

University of Rochester Medical Center

FEATURED STORIES:

Children's Hospital annual memorial service

Child pedestrian injuries peak in the fall

20th Anniversary Gala

Miracle Weekend a great success

3

5

6

8



Pediatric Treatment Center renovating, expanding

Day after day, the staff of Pediatric
Treatment Center at Golisano Children's
Hospital at Strong outfits kids with the
medicine they need to fight their battles
—battles against cancer, blood disorders
and bone marrow failure, even the
immune deficiencies they were born with.

Preparing these small soldiers is a big job. Each year, the center conducts more than 7,000 visits with children from Rochester and outlying areas—places as far away as Buffalo, Elmira, northern Pennsylvania and Rome. More than half of the kids come to receive chemotherapy, though the center routinely meets other needs, too, including delivering medicinal infusions, blood transfusions, enzyme replacement therapy, medical hydration and many other invasive treatment proce-

dures that can last anywhere from a brief 10-minute stint to a full eight-hour workday's worth of getting better.

A testament to the center's healing powers is 10-year-old Bryce Czekanski, who comes each week to receive synthetic enzyme-replacement therapy for Hurler-Scheie syndrome, a rare genetic disorder that affects only one in 115,000 people and that, if left untreated, would cause irreversible damage to his heart, liver and spleen, meanwhile clouding his vision and stiffening his joints.

Fortunately, Bryce is able to find help here, only minutes from his Fairport home. August marks five years of his receiving IV-therapy via once-weekly sessions that last six hours each.

It's not a boring visit for Bryce, *Continued on page 14*



Dear Friends—

People often associate certain holiday seasons with giving and philanthropy. But at Golisano Children's Hospital at Strong, it feels like every day is a holiday.

Board of Directors

Howard Jacobson, Chair * Al Chesonis, Vice-Chair * Dave Christa, Vice-Chair* Robert G. Jacobson, Vice-Chair* Mark Siewert, Vice-Chair * Michael Amalfi* Joseph L. Carbone, D.P.M. Jeffery Davis John L. DiMarco II Wanda Edgcomb Harvey B. Erdle Timothy Fournier Roger B. Friedlander Jay W. Gelb John Glynn Heather A. Goodbody Mike Goonan Deborah Haen* Michael Haymes Arnold Klinsky Todd Levine Kim McCluski **Brian Pasley** James G. Vazzana

Faculty

Richard E. Kreipe, M.D. Thomas K. McInerny, M.D. Jeffrey Rubenstein, M.D.

Honorary

Jeffrey D. Blanchard Judy Columbus Diane R. Doniger John L. Green, M.D. Richard A. Insel, M.D. Joseph E. Klarberg Donald P. McNelly

Ex-Officio

Bradford C. Berk, M.D., Ph.D. Steven I. Goldstein Frank Interlichia Douglas Phillips R. Scott Rasmussen * Nina Schor, M.D., Ph.D.* Elsa Steo

We are so fortunate to be the beneficiaries of generosity that knows no season. The critically-needed renovation of our Treatment Center, the free care provided by us to those who cannot afford to pay for medical care, the computers that allow our patients and their families to use Katelyn's Computers (an educational and entertainment system called GetWellNetwork which we told you we wanted to provide in last summer's issue)... none of these would be possible without the generosity of our community. The Radiothon, the Telethon, the Stroll, the Golf Classic, the Gala... so many have given so much time, in-kind goods and services, auction merchandise, money. We are truly blessed.

It is hard for me to believe I came to Rochester almost a year ago. And what a year it has been! We have launched a new hospitalist service (hospitalists specialize in treating hospitalized patients), recruited several of the country's most promising young biomedical researchers, introduced the region to miracle makers young and old, and sent word of the successes of Golisano Children's Hospital around the country and world via our research newsletter, seminar series, Web sites and presentations at national and international meetings.

In the pages of this Golisano Children's Hospital at Strong newsletter, you will read about our hopes and dreams for the future. We are working with the community to end obesity, prevent asthma attacks, stop the exposure of children to second-hand cigarette smoke, and ensure the health, well-being, and comfort of children who come to us for intravenous therapy. Enjoy and feel proud of the role all of you have played and continue to play in our successes and our future. It is the future of the children of Rochester, the U.S. and the world. And you are why we dare to dream.

Yours truly,

Mina F. Schon

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

^{*} Executive Committee

Annual memorial service helps familes keep kids close at heart

On the heels of Miracle Weekend a time marked by cheery celebrations that showcase the children's hospital's most dramatic success stories, or "Miracle Kids"—came a quieter, closerknit affair: the children's hospital's 4th annual Memorial Service.

The gathering drew more than 175 members of hospital staff and families, all linked by shared desires to remember more than 45 children who, in recent years, each bravely waged but ultimately lost their battles against illness.

"Every child is a miracle, especially those who must struggle so hard and endure so much," said Carla LeVant, senior social worker at Golisano Children's Hospital at Strong who helps families live in the face of loss and is part of the team that plans the service each year. "These children have become heroes and this is our chance to help build lasting legacies, both by honoring them and continuing to care for their families."

The remembrance service was held Sunday, June 10, at the Interfaith Chapel on the University of Rochester's River Campus. Attendees were offered teddy bears to squeeze during the hour (and take home after); candles flanked the altar, shimmering in memory of each child as poignant musical pieces filled

Laura Anderson

the air. Tributes were read and a children's story was shared. Encouragement messages, from parents and hospital faculty and staff, preceded a photo slideshow of the children who may be gone, but are far from forgotten.

"The slideshow really is an emotional high point in the afternoon," LeVant said. "For me, it's always a "Pay it Forward," which she'd watched dozens of times and "tried to live out," her mom said.

Coming to a memorial service is a big comfort, Anderson added. "Grief is such a lonely thing; but the moment you're in that chapel, cut off from the rest of the world and surrounded only by people who are there for the same reason,

"I take comfort in knowing that if I ever need to talk, or have a question answered, someone at the children's hospital will be there ready to help. This hospital doesn't forget people."

solemn reminder of how different each loss is for each parent—from NICU babies who never had their homecoming, to gorgeous high school photos of teenagers who, just blooming, were lost all too soon."

For many parents, like Nancy Anderson, it's a reunion, a chance to "see" their children again.

It was the second year that Anderson of Ogden attended to remember her 14-year-old daughter, Laura, who died of leukemia in early 2005.

Laura fell sick on her 14th birthday in early October 2004 with an especially virulent cancer that conceals itself from detection; a few days later, she was placed in a drug-induced coma. She died in February, never knowing exactly why she was ill.

Anderson still lights a candle each night to remember her daughter.

"I know it's natural for a parent to be in awe of their own child," she said. "That's what parents do. But what still strikes me is the letters that poured in from her teachers, the stories that came out after she was gone. She touched so many lives."

Laura loved riding bikes with her older brothers and was incredibly family-oriented; her favorite movie was it's a beautiful camaraderie," she said.

Sharing the pain, she added, lightens the load. And your simultaneous compassion for the other families helps to pull you outside yourself—which is admittedly hard to do in the midst of big loss.

"It's a little easier each day, but I'll miss her for the rest of my life," Anderson said. "Still, I take comfort in knowing that if I ever need to talk, or have a question answered, someone at the children's hospital will be there ready to help. This hospital doesn't forget people."

In addition to the annual Memorial Service, the hospital holds a support night for parents and siblings who are grappling with first holidays after loss. Offered between Thanksgiving and Christmas, LeVant says that the holiday meeting is a chance for bereaved families to "give each other permission" to talk about—and work through—their losses with others who can better empathize.

It was the holiday meeting — which Anderson also attended — that gave her the idea to burn a candle in Laura's honor.

The flame burns on.

Candy cigarettes make kids more accepting of the real thing

Children who have used candy cigarettes or bubble gum cigars are more likely to try the real thing as they grow up than those who never played with the fake tobacco products.

New research from an associate professor of Pediatrics at Golisano Children's Hospital at Strong shows that children who enjoyed the candy tobacco product often were even more likely to become adults who smoke. About 88 percent of both current and former smokers tried the candy as children compared to less than 78 percent of people who have never smoked. This is the first study to show that a history of candy cigarette use is associated with higher levels of smoking in adults.

"As parents and pediatricians, we need to understand that candy cigarettes are not harmless. More than 100 countries worldwide have banned the sale of candy and toy tobacco look-alike products that are made to appeal to children. Parents should realize that the use of candy look-alike tobacco products lets children 'play' at smoking, making them susceptible to pro-smoking images in tobacco ads and other media," said Jonathan Klein, M.D., M.P.H., author of the study in *Preventative Medicine* earlier this summer and director of the American Academy of Pediatrics' Julius B. Richmond Center of Excellence which is located at the hospital. The center specializes in research on the effects of smoking and secondhand smoke on children.

Tobacco industry documents have shown that early addiction of children was a specific goal of manufacturers and that both candy cigarette and tobacco companies thought candy cigarettes were "effective advertising for future smokers." In fact, tobacco manufacturers often allowed candy cigarette companies to use their logos or they turned a blind eye to copyright infringement. Research has shown that children are brand sensitive and can easily iden-

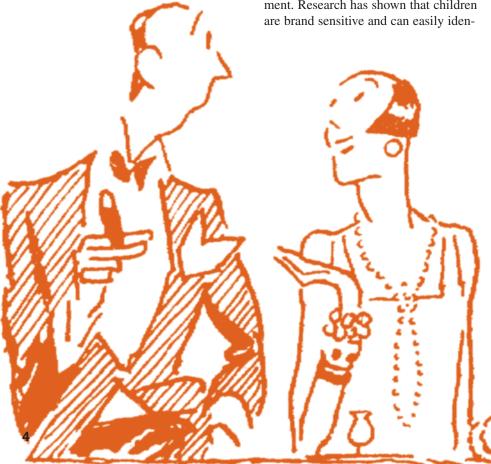
tify logos in packaging and advertising, such as Joe Camel and Marlboro.

Klein acknowledges the complicated and varied influences of tobacco use on children but said one simple way to begin to combat pervasive pro-smoking media messages is to take these products—which are specifically marketed to children—off the shelves. Wal-Mart Stores, Inc., is one of the few national chains that has agreed to ban sales of these products in its stores in all 50 states.

Other research

More than 30 Golisano Children's Hospital at Strong researchers presented findings at the annual Pediatric Academic Society Meeting this spring, including three who focused on childhood obesity.

- Klein reported that while almost all pediatricians say they are weighing and measuring children at well-child visits, many are still not using recently recommended BMI percentile measurements. Many feel they do not have time to address overweight issues well, and that counseling patient and families is not very effective.
- Stephen Cook, M.D., reported that almost 4 percent of children are at or above the 99th percentile for Body Mass Index, meaning that about 2.7 million U.S. children could be considered morbidly obese. That percentage is higher for boys, blacks, poor, and adolescent poor.
- Jennifer Foltz, M.D., reported that almost no adolescents are meeting all four key obesity prevention behaviors—eating five fruits and vegetables, spending less than two hours in front of the TV or computer, at least one hour of exercise and no sugar-sweetened drinks. Although some teens are meeting each goal separately, only 9 percent are eating the recommended servings of produce.



Child pedestrian injuries peak in the fall

Injury Free Coalition for Kids urges children head back to school safely

Even after a summer's worth of biking, crossing streets and inline skating — experiences rightly expected to teach kids some street-savvy — the number of local pediatric pedestrian injuries still peaks around September, according to an emergency room analysis from Golisano Children's Hospital at Strong.

"We see the big, seasonal jumps in pedestrian-related emergency room visits twice a year—first, in the spring, when the weather grows pleasant, and then again in the fall, when kids head back to school," said Anne Brayer, M.D. and co-director of the Injury Free Coalition for Kids Rochester at Golisano Children's Hospital at Strong. The number of pedestrian injuries triples from March to April, decreases as the summer progresses, and then doubles again from August to September.

"It's almost like kids need to relearn safe walking," Brayer said. "There's a seasonal learning curve."

Nationally, the most common riskgroup for pediatric pedestrian injury is kids between 5 and 9 years old, but in Rochester, local emergency room doctors see the whole spectrum.

"Believe it or not, more than half of the patients treated for pedestrian injuries at Golisano Children's Hospital at Strong last year were between 12 and 17 years old," Brayer said. "The idea, keep in mind, is that the formula for risk involves a whole host of factors, and no age group is 'too old' to be concerned."

Risk factors include obvious acts of carelessness, like pedestrians ignoring walking signals and drivers failing to come to complete stops at crosswalks. But even the most cautious pedestrians and drivers will encounter risks beyond their control, which include environmental conditions such as large traffic volumes, high speed limits and high incidences of curbside parking. Urban and underprivileged areas tend to be busy and crowded, making them particularly prone to pedestrian injury.

This year, as kids head back to school—many of them on foot—



Brayer and the rest of the Injury Free Coalition for Kids would like to see them do so safely. Tips to remind kids include:

- Look both ways Start teaching kids at a young age the value of checking "left, right, left" and to never dart out into the streets.
- **Double digits** Kids should be 10 years old or older before crossing alone.
- Choose routes with crossing guards
 If possible, opt for school routes that are staffed by crossing guards. "Kids aren't too versed in judging distances or speeds. Having an adult on their side helps tremendously and parents should encourage their kids to take advantage of and heed these helpers," Brayer said.
- Make eye contact with drivers When crossing before paused cars or buses, make sure to communicate with the drivers; eye contact is good, and a slight wave is even better, enhancing driverpedestrian awareness and allowing the driver to acknowledge kids and safely wave them across.

- Dismount If biking, kids should get off, become pedestrians and walk their bikes when crossing streets.
- Cross only at intersections Don't cross mid-block or from between parked cars. "It's important to be visible, and drivers are more attentive at intersections, where they are more on the lookout for possible pedestrians," Brayer said.

Nearly 5,900 pedestrians are killed by automobiles every year and 84,000 suffer nonfatal injuries, according to the National Safety Council. A disproportionate number of these pedestrian victims are kids under age 15, who experience one-third of the tragedies but constitute only 15 percent of the U.S. population.

Golisano Children's Hospital at Strong treated more than 100 pedestrian injuries in its pediatric emergency department last year.

"That's a number we'd like to see a lot lower," Brayer said. "A big help comes from parents, who are virtually professionals at saying 'be careful' already. Come September, they should step it up, helping their kids choose safe routes or if possible, walking with them. Even if their kids are bussed, parents should take time to review safety tips with them, stressing the importance of using crossing guards and making eye contact with drivers."

The Injury Free Coalition for Kids of Rochester is a child injury prevention program centered at the Golisano Children's Hospital at Strong. The program's main goal is to reduce the incidence and severity of childhood injury in the greater Rochester metropolitan area.

The Drive for Miracles reaps \$126,639 for area kids



Thanks to faithful 100.5 The Drive listeners, our Change Troopers, on-air personalities Gately and Haverly, the rest of The Drive crew, and — most importantly — our supporters who called in pledges; we raised \$126,639 for our community's children!

Special thanks to presenting sponsor, Landmasters Group, and our two phone-bank sponsors, TOPS Markets and Burke, Albright, Harter & Reddy, LLP.

The dedicated staff of 100.5 The Drive celebrate their success.



Children's Hospital rings in 20th anniversary gala

The 20th anniversary Gala, set for October 20 at The USAirports Hangar on Scottsville Road, will take a flight back through time, journeying back decades to a time when a single system of care for Rochester's kids was but a fledgling idea.

Today, it soars, having reached heights unthinkable two decades ago. All local community pediatricians have faculty appointments in the University's Department; they help with research, they refer patients for specialty care; our successes are their successes, and raising healthy kids is the bottom line.

To commemorate strides made for our community's children – among them, building state-of-the-art clinical spaces for pediatric surgical and acute care, recruiting top surgeons, clinicians and researchers to

Rochester, and faithfully training tomorrow's pediatric leaders – the Gala will integrate celebratory surprises into its traditional fundraising atmosphere. These include:

- Metal artist Paul Knoblauch, whose bright, whimsical butterflies, fish and kites already adorn hallways in the children's hospital, will fashion sculptures of hospital mascot Sandy Strong's cartoon friends. The "friends" will be up for bid during the live auction component and, once installed, will bear name plates engraved to honor the highest bidders the real-life "friends" of Sandy Strong.
- To reminisce, guests of honor former event chairs from past years – will be specially invited to attend the Gala, which will again sprawl across two hangars (bridged by an enclosed walkway, new this year).

- Nik and the Nice Guys will again perform live music, only with a new twist: they'll be joined by hospital "celebrities" for a special set (rumor has it, renowned surgeons, board members and hospital staff have been honing their singing voices for this very evening).
- Extra special prize packages in Sandy's treasure area – which typically bear goodies like restaurant gift cards, store gift certificates, even digital cameras – will feature a few dozen limited-edition Hickey Freeman ties with a Sandy Strong design.
- The live auction will showcase fabulous prizes, including: a trip for two to Casetta, a Tuscan farmhouse-turned-inn nestled in Italy's Chianti wine region; a special lunch with Louise Slaughter in Washington, complete with a tour of the White House; a Bears Playground playset.

"Over the past 20 years our Gala has become the event to attend for two reasons: it's a genuinely fabulous time and all the dollars raised help our region's kids," said the event's chair, Howie Jacobson.

This year's Gala, as in years past, is made possible by presenting sponsor ESL Federal Credit Union, together with special 20th Anniversary Sponsors, The Cabot Group, Palmer Foods, the William and Mildred Levine Foundation and Anthony J. Costello & Son, Inc.

To purchase tickets (\$175 per person), learn more about sponsorship opportunities or volunteer to help at the event, please call (585) 273-5948.

Guests at the 2006 Gala truly enjoyed the evening.



Wal-Mart wraps up 20-year anniverary campaign

In May, local Wal-Mart and Sam's Clubs stores launched a concerted effort to "Round Up for Kids," a special month-long campaign that invited customers to bump up their bill to the nearest whole dollar. The difference in change was donated to Golisano Children's Hospital at Strong. In just four weeks, our 11 local Wal-Mart and two local Sam's Club stores collected an impressive \$47,217.

The campaign culminated Thursday morning, May 31, with a "20 Years of Miracles" anniversary celebration. That same day, all across the country, in-store celebrations commemorated the corporation's 20th anniversary of partnership with Children's Miracle Network.

To celebrate locally, second-grader and Miracle Kid Timothy Eaton, his parents, hospital representatives, top fundraising employees and area store managers gathered for cake and cheer at Henrietta's Supercenter; local celebrities showed their support of Wal-Mart's charity by treating customers to some first-class service—helping to bag their goods.

Area celebrities who bagged goods in honor of Wal-Mart's commitment to helping local kids included: Dan Mason, general manager for the Rochester Red Wings • Spikes, mascot for the Rochester Red Wings • Sabretooth, mascot for the Buffalo Sabres, on behalf of Tom Golisano, the hospital's namesake • Holly Maynard, co-anchor for 13WHAM News This Morning • FINley, mascot for Rochester Razorsharks, plus Razorsharks players • Gately and Haverly, on-air personalities from 100.5 The Drive • Vanria Glenn, winner of the Miss Greater Rochester Pageant.

Staunch supporter Wally Straight, a greeter at the Newark Wal-Mart who has used his position to ask customers to donate a dollar at a time to help kids, delivered bittersweet news that day: he had plans to retire in early June. Thankfully, after raising \$171,000 for the Children's Hospital since 2002—mostly, a dollar at a time—Straight assured that he planned to continue championing kids in other ways. His constant, convincing smile and hallmark hat, dripping with dollar bills, will be sorely missed!















Miracle Weekend a success

Stroll pulls thousands to park, Telethon tugs heartstrings





11th annual Stroll for Strong Kids

More than 2,500 community supporters -families and friends of former and current patients, hospital faculty and staff, and local businesses — gathered at Genesee Valley Park Saturday morning, June 2, to celebrate the 11th annual Stroll for Strong Kids.

As one of the hospital's major annual fundraising efforts, the Stroll, a two-mile charity walk and family-fun picnic, has become a summertime staple for many area families. This year's event showcased face-painting, costumed

characters, sand art crafts, a "Dunk-a-Doc" tank, a bounce house and a noontime concert by Gary the Happy Pirate. Subway provided a free lunch to hungry participants.

The day was graced by loads of sunshine and high temperatures and netted nearly \$210,000. The funds will help to purchase state-of-the-art medical equipment and items that help children to heal speedier, and more comfortably.

24th annual Children's Miracle **Network Telethon on 10NBC**

This year's telethon aired Saturday and Sunday evening (June 2 and 3), garnering more than \$51,000 in online, phoned-in and direct mail pledges combined. Many of these donations were made in honor of former and current patients at Golisano Children's Hospital at Strong; these gifts and the honored kids were specially inducted into the "Sandy Strong Alumni Club." Many of their stories were shared on air.

Community support both nights













was inspiring; one caller phoned in six "\$20 by 12" pledges (monthly gifts amounting to \$240 each, or \$1440 total), motivated by a special incentive: that a stuffed animal would be donated to a current patient per pledge.

Also during the broadcast, local pediatrician Bennie Vitullo of English Road Pediatrics issued a challenge to all of the local pediatricians encouraging them to donate \$100 each. Vitullo and his group donated \$600, just to get the ball rolling.

The tote board, which represents a

year's worth of community fundraising efforts, in addition to telethon weekend pledges, blinked a final \$4,066,405 at the telethon's end. This amount is an amalgamation of the community's year-long generosity, and includes donations and gifts from local businesses, community groups and individuals; many of these groups brought checks to present on air.



The hospital wishes to extend sincere thanks to those who gave time and treasure to make this year's Miracle Weekend a success!

PRESENTING SPONSOR:

JPMorgan Chase

JPMorganChase

STROLL SPONSORS:

Advantage Federal Credit
Union
Affronti Excavating and
Trucking, LLC
Allworx
Brian and Kelly Meath, in
honor of Kyle Meath
Cadbury Schweppes
Americas Beverage
Closing USA
Complete Payroll
Processing

Davidson, Fink, Cook, Kelly & Galbraith, LLP Deloitte & Touche, LLP eBaum's World, Inc. First Niagara Benefits Consulting Genesee & Wyoming, Inc. JPMorgan Chase LeChase Construction M/E Engineering, P.C. Mom's Club, Penfield/East Rochester Chapter Monroe Ambulance PAETEC Communications
RE/MAX First and RE/MAX
1st Commercial
RMT Financial Services
Rochester Acoustical
Corporation
Salmin, Celona, Wehrle &
Flaherty, LLP
Schantz Homes, Inc.
The Coolie Group
Underberg & Kessler, LLP

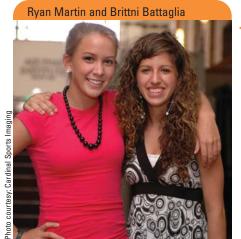
IN-KIND SPONSORS

Abbott's Frozen Custard Arlene's Costumes Bruegger's Byrne Dairy Cadbury Schweppes Cheshire AVKrispy Kreme French Hill's New York Apple Association Nietopski Sports Panera Bread Sirness Services Strong Memorial Hospital Food and Nutrition Services Subwav The DRIVE 100.5 Wendy's

Youth fundraising shifts into high gear

For creative teens and young adults, great charity ideas come to fruition

A wave of imaginative fundraisers—served up by high school and college students—has left us inspired. The photos below prove that just about any talent or interest—from hardcore bicycling to mass babysitting—can be put to work to support the kids at Golisano Children's Hospital at Strong. As long as you're willing to think outside the box, that is.



"Memories for Megan" Coaches' Showcase and Cheerleading Clinic honors injured athlete.

Rising Webster Thomas high school senior Brittni Battaglia solicited reality TV stars to give inspirational talks at a cheerleading showcase and clinic that drew athletes and coaches from around the area. The clinic, her senior project, doubled as a fundraiser; admission fees worked as donations to Golisano Children's Hospital in honor of former cheerleader and family friend, Megan Markus, whose life changed forever after a car accident in 1996. More than 40 cheerleaders and more than a dozen coaches attended the clinic, raising \$700.



Well-known cheerleading coach Donna Martin (left) spoke at "Memories for Megan," a fundraiser for Megan Markus (seated).



Brothers Patrick, Bryan and Mike Kent, and their friend Jon Lewis—all native to Webster—rode 320 miles in 24 hours on Saturday, July 7, as a fundraising challenge for Golisano Children's Hospital at Strong. The big bike trip, dubbed "The Brothers K Challenge," drew \$3,500 in donations and inspired many. The funds raised will bring comfort to our area's ill and injured kids as they brave their own journeys on the road to recovery.



Charity-minded babysitter Maureen Dever of Fairport transformed her garage into the silver screen for a night in June; 21 local kids came out for a special showing of Disney's "High School Musical," raising \$150 for the children's hospital.







Research examines why children with asthma suffer despite treatment

Only 20 percent of children with persistent asthma have a level of control that is optimal, according to a Golisano Children's Hospital study published earlier this year in the journal of Ambulatory Pediatrics.

"That leaves almost 80 percent who are suffering more than they need to," said the study's lead author, Jill Halterman, M.D., M.P.H., associate professor of Pediatrics at Golisano Children's Hospital at Strong. "They may be experiencing unnecessary symptoms, missed school days, and restrictions on activity. That's a problem."

Halterman said the survey results are striking because, in contrast, current therapies are very effective. In fact, according to reports issued by the National Institutes of Health, if used consistently and in conjunction with action plans and avoidance of environmental triggers, the therapies should ideally make it possible for children to experience no symptoms of asthma, no limitation in function and no serious exacerbations.

"That's a lofty goal to dangle before patients," Halterman said. "We wanted a closer look into why so many children weren't reaping the benefits of today's therapeutic advances."

Current guidelines recommend that all children with persistent asthma half of the 9.4 percent of children who have any form of asthma—are prescribed daily anti-inflammatory medication. In spite of this, the most recent study revealed that 37 percent received no preventive medication, and perhaps more shockingly, 43 percent did receive medications, yet they were still troubled by poor symptom control (experiencing either persistent symptoms or frequent asthma attacks).

"This second group—the children



Jill Halterman, M.D., M.P.H.

who were experiencing poor symptom control despite the use of preventive medications—has received relatively little attention until now," Halterman said.

Especially interested in this disconnect, Halterman and her colleagues began to examine the data and found several potential reasons for it, including children not using the daily medication consistently, being exposed

to environmental triggers, such as secondhand smoke, or allergens like mold or pets, or simply not receiving adequate education about what to watch out for or what to do in the case of an attack.

Even more surprisingly, this incidence of poor control despite medication use was prevalent across the board, regardless of the child's age or the household's income level.

much work that needs to be done in making sure that children with asthma receive appropriate and effective care: it's more complex than one might think," Halterman said. "Asthma care involves coordination on everyone's part. Parents and patients need to report and track symptoms, relay this information to their doctor, use medications as prescribed, and steer

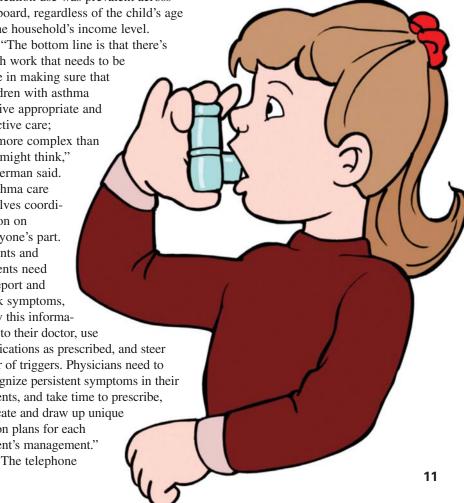
clear of triggers. Physicians need to recognize persistent symptoms in their patients, and take time to prescribe, educate and draw up unique

action plans for each patient's management."

The telephone

survey, which gathered parent-reported data on 975 children with persistent asthma from four states (Alabama, California, Illinois and Texas), also confirmed prior findings suggesting that poor and minority children receive inadequate asthma treatment. It also showed that spotty insurance coverage was associated with disrupting some children's access to needed medications.

The study was funded by grants from the Halcyon Hill Foundation and the Robert Wood Johnson Foundation's Generalist Physician Faculty Scholars Program.



Window shutting on tax-free IRA contribution to hospital



If you are older than 70 ½ and you've been thinking about making a donation to Golisano Children's Hospital at Strong, consider making a donation from your IRA—tax free—before Dec. 31.

The Pension Protection Act of 2006 allows individuals over the age of 70 ½ to make direct tax-free distributions to the University of Rochester from their IRAs without having to include those amounts in adjusted gross income. The transfer "counts" toward meeting the minimum required distribution for the calendar year and can be easily completed. While there is no charitable income tax deduction allowed because the gifted assets are tax deferred, many took advantage of this opportunity in 2006.

The process for donating is simple

- Contact the Office of Trusts and Estates to discuss your philanthropic interests and ensure that the University is prepared to receive your gift. Call (585) 275-7547 or (800) 635-4672.
- Call your advisor/representative at the bank/brokerage firm/financial
 institution that holds your IRA. Tell your representative that you wish
 to make a direct transfer from your IRA to the University of Rochester
 (Federal Tax ID# 16–0743209), pursuant to the Pension Protection Act
 of 2006.
- Ask your representative for details on how that transaction should be handled, according to that company's procedures.
- For payment by wire transfer to the University, ask your representative to call Debra Rossi, in the University's Office of Gift and Donor Records, at (585) 275-3903 or (866) 673-0181 for specific transfer instructions. Alternatively, contact Doreen Gross at (585) 275-6196 or (866) 673-0181.
- For payment by check, request that the check be made payable to the "University of Rochester," and indicate that it is "a qualified charitable distribution/normal distribution from the account of (Donor's Name)."
- Please mail a copy of your instruction letter to the University's Office of Trusts and Estates at 590 Mt. Hope Avenue, Rochester, NY 14620 or fax it to (585) 276-1986.

Some guidelines must be followed

- The gift cannot exceed \$100,000 per year.
- They must be made to a public charity (not a private foundation), and they cannot be to a supporting organization or a donor-advised fund.
- The gifts must be outright; for instance, they cannot be used to establish a gift annuity or fund a charitable remainder trust.
- They can be used to make a gift to the University of Rochester Annual Fund or to establish an endowed fund such as a scholarship.
- These tax-free distributions can be made only through Dec. 31, 2007 (unless extended by Congress).

Special Thanks

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

- Thank you to Caitlin Cucchiara, a senior at Webster Thomas High School who organized a dance concert benefit on May 10 that raised more than \$900 for the Child and Adolescent Eating Disorders Program at Golisano Children's Hospital.
- Kudos to The Monroe County Sheriff's Department, whose annual Miracle Ride on May 20 raised \$2,000 for children here.
- A special thank you to both Eliana
 Pudnicki and Kevin Blum, young people
 who each made donations to the hospital
 in lieu of receiving birthday gifts.
- Thanks to GBG Supply, Inc. for holding Grand Re-opening festivities that benefited Golisano Children's Hospital; the events raised \$1,985.
- New Breed Bike Club held their annual Poker Run on June 23 and raised \$500.
- Many thanks to the annual Greek Festival for choosing Golisano Children's Hospital as one of their beneficiaries again this year; the \$1,000 donation will help bring health to ill and injured kids.
- Hilton High School's Class of 2010 held a bake sale that raised \$140 for Golisano Children's Hospital.
- The Screaming Beavers Golf Tournament, held June 22, raised \$2,100 for our region's only children's hospital.
- Thank you to the Wayland-Cohocton School's fifth- and sixth-grade Life Skills class, whose bottle and can collection raised \$300 for Golisano Children's Hospital.

- Greece Olympia High School's baseball team held their annual 100 Inning Baseball game and raised \$170. Many thanks.
- Huge kudos to Webster Montessori School, along with other Montessori Schools in Rochester, who together organized a Penny Mile fundraiser that raised \$1,154.28.
- Thank you to Crane Elementary School whose students held an art and craft sale that raised \$1,003.50 for our children's hospital.
- Stephanie Sturm participated in a Work to Earn program at Thornell Road Elementary School in Pittsford and raised \$56 for the hospital.
- Hilton's Merton Williams Middle School's class of 2012 made a donation in the amount \$1,514.23 to Golisano Children's Hospital.
- Special thanks to Greece Olympia High School, whose Miracle Minute fundraiser (students ran around and grabbed as much spare change as they could in one minute) collected \$391.17 for Golisano Children's Hospital.
- Mint Jam, a local teen band, held a concert in June that raised \$157 for the children's hospital. Thank you.
- Amanda Padgham Photography gave a percentage of sales back to the hospital throughout the month of May, raising \$600.

- Kudos to Mommies for Miracles, who held their annual Summer Band Jam concert at High Fidelity on June 30 and raised over \$500 for Golisano Children's Hospital.
- The Brothers K Challenge (organized by brothers Patrick, Bryan and Mike Kent, together with their good friend Jon Lewis) rode 320 miles for 24 hours straight on July 7, raising more than \$3,500 for the children's hospital. Many thanks, Brothers K.
- The NICU Tile Painting event on April 29 drew more than 600 people and raised more than \$25,000 for the NICU; thanks to all who came out to celebrate.
- Many thanks to Mud About You, a paintyour-own-pottery studio in Penfield, whose grand opening weekend celebration held May 18 raised \$500 for the children's hospital.
- B&L Wholesale Supply held its 11th annual golf tournament at Shadow Lakes, Shadow Pines and Greystone golf clubs on June 27; the tournament raised an astounding \$104,041, which will support a major renovation and expansion of the hospital's pediatric treatment center.
- Memories for Megan, a cheerleading clinic/fundraiser organized by Webster Thomas High School senior Brittni Battaglia, was held July 7 at The Aquinas Institute. Admission prices doubled as donations to our region's only children's hospital.

Upcoming events

Sept. 14, 7th annual Frank Dianic Golf Tournament. Join us at LeRoy Country Club, 7759 E. Main Road, LeRoy, for a day of golf that advances pediatric cancer research underway at Golisano Children's Hospital at Strong. Cost for this four-man scramble style tournament is \$70 per person, which includes an 11 a.m. lunch buffet, plus a steak dinner. For more information, contact James Eby at (585) 726-4026 or James.D.Eby@Kodak.com, or visit www.gchas.org.

Sept. 28, 24th annual Flower Day

Last year, local community organizations and businesses banded together, selling carnations to raise more than \$5,000 for our region's only children's hospital! To make this year our best ever, we need your help; sign up to volunteer by calling Karen Eisenberg at (585) 273-1462.

Sept. 30, Penfield Challenge 5K Race Penfield Community Center, 1985 Baird Road,

Penfield Community Center, 1965 Baird Road, Penfield. Last year's racers garnered \$600 to help hospitalized kids. Entry fee is \$15 now through Sept. 24, and \$20 thereafter. To register or learn more, call Chris Bilow at (585) 340-8655.

Oct. 6, 2nd annual 12 Hours of Fitness

Iron Butterfly Health Club, 7493 Route 96, Victor. Come enjoy fitness, classes, refreshments and FUN! The gym will be closed off for this noon to midnight fundraiser (if that sounds daunting, just come for part of the time). Open to families of members and nonmembers alike, participants are asked to make a \$20 donation (kids 14 and younger, \$15) that benefits Golisano Children's Hospital; prize incentives will be awarded to those who raise the most funds above this minimum donation. For more information, call (585) 942-1540, or visit www.ironbutter-flyfitness.com or www.gchas.org.

Oct. 20, 20th Anniversary Golisano Children's Hospital Gala

Join nearly 1,000 attendees at the USAirports Hangar for our signature black-tie extravaganza. The evening brings cocktails, live and silent auctions, dinner and dancing (in case you missed it, turn to page 6 for a special article on the 20th anniversary festivities). For sponsorship, more information or to purchase your tickets (\$175 per person), please call Betsy Findlay or Angela Pullen at (585) 273-5948.



Pediatric Treatment

Center

Continued from cover an industrious fourth-grade artist and Yankees aficionado, who works on anything from origami to Sponge Bob sketches to football-themed latch hook rugs with "Patty the project lady," who, without fail, meets him with something new and fun to work on (besides his school lessons, which his teacher sends along, too, but are admittedly less fun).

In fact, Bryce would be the first to tell you that the hospital doesn't have to be a scary place. In a school essay, he wrote that most people he knows hate going to the hospital, "but that it is very fun once you get used to it."

Fun or not, however, the center's space is running tight. As more children depend on its services, more room is needed. Volume has doubled since the center first opened in 1996, and so, for shy teens who covet privacy, family members who want to keep their child company, and immune-compromised or contagious children who require protection or isolation in separate quarters, the three existing private rooms and four semi-private curtained-off quarters are inadequate.

"We're cramped," said Anne Swantz, R.N., the center's pediatric nurse manager. "On top of that, there are questions of



Bryce Czekanski (also on cover) laughs with treatment center nurse Cindy Annechino while receiving synthetic enzyme therapy.

how to help kids find the peace to rest, or nap, and of how we can offer better confidentiality for impromptu discussions between caregivers, patients and parents."

An expanded treatment center would help bring answers.

Expansion plans on the horizon

Thanks to a generous donation of their

annual golf tournament proceeds, the renovated center will be named in honor of B&L Wholesale Supply; work beginning in late winter to early spring next year will add seven more separate isolation rooms, bringing the total to 10 private spaces. Each will be furnished with televisions and top-quality infusion chairs that lie perfectly flat, doubling as beds for



Fun or not, the center's space is running tight. As more and more children depend on its services, more room is needed.

Volume has doubled since the center first opened in 1996.



Estrella Valle and social worker Eric Iglewski craft foam airplanes in the treatment center.

kids that need rest (four of the current chairs, one in each of the curtained-off spaces, recline only as far as a "V"a nuisance akin to napping in a car, versus your bed).

"You can't forget that some of these medicines make the kids feel sicker before they feel better; those children want a quiet space where they can rest. Other patients may be image-conscious kids or teens who have temporarily lost hair and don't exactly want to socialize," said Kathy Morris, R.N., the center's nurse leader.

"We've had people call in advance to ask for a private room, but warn them that we may have them move out if another child has greater medical need," Morris said. When that actually happens, it's difficult to break the news to a settled kid and family and ask them to surrender their space to another.

The expanded treatment center will also boast a new playroom area to house its air-hockey and craft tables, TVs, computers and play mats. In it, a sliding wall will allow for sectioning off part of the space, creating yet another private area for pre-procedure medical play (it's amazing how inserting an IV in a brave baby doll or stuffed animal first can jolt a child's courage, Morris said), or for

community groups, like CURE Childhood Cancer, which hold special coffee and chat hours to recharge (and caffeinate) parents while kids receive care.

Of course, all projects come with a price tag; at \$800,000, community support is the only way to make this private, family-friendly space a reality for kids like Bryce, and their relatives, who call it a second home one day a week, or more.

You can help

The good news is that the pump has been primed; B&L Wholesale Supply's generosity is joined by a gift from The Tim Milgate Charity Golf Tournament, which will name the toddler recovery room; Senator Jim Alesi has also pledged to help with the project.

Still, there's plenty of room for your donations. Kids need them. To help us build a more comfortable healing space for our region's children and their families, please call Development and Community Affairs at (585) 273-5948.

For those interested in making a more tangible donation, items, like IV poles, infusion chairs (like those mentioned in this article), playroom furniture, computers, blanket warmers and more are also available for purchase through the development office.

Golisano Children's Hospital **Development Office Staff**

Amy Chartrand

Gift Processing & Acknowledgement Coordinator

Karen Eisenberg

Associate Director, Leadership & Annual Giving

585-273-1462

Betsy Findlay

Associate Director, Special Events and Children's Miracle Network

585-273-5933

Heather Hare

Assistant Director, Public Relations

and Communications

585-273-2840

Becky Jones Public Relations Assistant

585-275-8490

Larry Kelly

Associate Director, Major Gifts

585-273-2690

Jennifer Montana

Administrative Assistant to Execuitve Director

585-273-5936

Angela Pullen

Program Assistant, Special Events and Children's Miracle Network

R. Scott Rasmussen

Assistant Vice President for Advancement 585-273-5932

Strong Kids News is published quarterly by the Department of Public Relations and Communications. Info.: 585-273-5948.

Editor Heather Hare Design Mitch Christensen





Non-profit US Postage PAID Permit No. 780 Rochester, NY

University of Rochester Office of Development and Community Affairs 300 East River Road PO Box 278996 Rochester, NY 14627–8996

Visit us at www.gchas.org

