that affects one in 2,000 infants.

"If nothing were done, the other bones would be forced to compensate, growing into an awkward shape and putting pressure on her brain," Silberstein explained. "In a few cases,

certain types of craniosynostosis can cause intellectual problems, developmental disabilities and even trouble with vision."

The surgeons assured the Joneses that they work in tandem to treat many cases similar to Autumn's every year—typically, with Silberstein removing the bone and Giroto reconstructing it. Their patients travel from across Upstate New York and even parts of Northern Pennsylvania, as the Craniofacial Center at Golisano Children's Hospital is the only fully staffed, multidisciplinary team in the Upstate region.

"Because our entire team works together—from pediatrician to surgeon—we are able to recognize craniosynostosis early. That lets us provide new, less invasive surgeries to each kid," Giroto said.

Diagnosed early, Autumn was one of those fortunate children; rather than having to undergo traditional reconstruction, which could last as long as six to eight hours, she was scheduled for a new, quicker, less invasive procedure.

Embarking on a year-long journey

Four weeks after her consultation, Autumn and Catrina wrapped up an afternoon of indoor trick-or-treating at

the mall and went home to pack for the surgery.

"We were pretty much business as usual until the pre-op appointment," Jones said. "That's when we crashed into a wall of emotions. Suddenly, we were thinking of the real risks that come with anesthesia. We were busy getting her vital signs, her weight, and a preview tour of the pediatric ICU (intensive care unit). It all seemed too real."

The next morning, Autumn, with a small good-luck angel doll tucked in tow, was taken into the operating room. Fortunately for her parents' nerves, the procedure was completed in just over an hour.

Bringing news of success, Giroto walked over to the Joneses. Smiling, he handed the couple a tiny tuft of Autumn's hair.

"Her first haircut, he said," Jones remembered. "It was nice knowing that, in all of this, he and Dr. Silberstein were not only thinking about Autumn. They were also caring for me, as her mom."

Autumn continued to improve right on schedule. Though the Joneses had been warned that she would "puff up like a little pumpkin," she only swelled slightly, and only on one side—another
Continued on page 14



Charles Robinson, registered technician and certified fitter in orthotics, helps Autumn put on her newly-resized helmet.

Donors endow two professorships: Golisano Children's Hospital adds new faculty

When a donor endows a professorship within the Department of Pediatrics, that donor receives more than a plaque on the wall. That donor gets in on the ground-floor of important research, teaching or clinical care.

"Donors endow professorships because they want to have a major role in launching a program or research initiative or funding the teaching and mentoring mission," said Nina F. Schor, M.D., Ph.D., chair of Pediatrics and pediatrician-in-chief of Golisano Children's Hospital at Strong. "They also endow professorships because it affords them an intellectual relationship with the recipient. That way, they have an inside track on new discovery and initiatives."

Schor received the William H. Eilinger Chair of Pediatrics, and Francis Gigliotti, M.D., chief of the Division of Pediatric Infectious Diseases, received the Lindsey Distinguished Professorship for Pediatric Research earlier this year. Endowed chairs are given to faculty who are viewed as having demonstrated exceptional vision and services critical to the mission of their fields and institutions. They are one of the highest honors bestowed by the academic community.

"I felt very honored to get this award, especially since it was made possible by Porter Anderson who was one of my mentors during my fellowship

training," Gigliotti said. "For the very same reason, I also feel a deep sense of obligation to live up to the award."

In times when traditional National Institutes of Health resources are extremely tight, Gigliotti said this type of funding is extremely valuable in keeping the lab running between grants or in providing the means to investigate new ideas.

Endowed professorships often provide funding for academic missions and projects and can support teaching and research initiatives that are "outside the box" or too early in the project to obtain traditional funds. Schor said she hopes to have one in each of the divisions.

In addition to adding professorships, the Hospital has added new faculty members in several divisions and programs, including the new pediatric hospitalist program.

APPOINTMENTS

- Kate Ackerman, M.D., has joined the Division of Pediatric Critical Care and also holds an appointment in Biomedical Genetics.
- Michael Bulger, Ph.D., has joined the Pediatric Center for Biomedical Research and also holds an appointment in Biochemistry and Biophysics.
- David Dean, Ph.D., has joined the Division of Neonatology and also holds an appointment in Biomedical Engineering.
- Rita Dadiz, D.O., has joined the Division of Neonatology.
- Michael Leonard, M.D., M.S., is joining the Division of Pediatric Critical Care as a hospitalist in April.
- Sara Horstmann, M.D., has joined the Division of Pediatric Critical Care as a hospitalist.
- Ted Siegrist, M.D., has joined the Division of Pediatric Critical Care as a hospitalist.
- Karen Wilson, M.D., M.P.H., has joined the Division of Pediatric Critical Care as a hospitalist.
- Amy Blatt, M.D., has joined the Division of Pediatric Critical Care as a hospitalist.
- Jan Schriefer, N.P., Dr. P.H., has joined the department to work on quality assurance and quality improvement.
- Eugene Daugherty, M.D., is joining the Division of Pediatric Critical Care this summer.
- Keely Dwyer-Matzky, M.D., has joined the Division of Pediatric Critical Care as a hospitalist.
- Ayesa Mian, M.D., has joined the Division of Nephrology.
- Soundarapandian Vijayakumar, M.D., has joined the Division of Nephrology.
- James Sanders, M.D., has joined the Department of Orthopaedics and Rehabilitation and will be treating pediatric patients.



Dr. Schor and her family were honored during her induction as the William H. Eilinger Chair of Pediatrics. President Seligman and Eilinger's friend Clara Gilman were part of the ceremony.



photo courtesy of: PhotoFX, Frank X Byrne.



Community Spotlight

Year round, creative and self-motivated community fundraisers serve as some of Golisano Children's Hospital's best allies — and this past holiday season proved no exception. We were delighted by the imaginative mix of events, promotions and benefits held during this most generous time of year.

Panera Bread's Bottomless Mug Kept Folks Cozy with Coffee

For only \$5 each, Panera Bread sold stainless steel coffee mugs that served as free passes for unlimited coffee refills at any of Rochester's area stores between Oct. 1 and Dec. 31. Caffeine junkies across the county rejoiced, knowing that \$3 from the sale of each mug was donated to Golisano Children's Hospital at Strong, ultimately raising \$8,370.

And, new this year, Panera Bread is placing "Operation Dough-Nation" change boxes nearby registers at their Rochester stores. All funds collected through these boxes also benefit the children's hospital; better yet, to encourage customers to give, the store promises to match 50 percent of the year-end total!

7th annual Rainbow Classic Honored Former Students

This year's Pittsford Mendon and Pittsford Sutherland High School basketball game, held Friday, Dec. 21, at the University of Rochester Palestra raised more than \$24,000 for Golisano Children's Hospital. Each year, the game honors Katelyn Pasley and Ryan McCluski, former patients at the children's hospital.

Annual Nutcracker on Ice Brought Cheer, Charity

Giant rats and sugar plum fairies laced up their skates, not their ballet slippers, for the Sunday, Dec. 16, "Nutcracker on Ice Holiday Show" at ESL Sports Centre. In true holiday spirit, a portion of the profits was donated to Golisano Children's Hospital at Strong. The show starred dozens of performers, ranging from local beginners at the ESL's skating school to high-level skaters.

Talent for Tots & Teens Holiday Showcase

Unlike your average holiday pageant, this one was without any trios of wandering wise men or Ebenezer Scrooge epiphanies. Nevertheless, folks who ventured out on Dec. 1 to see Rochester's talented youngsters performing for top honors at this fundraising talent show were not only well-entertained — they also helped to raise more than \$3,100 for the children's hospital.

You can help Golisano Children's Hospital all year long! For more information on how you can make a difference for the kids here, visit www.gchas.org or call the children's hospital's Office of Development and Community Affairs at (585) 273-5948.

Straight from a “NICU” mom

Kristen Warburton tells what she learned after her youngest daughter, Mariah, spent nearly two months in the NICU.

Strong Kids News Kristen, you learned pretty early in your pregnancy that Mariah would spend time in the NICU after she was delivered?

Kristen I did. When I was about 20 weeks along, an ultrasound revealed that Mariah would be born with a diaphragmatic hernia and need surgery for it very soon afterward. My husband, Geoff, and I were given an advance tour of the NICU and told that we should begin to brace ourselves for this unit becoming our home-away-from-home—perhaps even for a few months. As it turned out, Mariah had surgery just 16 hours after she was born and would spend 57 day in the hospital fighting to get stronger.

SKN How did you adjust to the idea of playing mom in two places at once?

K Our other daughter, Madeline, just turned 6 this January. So, while Mariah was in the NICU, it was through a mix of finding babysitters, family, or taking turns with my husband that we managed. That, and a lot of prayer!

SKN Was Madeline ever able to come with you and Geoff to visit her baby sister?

K She could, since she was healthy, old enough and up to date on her shots. But we chose to wait to bring her until Mariah was 17 days old and looking a little stronger. We wanted that first meeting to be as special as possible—and it was. When Madeline saw Mariah, she thought her little sister was beautiful.

SKN How well did Madeline understand the situation?

K She actually had a really good handle on things. The child-life specialist used dolls and “medical play,” as they’ve dubbed it, to explain what was going on in a way Madeline could appreciate. All the messages stuck. She now wants to be a nurse and can talk at length about Mariah’s experience, with an impressive grasp of some of the



complex ideas. She even plays nurse at home—our living room is often transformed into a NICU pod, where she tends to her “babies” while wearing a pair bright pink

scrubs she got for Christmas.

SKN That’s adorable. But what about you and Geoff—were you two also empowered to be part of Mariah’s care team?

K Yes, all around. We were involved in so many parts of her stay, and had strong voices and distinct roles to play as Mom and Dad. We learned the medical language, had our questions answered ... and answered a second or third time, when we forgot! We also were able to take her temperature, change her diapers delicately and bring in clothes to put on her, which helped give us a sense of control and inclusion even when she was most fragile.

SKN Was there a special memory—something you’ll never forget from her stay?

K When Mariah was one month old, we could finally hold her. The elation of that moment washed away a great deal of the grief we’d held onto after waiting so tentatively, for so many days, to touch and bond with her this way. I remember as Geoff and



Special chance to celebrate your NICU Legacy

Last year, we were thrilled to install the first ever “Wall of Miracles and Memories” just outside our NICU. This tile wall, created by our past “graduates” and their families, is a beautiful testament of the miracles that have happened here at Golisano Children’s Hospital.

Due to the overwhelming response and success from installing the first round of tiles, we are excited to offer another opportunity for you to be a part of this memorable project. We will be putting together the second phase of this wall and invite you to join us and other NICU families from 11 a.m. to 2 p.m. Saturday, June 7 for the another tile painting party to benefit the Neonatal Intensive Care Unit at Golisano Children’s Hospital at Strong.

We hope you’ll take part in this opportunity for you and your child to leave your family’s legacy on a wall that will be displayed for years to come. Please call (585) 273-5948 for more information.



Tiles costs are as follows

4" x 4" tile — \$75 donation

6" x 6" tile — \$150 donation

8" x 8" tile — \$250 donation

(Photos can be added to the tiles for an additional cost of \$40 per tile.)

I were heading out the door on our way home after, one of the nurses caught my eye with a smile. She said, “Looks like Mother’s Day came a little bit early this year.” I’ll always remember that. She was right.

SKN Tell me more about living with the ups and downs. How difficult was the uncertainty of things being touch-and-go?

K I’ll be honest, it was tough. Especially after surgery, when Mariah exhibited a heart condition that didn’t show during the pregnancy tests—not during the amniocentesis, the ultrasounds, anything. This would demand surgery as well, so you can imagine the emotional backlash we felt, so certain we have this licked, and then learning it wasn’t over quite yet. Thankfully, I was lucky to find some good ways to cope. I talked to everyone, and developed an extensive support network of good listeners. And, I could trust my nurses and doctors to give me straight answers, if not always easy ones. I needed that.

SKN You’re a strong woman. But I have to ask—it’s a busy unit, usually filled with 50 or more newborns at once. Did you feel like you were just one of many?

K Not a bit. The care and attention from the nurses and doctors is incredible. To give you one example—for a long time, Mariah relied on ECMO, which sort of functions as a heart-lung machine. She was sedated while using



it, so her eyes were puffed shut. For more than a week, we waited to see her open them again, and one of the nurses had an idea. We’d bring a disposable camera to keep by her isolette; that way, the moment she did, she’d have her own personal paparazzi capturing the memory.

SKN And someday when she’s older, you’ll be able to share that, showing her everything she’s come through. But can you tell us about how your brave little girl is doing now?

K Well, she finally had her heart surgery just after New Year’s—so, now she has a “perfect” heart, according to her surgeon. It’s a new start for all of us, and a real blessing just to have her home, with no surgeries looming. As for her budding personality, she’s mellow, like me, but giggles up a storm when Madeline plays with her. She’s really got a sweet disposition, in spite of all she’s weathered. For that, for everything, we’re incredibly thankful.

Telemedicine expands to help kids who need access to docs most

Health-e-Access, Golisano Children's Hospital's telemedicine program, provides a platform for interactive, Internet-based health care visits to diagnose and treat routine childhood symptoms in 19 urban and suburban schools and childcare centers. Since the program's inception in 2001, these visits have virtually eliminated the mid-day scrambles to the pediatrician that disrupted parents at work, kids at school and were often tricky to schedule.

Now — thanks to a generous gift of equipment and funds from the B. Thomas Golisano Foundation, which primed the pump — a grant exceeding \$828,000 from the Agency for Healthcare Quality and Research (part of the National Institutes of Health) will promote continued testing of telemedicine's healing powers. This time the technology will serve a whole new population — students with special needs.

Rochester's Mary Cariola Children's Center, which provides high-quality individualized services to both children with developmental delays and with complex or multiple disabilities, will serve as one study site for the project.

"We're eager to learn how telemedicine can provide even greater value for these unique students," said Ken McConnochie, M.D., M.P.H., program director, pediatrician and professor of Pediatrics at Golisano Children's Hospital at Strong.

At the Mary Cariola and Akron sites — much like other Health-e-Access sites — trained "telehealth assistants" simply dial up the child's pediatrician, and, wielding a camera and electric diagnostic tools, can shoot stills and video inside the ear, videoconference, or even use an electronic stethoscope to allow the pediatrician to listen in to the child's lung sounds.

Being able to bypass the mid-day doctor visits is a small miracle for these kids, their parents and their caregivers. Just to begin to appreciate how it might



transform daily life at these centers, consider a toddler whose anxiety gets the best of him at the doctor; the child throws a tantrum. Challenging this tot's iron-will would be no picnic, sure, but it pales in comparison to reasoning with a teenager with disabilities who, also nervous, might respond with the same kicking and screaming.

"That's just one example of what caregivers might encounter in a visit away from safe and familiar faces and places these students are used to," said Nancy Wood, Health-e-Access program coordinator. "But with telemedicine, kids see themselves on video, and can even help hold tools, making the 'visit' not only bearable, but fun."

These children often require more frequent medical attention, even for routine childhood conditions such as ear infections, asthma, sore throats and skin conditions.

And, to receive it, they often require special transportation, which makes mid-day trips to the doctor more complicated. Since Mary Cariola's top-notch programs have such a powerful reach, the 400 children and youth they

serve come from more than 10 counties. Some kids are even bussed in from more than an hour away; the convenience now afforded to their families is especially dramatic.

Mary Cariola's lead nurse Anne Pawlowski, R.N., hopes the program continues for years to come.

"The families of the students who have used telemedicine visits have been extremely thankful," Pawlowski said. "Since many of these students are autistic, unfamiliar environments can be very upsetting for them. The opportunity to be 'seen' in a familiar classroom staff, with nurses they know, makes a world of difference."

Pawlowski adds that, because the Center is also able to use its own behavior therapists to assist nurses and the child with the 'visit,' pediatricians may be able to, at times, conduct a much more successful exam than they would in their own offices.

To learn more about Health-e-Access, or how you can support this initiative and others like it, please call the Office of Development and Community Affairs at (585) 273-5948.

Metabolic syndrome affects nearly 1 in 10 teens

GCHaS participates in national effort to define syndrome in children

More than nine percent of teenagers may have metabolic syndrome, a clustering of risk factors that puts them on the path toward heart disease and diabetes in adulthood, according to Golisano Children's Hospital at Strong research. This shocking statistic represents some of the first concentrated efforts to define and measure metabolic syndrome in children and adolescents—a necessary starting point for combating the problem, but one that has proven even trickier in youth than it has been in adults.

With the number of obese children in the United States rising at an alarming rate, pediatricians, family practitioners and researchers are concerned about what it means for children's future health. The U.S. cholesterol guidelines have defined the metabolic syndrome for adults who have a cluster of risk factors, including increased waist circumference, elevated blood pressure, low HDL (good) cholesterol, elevated triglycerides and an elevated fasting glucose. Even though these same components can be found in children, they have not been developed into a universal definition or diagnosis.

In the summer of 2006, a handful of national experts, including Stephen Cook, M.D., M.P.H., assistant professor of Pediatrics at the University of Rochester Medical Center's Golisano Children's Hospital at Strong, were convened by the National Institutes of Health with a task to define the metabolic syndrome for children and adolescents. The Pediatric Metabolic Syndrome Working Group (PMSWG) chose to tackle this problem affecting overweight and obese youth, tapping Cook to participate.

As part of the committee, Cook performed a study, published with a collection of reports from the working group in February's *Journal of Pediatrics*, which analyzes how many teens in the U.S. could be considered to have the metabolic syndrome based on

different definitions of it.

The definition Cook developed in Rochester (a waist circumference at or above the 90th percentile for age and sex; blood pressure at or above the 90th percentile; a high triglyceride level at or above 10 mg/dL; a low HDL cholesterol level at or above 40 mg/dL; and an impaired glucose metabolism at or above 100 mg/dL), reveals that 2.9 million teens—9.4 percent of teens overall, and over a third of obese teens—could have the metabolic syndrome.

The original work by Cook and colleagues published in 2003 showed only 4 percent of teens meet this definition and that the increased prevalence is driven by the rise in obesity.

“Even if there is no consensus on a pediatric-specific definition, the fact that

1 in 4 obese teens meet the adult definition for this clustering of cardiovascular disease risk factors is enough of a concern,” said Cook, who is a pediatrician and adult-internist at Golisano Children's Hospital at Strong. “Many longitudinal studies have shown that adults with this definition are at increased risk for developing type 2 diabetes, heart disease and dying prematurely from heart disease.”

Cook said there have been advances in technology, pharmaceuticals and tremendous public health victories seen with reductions in tobacco use and exposure, so the increased rates in cardiovascular risk factors in young adults must be considered “the first wave of severe consequences of the modern obesity epidemic.”



Awards for doctors

Music Therapy Pioneer Honored

In November, Olle Jane Sahler, M.D., professor of Pediatrics, Psychiatry, Medical Humanities, and Oncology, received the Advocate of Music Therapy Award at the American Music Therapy Association's national conference in Louisville, Ky.

Sahler was recognized for her compassion in her clinical work, as well as for her scientific research endeavors. A widely-published NIH investigator, some of her most recent projects include investigating the power of music therapy to confer benefit to patients.

For more than 10 years, her fruitful collaboration with Nazareth College has produced research grant monies, Rochester's first full-time music therapy program in a general hospital setting, a thriving music therapy internship program and a medical humanities course that explores creative arts therapies.

AAP Honors Szilagyi for Commitment to Children in Foster Care

The American Academy of Pediatrics' Council on Community Pediatrics named associate professor of Pediatrics Moira Szilagyi, M.D., Ph.D., the second recipient of the Calvin C. J. Sia Community Pediatrics Medical Home Leadership and Advocacy Award, at a special luncheon in October.

The award, presented at the AAP's National Conference and Exhibition in San Francisco, recognizes a pediatrician who has demonstrated clinical excel-



lence, community action and advocacy for children with unique care needs. Szilagyi was honored for her work as medical director at Starlight Pediatrics, a specialty-clinic based at the Monroe County Department of Health that is exclusively dedicated to the health of children and adolescents in foster care.

With only a shoe-string budget, Szilagyi and her staff of a dozen have transformed the fledgling clinic into a national model for foster care pediatric services.

Ruth A. Lawrence Wins Rochester Women's Council's Top Honor

Ruth A. Lawrence, M.D., professor of Pediatrics, and Obstetrics and Gynecology, at the University of Rochester Medical Center, was named the winner of the 22nd annual ATHENA Award in January.

The award, an international program introduced to Rochester in 1987 by Women's Council of The Rochester Business Alliance, Inc., celebrates women of achievement in the community,

noting their professional excellence and community service, and their active and generous assistance in helping other women develop professional excellence and leadership skills.



Lawrence is a pediatrician and neonatologist at Golisano Children's Hospital at Strong and the medical director of the Ruth A. Lawrence Poison and Drug Information (formerly the Finger Lakes Regional Poison and Drug Information Center). She is an international expert on breastfeeding medicine, and helped to create Rochester's first Neonatal and Pediatric Intensive Care Units, as well as the poison and drug information center (housed in the University of Rochester Medical Center) that now bears her name.

Pediatrician and Researcher wins Forty Under 40 Award

Jill Halterman, M.D., M.P.H., associate professor of Pediatrics and pediatric asthma expert with Golisano Children's Hospital at Strong, was honored by the Rochester Business Journal as one of Rochester's Forty Under 40 in November. The award recognizes men and women,

under the age of 40, who have achieved professional success and have also made significant civic contributions to our community. Halterman was

selected as an honoree by a committee of business leaders from a pool of hundreds of nominees. She is a health services researcher, with a particular passion for improving the delivery and quality of care in health outcomes for vulnerable children who have chronic disease and live in poverty. Halterman has spent the majority of her effort around the major public health area of childhood asthma. In addition, Halterman is a superb pediatrician who has a wonderful style, both warm and thoughtful, and she has developed a very large following of patients.



The Miner Library: a resource for families

When children are admitted to Golisano Children's Hospital at Strong or receive a diagnosis in the outpatient clinic, parents don't always know where to go for more information about their child's condition. And they probably have no idea where the Miner Library is, nestled in the middle of the sprawling University of Rochester Medical Center. But two new Miner Library programs are showing parents that the Miner Library isn't just a place for medical students to study—it's also a place where they can find information they desperately need.

Ask a Medical Librarian

The last thing parents should do when hearing their child has a disease is go to the Internet and do a search. While the Internet has a lot of valuable information on medical conditions, it also has a lot of unreliable information that can confuse an already stressful situation. That's why the Edward G. Miner Library began the Ask a Medical Librarian (AAML) service.

The heart of the AAML service is the "information prescription." Physicians, nurses and social workers can write a "prescription"—much like a drug prescription—for information on behalf of the patient or their family for the Miner librarians to fill. If a child receives a diagnosis for a very rare disease, such as Steven-Johnson Syndrome (which ranges from mild skin and mucous membrane lesions to a severe systemic disorder), a physician, nurse or social worker can ask the librarians to research the disease for the family. The librarians then find reliable and consumer-level information for the parents and deliver it to the family.

This not only frees up the parents to focus on their child and family, but it also guarantees that the information they receive is accurate. In fact, the physician who writes the prescription can also ask to preview the information before it is



passed along to the family to ensure that it will meet the family's needs.

The Miner Library has opened the program up to include community pediatricians. To write a prescription for information, pediatricians can visit www.urmc.rochester.edu/hslt/miner/InfoRx/.



Scott Sturge Family Cancer Information Center

The Miner Library also worked with John and Judi Sturge whose son, Scott, died of cancer. Together, they created a Web site (www.sturgetcancer.org) for children and teens diagnosed with cancer. This informational clearinghouse doubles as a place where patients and family members can network.

"It's not only a source of information, it's also a source of support," said Mary Beth Klofas, nursing and patient outreach coordinator at Miner Library and coordinator of the project. Eric Iglewski, a pediatric social worker who works mainly with patients diagnosed with cancer, said the site is one of the first things he directs families to.

"At the beginning when their child is faced with a life-threatening diagnosis, parents are often too emotionally overwhelmed to seek good information to make sense of their situation," Iglewski said.

Iglewski said the site also helps families find information on coping, sibling issues and financial matters. The site includes lists of links to outside organizations that may have helpful services or information, and it links back to information about programs within Golisano Children's Hospital, making it very useful for local families.

Another important aspect of the site is that it doesn't treat teens like children.

"Their needs are different than a younger child and we wanted to break them out as a specific group," Klofas said.

For more information about either of these programs, contact the Miner Library at (585) 275-2487 or email Mary Beth Klofas at marybeth_klofas@urmc.rochester.edu. To find out how you can support these or other programs, please call the Office of Development and Community Affairs at (585) 273-5948.

Special Thanks

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

- * Many thanks to members of the Kids Miracle Making Club, who hosted the Smiling Pumpkin Halloween Party at the Penfield YMCA and raised \$978.
- * Congrats to Pavilion School's Backward Basketball Game, which raised \$1,019 for Golisano Children's Hospital at Strong.
- * Kudos to Ida Wheeler, who hosted her first Holiday Showcase talent performance and raised \$3,121.
- * Thumbs up for players, organizers and attendees of the Pittsford Sutherland and Pittsford Mendon 7th annual Rainbow Classic, which drew \$24,800 to help us help kids.
- * Thanks to John Paradiso for organizing the 3rd annual December to Remember. The evening featured local musical talent, raising funds and collecting toys for the Children's Hospital.
- * Kind thanks to Panera Bread, whose stores raised \$8,370 for Golisano Children's Hospital through the sale of travel mugs (complete with up to three-months of free refills!)
- * Thanks to the Rochester RazorSharks for their two new commitments this season: first, to donate \$30 per three-point-shot scored, and second, for their promise to purchase a new table and chairs for the play deck if more than 30,000 fans attend their games over the course of the season.
- * Thanks to the Nazareth College student-athletes for organizing the first-ever "Battle of the Beaks" fundraising game against the St. John Fisher Cardinals. The night's competition raised more than \$7,000. Soon after, the athletes also held a winter dance fundraiser to further support the Children's Hospital — raising another \$3,000, for a total of \$10,000.
- * In February, the 3rd annual Cycle for Hope spinning fundraiser, spread over a dozen clubs across Rochester, raised more than \$22,000 for the Children's Hospital and Camp Good Days & Special Times.
- * Props to organizers of the 6th annual Ski Invitational at Bristol Mountain. The outing garnered \$51,700 to help ill and injured children.
- * Thanks to Despina and Scott Mitchell and their efforts in executing a special NICU benefit at J.B. Quimby's in February. The night of raffles, food and fun raised \$8,269 to help renovate the family room in the NICU, where parents find rest and comfort during some of life's most tenuous moments.
- * The Rochester Policeman's Ball, held at the Hyatt Regency Hotel in February, raised funds for the Children's Hospital.

Finally, we'd be remiss to not extend our gratitude for the countless donations of toys and gifts for the patients at Golisano Children's Hospital during the holiday season. Your generosity brightened holidays away from home for many children, teens and their families — we wish you could have seen the smiles!

Save the Date

4th annual Girls Day Out

When 2 to 5 p.m., Sunday, May 4

Where Rochester Riverside Convention Center

Events Enjoy a day of pampering, fashion and fun for girls of all ages! It's Shear Ego styling and mini-manicures for the younger girls, ceramic painting by Color Me Mine, a fashion show by The Gap, and massages and Mary Kay makeovers for the moms (and the aunts, etc.!) Not to mention great eats and dance-worthy tunes...

Cost \$15 for adults, \$20 for girls 18 and younger. Call (585) 273-5948 for more information.

12th annual Golf Classic

When Monday, Sept. 8

Where We'll once again spread across four courses to accommodate this premier tournament that benefits kids at Golisano Children's Hospital at Strong.

Events Lunch and registration begin at 11 a.m.; shotgun start to kick the competition off at 12:15 p.m. Dinner at Monroe Golf Club immediately follows the day of golf. Call (585) 273-5948 for more information.

21st annual Gala

When Saturday, Oct. 18

Where The USAirports Aircraft Hangars

Events Once again, two hangars will transform into a glamorous setting for a fun-filled evening of food and drink, silent and live auctions, and dancing.

Info For tickets or sponsorship information, call (585) 273-5948.

CMN News: “Balloons up, up and away”

They keep your car fueled, outfit your golf game, twist pretzels and more, but the common thread knit between the businesses and groups that plug into the Children’s Miracle Network is this: they love Rochester’s kids and want to keep them healthy.

As CMN sponsors, many of these businesses sold — and, this spring, many are selling again — orange- and-yellow paper Miracle Balloons for only \$1 each. Since the hallmark of CMN is that all the money raised stays to work in the local community, your faithful support of balloon sales adds up for kids right here at Golisano Children’s Hospital.

- Many thanks to our local Sunoco stations, whose staff once again rallied behind our children’s hospital, selling



Left: Express Mart Manager, Brad Mannix, shows off a paper snowflake sold at an Express Mart in Victor. His store rallied to raise \$800.

Right: Manager Twanda McFadden’s Sunoco store on Latta Road raised almost \$5,000 in their most recent campaign. MacFadden’s 5-year-old son, D’Andre Hunter was a big help!



- Miracle Balloons to raise more than \$21,000.
- Props to this year’s newest partner, Express Marts. The local Express Mart locations sold “Miracle Snowflakes,” jointly raising more than \$1,850.
 - Kudos to Golf Galaxy for selling Miracle Balloons this past holiday season (Nov. and Dec.) and earning \$1,096.
- Since spring is the busiest time for our CMN partners, you’ll see thousands of Miracle Balloons cropping up at many local businesses. Consider purchasing one — and making a difference — when you visit the locations below:
- Kinney Drugs, March 10 to May 18
 - Rite Aid, March 23 to May 11

- Auntie Anne’s Pretzels, March 17 to April 26.
- Wal-Mart and Sam’s Club, during “Miracle Months” of March, April and May



Calling all golfers!

2nd annual Golfing for Kids Tournament, sponsored by CMN partners, Wal-Mart and Sam’s Club, and presented by PepsiCo, is set for Monday, May 19, at Shadow Lake and Shadow Pine Golf Clubs. Registration begins at 9 a.m.; shotgun start follows at 10. Join us for this power-packed charity competition (last year’s drew more than 160 golfers, who joined us to raise more than \$43,000 for Golisano Children’s Hospital at Strong!) For information, or to sponsor this event, please contact Betsy Findlay or Angela Pullen at (585) 273-5948.

25th Annual Children’s Miracle Network Telethon

June 1, 2008

8 a.m. to 1 p.m. and 7 to 11 p.m., News 10NBC

Stories of strength and courage will air on local television sets. Hosts Brett Davidsen, Robin DeWind and Rich Funke will chronicle the journeys of this year’s Miracle Kids and their families.



Head-strong

Continued from page 3

benefit of the minimally-invasive techniques. Within 24 hours, she was out of the PICU and transferred to a step-down nursery. The day after that, she was home.

"But that's when the other work began," Jones said.

Five days after surgery, Autumn was ready to begin a marathon of orthotic appointments, where a snug helmet would support and protect her small, healing skull, helping it to mold into a proper shape.

If new parents find diapering, clothing and bathing hard, try being ginger enough to put a "football helmet," bedazzled with purple butterflies, on a 3-month-old whose head is stitched and sensitive.

"I have to take it on and off three

times a day, to let her skin breathe," Jones said. "And then we follow that up with weekly re-sizing appointments." Thankfully, Autumn is a trooper and doesn't mind wearing it, her mom said.

"I think she may have adjusted to it even faster than we did," Jones said. "Being a mom, I hate not having immediate access to kissing or stroking my baby's head."

All the same, Jones admits that it is worth it.

"If all goes as planned, Autumn should finish with her helmet therapy in less than a year and then go on to live a normal life," she said. "This hope—that down the road she can be like every other kid—is what keeps us going."

Autumn, for her part, is oblivious to anything being out of the ordinary. Jones said she's a happy baby who loves to be the center of attention, and hates to be set down or left even for a moment.

"She has a stubborn side," Jones

smiled. "I think it's because she's a redhead, like her mom."

You can help

To learn more about craniosynostosis, helmet therapy and other services offered at the Cleft and Craniofacial Center at Golisano Children's Hospital at Strong, visit www.stronghealth.com/services/childrens/craniofacial, or call the Craniofacial Center directly at (585) 273-FACE, or our clinical line at (585) 275-1000.

To make a donation that help our region's only children's hospital as it serves local patients and their families, call the Office of Development and Community Affairs at (585) 273-5948.

rain or
shine

SAVE the DATE

12th Annual Golisano Children's Hospital at Strong

stroll for strong kids

presented by

JPMorganChase

SATURDAY, MAY 31, 2008

GENESEE VALLEY PARK

Join us for our 12th Anniversary Celebration of this family-fun fundraising walk to benefit Golisano Children's Hospital at Strong.

Children's activities, costumed characters and concert by *Gary the Happy Pirate* · Lunch provided by Subway for all participants · Prizes awarded to high fundraisers.

For information call 585-273-5948 or e-mail strongkids@admin.rochester.edu. Beginning April 1, registration forms will be available on-line at www.gchas.org.



Upcoming Events

March 14 and 15, 35th annual Brockport High School Dance Marathon

Brockport High School. Students and faculty will dance the night away, hoping to raise thousands for leukemia research underway at Golisano Children's Hospital. For more information contact Ann Hamlin at (585) 637-3240.

March 29, Strong Spells Magic Show

Advancement & Alumni Center, 300 East River Road, Rochester. Doors open at 6:30 p.m., show starts at 7 p.m. For more information, call (585) 273-5948.

April 4, 6th annual Talent for Tots and Teens Talent Show

Advancement & Alumni Center, 300 East River Road, Rochester. Watch some of Rochester's most talented youngsters as they perform to compete for top honors at this fundraising talent show. For more information or to purchase tickets, please contact Ida Wheeler at (585) 273-5907 or IWheeler@Alumni.Rochester.edu.

April 5, "Erg-a-Thon"

Eastview Mall, Victor. Members of Pittsford Crew, a non-profit organization that offers club scholastic rowing at both the novice and varsity levels, will collect pledges to row on stationary machines in the Bon Ton Court. Half of the event proceeds will benefit Golisano Children's Hospital at Strong. For more information, call (585) 273-5948.

April 12, Monte Carlo Night Fundraiser

Eagle Vale Country Club, Route 250, Penfield. From 7 to 11 p.m., Tops Markets and Martin's Super Food Stores deliver casino style fun at this special benefit for Golisano Children's Hospital at Strong. Admission is \$40 per person, \$70 per couple, and provides 250 chips per person, complimentary hors d'oeuvres and gaming. To purchase tickets or for more information, ask for Cheryl Emmerling or Debbie Griffith at the customer service counter at Martin's Super Food Store in Fairport, or call (585) 425-0020.

May 4, 4th annual Girls Day Out

Rochester Riverside Convention Center, 123 East Main Street, Rochester. 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 31, 12th annual Stroll for Strong Kids

See mention on page 14.

June 1, 25th annual Children's Miracle Network Telethon on News 10NBC.

See mention on page 13.

June 7, NICU Tile Painting Party

See mention on page 7.

June 25, B&L Wholesale Golf Tournament

Shadow Lakes, Shadow Pines and Greystone Golf Clubs. For more information, call Lisa Chatt at (585) 546-6596.

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AT STRONG**

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