Wilmots create “Crosby’s Fund” in memory of their beloved son

At just 13 months old, Crosby Wilmot was diagnosed with neuroblastoma, a rare cancer of the sympathetic nervous system that accounts for half of cancers diagnosed in infants. By the time of diagnosis, the disease has already spread throughout most children’s bodies. The same was true for Crosby, who bravely battled for 11 months. He passed away on August 4, 2011, just one month shy of his second birthday. Crosby’s spirit, however, continues to live on in many ways and has been honored by his family with the creation of Crosby’s Fund, a local philanthropic initiative, through the James P. Wilmot Cancer Center and Golisano Children’s Hospital at the University of Rochester Medical Center (URMC). It funds research in childhood cancer, with a focus on neuroblastoma.

“Crosby spent 85 percent of his illness in the hospital,” said Zoe Wilmot, Crosby’s mother. “We knew when he relapsed that we would want to one day help raise money for neuroblastoma research.”

In order to raise the significant level of funds that would be required to finance research, Crosby’s parents, Kevin and Zoe Wilmot, have made Crosby’s Fund a part of community events, including George Eastman House’s PhotoFinish 5k and Rochester’s Midtown Athletic Club’s Ultimate Xtreme Challenge. They also promote giving through social media sites.

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If you have been in or near the University of Rochester Medical Center lately, you could not help but have noticed that we have begun laying the literal foundation for our new Golisano Children’s Hospital at URMC.

And while we are excited and know that families from deeper within and further away from Rochester are benefitting from our services, affirming that the new hospital is of critical importance for Upstate New York, we are a bit anxious, too. Whenever there is a public fundraising campaign, there evolve lots of complicated formulas and catchy slogans that urge you to give and proclaim vast success. But our message, and the reasons for our angst, are very simple: we have 28 months until we open the building and $20 million to raise between now and then to meet our obligations to those who plan and build it. That’s roughly $1 million per month. Are our kids and families worth it? You bet they are. But we can no longer just cheer for them; we must all put our money where our mouths are.

The year 2012 saw some amazing things right here in Rochester. It saw Dr. Richard Bloom, a community pediatrician and member of the URMC clinical faculty, personally visit every other community pediatric practice office in Rochester to urge physician and staff participation in ROC the Day for Golisano Children’s Hospital. It saw the DiMarco family, Danny and Stenci Wegman, Manning & Napier, the Pike Company, Constellation Brands, Earthlink Business, and our own URMC Department of Surgery, make major commitments to Golisano Children’s Hospital through the Toast to Your Health Wine Auction (see story on page 4). It saw our Golisano Children’s Hospital nurses step up in a big way to help fund the Nursing Education Center in the new hospital.

But, it also saw weeks at a stretch when our beds, and those of our partner, Rochester General Hospital Department of Pediatrics, were full, and children stabilized in our Emergency Department had to wait there for a bed to free up, while others out in the community had to be routed to Emergency Departments in Buffalo or Syracuse. While the average age of the people in Upstate New York may be climbing, the technological and medical equipment needs of our community have also skyrocketed. And I pray every night that I won’t have to say to even one family, “Yes, this treatment is theoretically available, but not right now or not right here for your child.”

Watch us build and grow through our East and West webcams, which are accessible Monday through Friday at www.urmc.edu/childrens-hospital. Then, give as much as you can — in person, by mail, through our telethon and radiothon, or online at www.givetokids.urmc.edu. Our region’s children and families are counting on each and every one of you.

With thanks and all the very best wishes for a happy, productive, and, especially, healthy 2013.

Sincerely,

Nina F. Schor, M.D., Ph.D.
Pediatrician-in-chief,
Golisano Children’s Hospital,
William H. Eilinger Chair of Pediatrics
Continued from cover

Crosby’s Fund has raised a total of nearly $500,000, with $250,000 coming from the first year of participating in the PhotoFinish 5k in 2011. “It is amazing to see how many people get involved and simply want to help,” Zoe said.

Determined to make the largest impact with the funds raised, Crosby’s family met with many doctors, researchers, and administrators from Strong Memorial Hospital, the Wilmot Cancer Center, and Golisano Children’s Hospital at URMC. Their efforts led them to Nina Schor, M.D., Ph.D., William H. Eilinger Chair of Pediatrics and pediatrician-in-chief of Golisano Children’s Hospital. Schor is nationally known for her research in neuroblastoma and leads the Laboratory for Pre-clinical Neuropharmacology, a lab funded by the William H. Eilinger Endowment (and, now, the Crosby Wilmot Fund for Pediatric Cancer Research). The lab focuses particularly on research of drugs to target neuroblastoma cells and their resistance to chemotherapy.

“We were excited to find someone who was as excited about neuroblastoma research as we are,” Zoe said.

“Only 1 or 2 in 10,000 children develop cancer of any kind,” Schor said. “For this reason, when finances are so limited, funding for childhood cancer is very low compared to that of adult cancer and, therefore, depends more and more heavily on foundations, like Crosby’s Fund, that specifically fund childhood cancer research.”

With the support of Crosby’s Fund, Schor was able to recently expand her lab and hire Xingguo Li, Ph.D., as a research assistant professor. Li’s research is focused on the Sine Oculis Homeobox (SIX) family of proteins that play a large role in cell proliferation and growth in healthy cells and in many cancer cells, including neuroblastoma.

The researchers hope to use the proteins to differentiate enough between normal cells and tumor cells so that they could aim a drug to kill only tumor cells, without harming the normal cells.

In addition to supporting Li’s position, Crosby’s Fund also finances a seed grant focused on neuroblastoma. The grant was recently awarded to Mark Noble, Ph.D., professor of neurology, genetics, neurobiology, and anatomy and director of the University of Rochester Stem Cell and Regenerative Medicine Institute.

He is one of the pioneers of stem cell research and directs research on a number of topics, including cancer. With the award, Noble will develop new research that he hopes will prove competitive for future NIH funding. The seed grant started Jan. 1, with $50,000 of backing possible for the first year.

“We heard the message over and over again when we were in the hospital that there is not enough money for pediatric cancer research,” Zoe said. “We feel that we owe it to Crosby and all of the other kids that aren’t getting the research to make a difference for them and, hopefully, one day find a cure.”

To find out how you can support Crosby’s Fund, or how to create your own fund, please contact Scott Rasmussen, assistant VP for URMC Advancement, at (585) 273-5932.
Night of Wine and Winter Benefits Pediatric Surgery

The 400 guests at the 12th annual Toast to Your Health Fine Wine Auction were treated to an evening of incredible wine surrounded by a serene winter landscape in the country. The Nov. 12, 2012, black-tie event was hosted by the Wegmans and held at the Robert B. Wegman Conference Facility where the Wegmans’ organic barn was recreated in order to immerse guests in the country winter theme - without the freezing temperatures.

Every year, guests’ generosity supports crucial patient- and family-centered care and research initiatives at the University of Rochester Medical Center (URMC). With the help of wine aficionados and supporters of Golisano Children’s Hospital and URMC, this year’s sold-out auction, chaired by Marc D. Tommasi of Manning & Napier, impressively raised more than $850,000 in net proceeds for Pediatric Surgery at Golisano Children’s Hospital at URMC.

“It was a wonderful event. It was more like a fun night out than a fundraiser,” said John DiMarco II, whose family has had first-hand experience with the hospital’s pediatric surgeons. He appreciated the theme and decorations. “It was almost like you were in a Hollywood set as opposed to watching it.”

The John DiMarco family was the Fund In Need sponsor, having underwritten that portion of the evening with a $100,000 gift. DiMarco said it was important to his family to support the Pediatric Surgery program, which is one of the focus areas of the hospital’s current fundraising campaign.

Since the division’s founding in the mid-1990s, Golisano’s pediatric surgeons have saved, and changed, the lives of thousands of children. During the event, a video featured two of these children, James Daniels and Hailey Coniber, as a reminder of the remarkable work performed every day by Golisano Children’s Hospital’s surgeons. While the number of seriously ill children coming here for help is increasing, there is a critical shortage of pediatric surgeons nationwide.

Funds raised during the event will help ensure that Golisano Children’s Hospital can provide the highest quality and most innovative care for children and their families, promote excellence in the pediatric surgical field, and foster a vibrant and viable community of pediatric surgeons.

“Thanks to our generous hosts, Danny and Stency Wegman, and our devoted sponsors and guests, particularly the John L. DiMarco Family and Earthlink Business, our pediatric surgeons will be able to help the most ill children not only in Rochester, but from across the Northeast,” said Bradford C. Berk, M.D., Ph.D., CEO of the Medical Center.
Looking back at photos from Brenton Schiffer’s 3rd birthday party, Lynn Bickley said she wonders how she and her husband, Randy Schiffer, could have missed that their son was already sick.

They, along with many of the party guests, were physicians at the University of Rochester Medical Center at the time.

“He was so pale,” Lynn said.

David Korones, M.D., who was Brenton’s oncologist two decades ago when he was diagnosed with acute lymphoblastic leukemia (ALL), was quick to reassure Lynn on a recent visit. It would have been almost impossible for them to see the subtle changes in Brenton from day-to-day, Korones told her.

It is that quiet compassion and expert care that the family remembers and wants to honor with their recent gift of $300,000 aimed at enhancing research in hematopoietic diseases, including ALL. The gift is part of Golisano Children’s Hospital’s $100 million campaign that launched publicly in October 2011.

In addition to raising funds to build a new 245,000-square-foot children’s hospital, the campaign will enhance seven priority programs, one of which is childhood cancer.

Lynn, Randy and their son Lt. Sgt. Brenton B. Schiffer of the United States Navy returned to URMC recently to reminisce and make their gift.

“It’s very moving to be back here,” said Brenton, 25, who had traveled from San Diego where his ship, the USS Hampton, is stationed. “[Being a cancer survivor] isn’t something I think about often, but it was a big part of my childhood.”

The family’s connection to the Medical Center was deep before Brenton was diagnosed. Lynn first came to Rochester to study at the School of Medicine and Dentistry and Randy was an intern. They met, fell in love, married and had Brenton. By the time the family left in 1998, Randy was a professor of Neurology and Psychiatry and Lynn had graduated from medical school and progressed to an associate professor of Medicine.

But also by that time, Brenton had been diagnosed with cancer and had completed his treatments. The bonds between them and the children’s hospital’s providers were as deep as family, and it went both ways. In fact, Brenton’s oncologist, Korones, couldn’t pass up the chance to see him and his parents again, and one of Brenton’s nurses, Rose Holloway, and her husband, acting Chair of Neurology Robert Holloway, in addition to Pediatrics Chair Emerita Elizabeth McAnarney also came to see the trio.

Chief of Pediatric Hematology/Oncology Craig Mullen, M.D., Ph.D., told the family that their incredible gift would go toward ALL research and invited the family to come back to talk to the researchers using the gift and see the progress.

“We’re very grateful for your gift,” Mullen said.

Lynn recalled a very bad night with Brenton during inpatient treatment when it seemed as though an antibiotic treatment wasn’t working. It was a Saturday when Korones was not in the hospital, but he came in, changed Brenton’s antibiotics and made sure he was comfortable. Lynn remembers it as a turning point in a very difficult course of treatment.

“We’re just so grateful for all the care we had here.”
Elizabeth R. “Lissa” McAnarney, M.D., professor and chair emerita of Pediatrics at the University of Rochester Medical Center, will receive the 2013 John Howland Medal from the American Pediatric Society, the highest honor bestowed by the American Pediatric Society.

McAnarney earned the award because of her groundbreaking work helping to develop the board-certified subspecialty of Adolescent Medicine, her research examining the best ways to care for pregnant adolescents and her career-long commitment to education and mentorship. She will officially receive the Howland medal and an honorarium in May 2013 at the Pediatric Academic Society meeting in Washington, D.C.

“All over this country, you can see the indelible mark Dr. McAnarney has made on the field of Pediatrics, and more specifically, Adolescent Medicine,” said Mark Taubman, M.D., dean of the University of Rochester School of Medicine and Dentistry. “You can see it in the fact that Adolescent Medicine exists as a subspecialty. You can see it in the way we now treat pregnant adolescents, recognizing that although they are mothers, they still have many of the needs of childhood. And you can see it in the army of advocates her teaching and mentoring have created. We couldn’t be prouder of Dr. McAnarney and her incredible accomplishments.”

McAnarney was elected to the elite status of Fellow in the American Association for the Advancement of Science in 1998 and the Institute of Medicine in 2000. She served as president of the American Pediatric Society (2005–2006); the first woman chair of AMSPDC (American Medical School Pediatric Department Chairs (1999–2001), and the president of the Society for Adolescent Medicine (1983–1985). She was elected to the Society for Pediatric Research in 1981 and the American Pediatric Society in 1984.

McAnarney served on the initial Adolescent Medicine Sub-Board of the American Board of Pediatrics (1991–94), was the editor of the first Textbook of Adolescent Medicine (published in 1992) and served as the Charter Editor for the first Adolescent Medicine Sub-Board Certification Examination 1994. She was the only President of the Society for Adolescent Medicine (SAM) (now the Society for Adolescent Health and Medicine) to have served a two-year term, so that she could help the then-young organization create an identity separate from the American Academy of Pediatrics (AAP) while maintaining its strong ties.

In recognition of her leadership, she subsequently won the Adolescent Health Award from the AAP and the Outstanding Achievement Award in Adolescent Medicine from SAM.

“Clearly the most influential individual in the field of adolescent medicine over the past 40 years, Dr. McAnarney continues to provide guidance and direction to adolescent medicine as one of the most respected stakeholders in the field,” said Nina F. Schor, M.D., Ph.D., The William H. Eilinger Chair of Pediatrics and pediatrician-in-chief of Golisano Children’s Hospital. “At the same time, she has worked diligently to make Rochester a beacon for pediatric care in the region. Without the incredible foundation she built with our community’s support, we would not be building a new children’s hospital right now.”

McAnarney’s local service has been recognized by awards at the highest level, including a Women in Science Faculty Mentoring Award, Rochester Business Alliance Women’s Council Athena Award, and the Boys & Girls Club of Rochester Commitment to Community Award.

The University of Rochester Medical Center has a long history of outstanding pediatric education, research and care. In fact, McAnarney was mentored early in her career by two Howland recipients and University faculty, Robert J. Haggerty, M.D., and Gilbert B. Forbes, M.D.

McAnarney’s career-long focus on improving outcomes for teenage pregnancy fits well at the University of Rochester where the terms “community pediatrics” and “behavioral pediatrics,” and the biopsychosocial model were coined and developed. Her research changed the way providers cared for pregnant teens and their babies by helping to understand the unique needs of pregnant adolescents, which were not considered previously. Nor was teenage pregnancy framed as a pediatric dyad (mother and baby), each with specific and interrelated developmental needs. McAnarney was selected to serve on the Institute of Medicine Committee that wrote Weight Gain During Pregnancy: Reexamining the Guidelines, published in May 2009.

McAnarney was nominated for the award by Richard Kreipe, M.D., the Dr. Elizabeth R. McAnarney Professor in Pediatrics Funded by Roger & Carolyn Friedlander, whom McAnarney has mentored throughout his career as an adolescent medicine specialist and eating disorders expert.

“At all times she role-models the dignity and respect that she shows to all colleagues, patients and families in ways that are sometimes not demonstrated by high-powered leaders in academic pediatrics,” Kreipe said. “She embodies the University of Rochester motto, meliora, to do ever better.”

Faculty in the Department of Pediatrics have had a banner year of national honors. In addition to McAnarney’s award, Chin-To Fong, M.D., geneticist and associate professor of Pediatrics, received the 2012 AAMC Arnold P. Gold Foundation Humanism in Medicine Award; Richard Kreipe, M.D., professor of Pediatrics, was recognized for Outstanding Achievement in Adolescent Medicine from the Society for Adolescent Health and Medicine (SAHM); Thomas K. McInerny, M.D., was elected president of the American Academy of Pediatrics; and Nina F. Schor, M.D., Ph.D. was named president-elect of the Child Neurology Society.
NK grant takes successful school-based asthma program to next level

A new $3.6 million NIH grant will help pediatric researchers at Golisano Children’s Hospital at the University of Rochester Medical Center (URMC) connect their Rochester City School-based asthma management program to doctors’ offices.

This new program builds off a long-standing URMC collaboration with the city schools to improve asthma care, as well as Rochester’s successful school district-wide telemedicine program.

“We hope that by adding telemedicine visits for systematic asthma assessments, we will be able to improve asthma symptoms even more than with our previous work,” said Jill Haltermann, M.D., M.P.H., principal investigator of the study and associate chair of Clinical Research in the Department of Pediatrics at URMC. “And because we are building off two existing – and successful – programs, it has the potential to become a sustainable model other communities can use to improve care for children with chronic illnesses.”

Almost 7 million children in the U.S. have asthma. That’s more than 9 percent of children in the U.S., and as in many urban areas with high concentrations of poverty, the city of Rochester’s rate is more than 10 percent. Among U.S. children ages 5 to 17, the Centers for Disease Control and Prevention name asthma as the leading cause of school absences from a chronic illness, accounting for 14 million missed school days per year and more hospitalizations than any other childhood disease. Unfortunately, many children with asthma do not receive optimal preventive treatment, and suffer from illness that may be preventable.

“If this model of preventive care is successful and sustainable, we’d be able to make a huge impact on the health and, by extension, the educational experience, for high-risk children with asthma,” Haltermann said.

The School-Based Asthma Therapy trial that the University of Rochester launched in 2006 partnered with the Rochester City School District and school nurses to provide preventive asthma medications in school to children with persistent asthma. This ensures that these children get the medicine that they need and are taking it properly, in order to avoid asthma symptoms. The trial improved children’s symptoms, reduced absences due to asthma, and reduced the need for urgent visits. The pediatric telemedicine program uses specialized equipment and trained health care assistants to gather health information and sends this information, through the internet, to a health care provider. Telemedicine has expanded to include every school in the Rochester City School District and has shown a 63 percent reduction in absences due to illness. It allows children who are in school and ill to be seen by a provider who can often diagnose and begin treatment for common childhood illnesses — without the child ever leaving school or the parent leaving work.

This new trial, which started enrolling students in the fall, will allow children with asthma in the intervention group to not only continue to receive their preventive treatments at school, but it will also connect them with their health care provider through the telemedicine program. Ongoing contact with a health care provider will help ensure that guideline-based asthma medications are prescribed and adjusted as needed in follow-up visits. The control group will receive their usual asthma treatment from their health care provider.

“We hope this will streamline care for children with this common disease and improve their symptoms. Further, if it is successful, this model of care could be implemented in other communities around the country,” Haltermann said.
Mike Fess’ passion for art began at a young age. When learning to write his name, Mike focused on the horizontal and vertical structure of each letter and began forming them into blocks.

“It was like he was putting together a puzzle,” said Tom Fess, Mike’s dad. This was the first realization of Mike’s special gift and what would soon grow into a passion for drawing animals and sharing his work with people throughout the Rochester community. Diagnosed with autism at 4 years old, Mike was enrolled at Stepping Stones Learning Center, a preschool that provides services for children birth to 21 years of age with and without special needs. Thanks to hard work by Mike and his family, and with the help of Stephen Sulkes, M.D., neurodevelopmental and behavioral pediatrician, and Jonathan Mink, M.D., chief of Child Neurology, at Golisano Children’s Hospital at the University of Rochester Medical Center (URMC), Mike has advanced and is doing well today.

Mike can finish most of his detailed illustrations within three minutes. He enjoys drawing a variety of animals, from dinosaurs to any breed of dog. “When I was a kid, I looked at picture books and TV shows that mostly featured animals and I wanted to draw the animals by studying their design,” Mike said. “Through the creative process, I got better over time.”

Mike was recognized for his art work in sixth grade when the animal menagerie he created was selected as art of the year out of a district-wide search. “It still hangs in the hallway at the Iroquois Middle School,” Mike said.

After graduating from West Irondequoit High School, Mike attended a 2-year transition program that was run by the school district, BOCES, and St. John Fisher College. Throughout the two years, Mike learned various life skills, such as how to do laundry, how to use debit cards, and how to fill out a job application. He also spent time learning how to be his own advocate.

As prevalence rates have risen to 1 in 88 children (1 in 54 boys), Golisano Children’s Hospital has expanded its clinical, research and educational programs. In fact, the Autism Spectrum Disorder program is one of the seven priority pediatric programs being enhanced with Golisano Children’s Hospital’s $100 million campaign, which launched publicly in October 2011. In addition, the hospital is a very active member of the Autism Treatment Network, a group of North American hospitals working together to establish a standard of care for children and youth with autism.

Now 21-years-old, Mike has shared his artistic talents with the community in a variety of ways. Mike has worked with St. John Fisher College in illustrating bookmarks and helping create an animal mural for preschoolers at School 16 in the Rochester City School District. He has designed t-shirts for autism walks and recently drew pictures of animals for guests at Seneca Park Zoo’s Zoolfest.

Mike recently added a new accomplishment to his list of drawing endeavors. He started drawing for an e-card program called Drawn to Give. The program is a platform for organizations, such as Golisano Children’s Hospital, to raise funds through the sale of cause-specific electronic greeting cards.

Mike has contributed a variety of fun drawings to the Drawn to Give page. “I think that my drawings should definitely be perfect gifts for the children in the hospital, so they can feel happy and start feeling much better,” Mike said. “I’m honored to share my love for art and to give some of my art to all the children in the hospital.”

Help share Mike’s love for art and donate to Golisano Children’s Hospital while doing so. Don’t want to send a traditional card? Thinking of a creative way to send greetings to your business clients?

Visit https://drawntogive.com/golisano-childrens-hospital to find a card, or two, and make a difference!
For the past 16 years, the University of Rochester’s Reaching Out to Kids (ROK) program has paired medical students with pediatric patients at Golisano Children’s Hospital, fostering long-term friendships and community partnerships.

The mentorship program matches patients who have chronic medical conditions with medical students – their “buddies.” The program allows the buddies to learn about each other and explore areas in the community that the patients may otherwise not see.

ROK was organized in 1996 by second-year medical students under the guidance of the University of Rochester’s School of Medicine and Dentistry’s community service program, Students of Rochester Outreach (SRO).

This year, ROK is being coordinated by two second-year medical students – Ben Cocanougher and Rachel Cameron. While in the program, the medical students’ main role is to act as a friend or buddy to the patients and not a medical provider. It is recommended that buddies spend time together at least once every two weeks or five hours a month.

“As a medical student, it is easy to get caught up trying to memorize the thousands of pages of material we need to learn about disease and, in the meantime, lose focus on the patient,” said Cocanougher. “This program, however, has allowed me to slow down and get to know patients, their families, and their disease, on a more personal level.”

Members of ROK participate in a variety of activities with their buddies, such as going bowling, getting help with homework, and exploring the Rochester community. Many community organizations, including the Seneca Park Zoo, Memorial Art Gallery, and Rochester Museum and Science Center, have opened their doors to ROK members, free of charge.

“Our community partners have been generous enough to sponsor ROK members’ admission fees, which is a great benefit for many of our families with more limited means,” said Thilan Wijesekera, fourth-year medical student and former ROK coordinator. “Families who wouldn’t otherwise get the chance to appreciate Rochester can share in its culturally enriching opportunities with their buddy, further strengthening their unique bond.”

After noticing that Michael, Wijesekera’s 13-year-old buddy of three years, was sketching a variety of detailed images in his notepad, he thought it would be a great idea to expose him to different genres of art. Wijesekera recently brought Michael to the Memorial Art Gallery, a place his buddy had never visited, despite it being across the street from his performing arts school.

“After previously discovering graphite and watercolors, Michael and I were able to share in oil paintings, metallic conglomerations, optical illusions, and even ancient mummies,” Wijesekera said. “Michael left the gallery excited – chattering away about the interesting artwork we’d seen and different types of endeavors he might want to pursue in the future.”

“A large part of ROK is about helping to open up the world of fun and adventure these families can rarely afford,” said O.J. Sahler, M.D., professor of pediatrics and Reaching Out to Kids faculty mentor. “We hear a lot about people having to make the hard choice between buying their medicine or paying their rent and, with support from community organizations, no choice has to be made between buying medicine or going to the zoo or museum.”

“Current ROK patients range in age from 5 to 18. Golisano Children’s Hospital staff, including social workers, nurses, and Child Life specialists, choose patient-participants whose parents have expressed interest in Reaching Out to Kids. Patients can come from any pediatric clinic, including Hematology/Oncology, Pulmonary, Endocrine, Renal, Developmental Disorders, etc. Although all patients in the program have chronic medical conditions, some students have been paired with patients who have a terminal illness. Four patients have passed away, causing some of the students to take a leave of absence to help the families make arrangements.

ROK has a total of 21 active matches and continues to generate creative programs for participants, including an anticipated tennis clinic for the spring of 2013. “We are eager to see Reaching Out to Kids continue to expand its members and community partnerships and we hope the community will see the students’ work as worthy of its support,” Sahler said. If your community organization has an idea for an event, or would like to open its doors to members of Reaching Out to Kids, please contact Thilan Wijesekera at thilan_wijesekera@umro.rochester.edu or (484) 574-0124.
Rainbow Classic “shoots and scores” for area kids

For the 12th consecutive year, the Pittsford Mendon and Pittsford Sutherland boys’ and girls’ varsity basketball teams faced each other in a sold-out, tremendously spirited, and extremely close Rainbow Classic. On the evening of Dec. 21, community members filled the University of Rochester’s Louis A. Alexander Palestra bleachers for the long-established competition. The rivals came together to support and raise money for Golisano Children’s Hospital at the University of Rochester Medical Center (URMC). This year, both Pittsford Mendon teams ended the night as champions.

In 2001, Pittsford residents Brian and Barb Pasley created the Rainbow Classic in memory of their daughter, Katelyn, who was treated at Golisano Children’s Hospital. The Pasleys were soon joined by their friends Steve and Kim McCluski who lost their son Ryan. In honor of their children, the two families have raised funds that have supported many Golisano Children’s Hospital patients and programs, totaling nearly $300,000 over the last 12 years.

For the second consecutive year, funds from the Rainbow Classic were donated to the children’s hospital’s Child and Adolescent Eating Disorder program.

“The Rainbow Classic is a wonderful way for the community to gather and support the children’s hospital and one of our premier programs,” said Richard Kreipe, M.D., the Dr. Elizabeth R. McAnarney Professor in Pediatrics Funded by Roger and Carolyn Friedlander and director of the Child and Adolescent Eating Disorder program. “The successful basketball event helps us continue to help young people and their families move toward a healthy adulthood.”

Kreipe spoke at the event on behalf of the children’s hospital and was presented with a $26,000 check for the eating disorder program. Pittsford Mendon senior and varsity cheerleader Anna Grace Kelly was also recognized for selling the most advertising space in game programs. The junior varsity and varsity cheerleaders raised $8,200 for Golisano Children’s Hospital. Kelly sold $2,465 worth of ads, representing 31 of the 92 featured local merchants.

Money raised by the Rainbow Classic will benefit the program in a number of ways, including providing researchers and clinicians the resources to better understand the roots of the disorder, training future health care experts, and developing more effective methods of prevention and treatment.

“We feel strongly about supporting the program because it is important to recognize challenges associated with an eating disorder and how it impacts people in our community and the Rochester region, as well as nationally,” Brian Pasley said.

Millions of young people across the country struggle with eating disorders, such as anorexia nervosa and bulimia nervosa. In many cases, these diseases become life-threatening. Fortunately, more than 80 percent of patients treated for an eating disorder at Golisano Children’s Hospital attain a healthy eating pattern and body weight that enables them to go on to live healthy, productive lives.

The 25-year-old program, located within the Division of Adolescent Medicine, has been recognized as a designated referral site for the New York State Comprehensive Care Center for Eating Disorders of Western New York. The particular model of the program is viewed as the cornerstone for a statewide, integrated, coordinated system of care serving children, adolescents, and young adults from across New York State and has developed treatment guidelines with support from the American Psychiatric Association and the Society for Adolescent Medicine.

Designed to evaluate and treat individuals who have diagnosed eating disorders and to aid those who have been exhibiting signs and symptoms, the program is made up of clinicians and researchers who specialize in adolescent medicine, psychiatry and psychology, nutrition, nursing, social work, and teen life and offers both inpatient and outpatient services. The program continues to develop and draw upon the most up-to-date and proven methods of treatment and serves as one of seven priority programs of Golisano Children’s Hospital’s $100 million capital campaign.

To donate to the Child and Adolescent Eating Disorder program, please contact Scott Rasmussen, assistant VP for URMC Advancement, at (585) 273-5932.

To view more pictures of the Rainbow Classic, please visit our online newsletter, Strong Kids, at www.givetokids.urmc.edu/strongkids.
Kiwanis pledges NICU room in honor of “Amazing Grace”

At only 16 months old, “Amazing Grace” Esposito, daughter of Irondequoit Kiwanis President Vinnie Esposito and 13WHAM Anchor Jennifer Johnson, touched so many lives.

A 2012 Golisano Children’s Hospital Miracle Kid, Grace was born on Sept. 19, 2011, with a severe congenital diaphragmatic hernia (CDH), a hole in the diaphragm that separates the organs of the belly from the chest.

Grace had virtually no diaphragm on the left side. As she formed, it allowed her intestines, stomach and part of her liver to move up and push her heart out of place. It also left very little room for her lungs to form and grow.

Grace pushed through and stayed strong for months to come, inspiring her family, providers, the community, and other CDH families. Sadly, after a surgery to repair a new hole that formed in her diaphragm, “Amazing Grace” passed away on February 16, 2013.

With the help of Rochester-area Kiwanis Clubs and 13WHAM, Grace’s parents started a fundraising campaign in her honor a few months before her last surgery. Even though Grace has died, Vinnie and Jennifer continue to feel inspired to give back to the hospital and its providers because of the time they were able to spend with Grace, who they described as being born “not equipped for this world.”

“We want to honor them and thank them by helping them build a new hospital where they can work so hard on more miracles. We started this fundraising effort months ago and feel more passionate about it now than ever;” they said days after Grace died.

As Children’s Miracle Network Hospitals sponsors, Rochester-area Kiwanis Clubs have always been supporters of Golisano Children’s Hospital at the University of Rochester Medical Center. The 18 Kiwanis Clubs of the Genesee Division stepped up in an incredible and very personal way by pledging to raise $100,000 to name a room in the new hospital in honor of “Amazing Grace.”

The Kiwanis Clubs are channeling the strength Grace had, and the inspiration she was, as they pull out all the stops to be as creative as possible in raising the funds to build a Neonatal Intensive Care Unit (NICU) room in the new $145-million Golisano Children’s Hospital. The new hospital will be 245,000 square feet and includes a greatly expanded Gosnell Neonatal Intensive Care Unit — with private rooms — on the third floor.

Jennifer and Vinnie have become some of the hospital’s biggest advocates and are carrying that forward into their new role as co-chairs of the Kiwanis campaign. The campaign was announced at an October 2012 event at the Seneca Park Zoo when Vinnie was installed as the president of the Irondequoit Kiwanis Club and when Grace celebrated her first birthday.

That event, alone, raised almost $4,000. The 13WHAM Spectacle of Lights at Camp Eastman was a winter festival in Irondequoit that raised another $20,000.

“It was enormously successful for a first-time event,” Vinnie said. “We learned a lot and so many people told us they really appreciated who the beneficiary of the event was, Golisano Children’s Hospital.”

Along with additional Kiwanis gifts, Vinnie said the clubs raised a quarter of the $100,000 goal in its first four months. Since the passing of Grace, a spirited and beautiful little girl whose hair was barely long enough for the pigtails she wore the morning of her last surgery, the community has embraced Vinnie and Jennifer’s wish and donated thousands more in her honor.

To donate to the Genesee Division Kiwanis Club NICU room in honor of Grace Esposito, please go to www.givetokids.urmc.edu/kiwanis.
Robert G. Jacobson
Long-time board member and dedicated advocate for kids, passes

One of Golisano Children’s Hospital’s longest-serving board members passed away on Feb. 5. Robert G. Jacobson, who was known as “Bob J” around the halls of the hospital for more than two decades, was often the first to raise his hand when the hospital needed a volunteer.

“If it involved (Golisano Children’s Hospital), Bob was there championing our mission,” said Nina F. Schor, M.D., Ph.D., William H. Eilinger Chair of Pediatrics and pediatrician-in-chief of Golisano Children’s Hospital. “Our hearts go out to his wife, Pat, their two daughters, and their grandchildren. We will miss Bob greatly.”

Mr. Jacobson was vice-chair of the Golisano Children’s Hospital fundraising board, a member of the board’s executive committee and co-chairman of the Community Fundraising Committee. He was the director of Human Resources for B&L Wholesale Supply, Inc., one of the hospital’s most committed corporate supporters.

B&L, which distributes residential roofing, siding, windows, doors, decking, veneer stone and commercial roofing, and has the largest inventory and delivery fleet in the Finger Lakes region, has a long history of giving to Golisano Children’s Hospital. B&L’s involvement with the hospital dates back to its first Charity Golf Tournament in 1995, when it raised $3,000. To date, the company has raised more than $1 million and recently committed to raising $500,000 to name the new hospital’s PET/MRI Suite. Mr. Jacobson has played a large role in facilitating those gifts from B&L owners Don Tomeny, Art Finocchario, and Bob Latour.

“We owe an incredible debt of gratitude to Bob, for his years of service to the board and the level of dedication he had for our region’s children,” said Scott Rasmussen, senior assistant vice president of Advancement.

Mr. Jacobson served on the board through the most transformative times of the children’s hospital. When he first joined the board in 1990, the children’s hospital was still a center. In the years since, the hospital has added a robust outpatient program and it became a hospital-within-a-hospital. In 2002, with a $14 million commitment from B. Thomas Golisano, the hospital became Golisano Children’s Hospital. And Mr. Jacobson recently helped the hospital launch a $100 million campaign to build a new hospital on Crittenden Boulevard.

Mr. Jacobson had already served more than a decade on the board when current-chair Mark Siewert joined. Siewert’s son was in the Pediatric Intensive Care Unit when he attended his first meeting, which also happened to be a night when a photographer was there to take portraits of all the board members. Siewert was, understandably, not dressed for the occasion. Mr. Jacobson noticed and came to the rescue, taking off his sport coat and lending it to Siewert.

“That was the kind of guy Bob was. He would, literally, give you the shirt off his back. Or, in this case, the sport coat,” Siewert said.

Mr. Jacobson is survived by his wife, Patricia; daughters, Christa (Josh) Gates, Lisa (Kevin) Harrington; 6 grandchildren, John, Hannah, Ryan, Ella, Payton and Avery; sister and brothers, Barbara, Glenn and William. Gifts in Mr. Jacobson’s memory can be directed to Golisano Children’s Hospital, 300 East River Rd., P.O. 278996, Rochester, NY, 14627.
With new toys consistently hitting store shelves, there is a lot to consider when picking the perfect gift for a child. While young ones may be focused on receiving the coolest new gadgets, buyers need to pay careful attention to product warning labels regarding what is age appropriate. Cases of children swallowing toys are becoming more prevalent in emergency rooms and could lead to emergency surgery, and possible long-term hospitalization.

The risk of ingestion is especially worrisome with magnets, like those used in building sets and other toys. The popular magnetic Buckey-balls and Buckycubes, marketed as desk toys, were discontinued late last year because of the threat they posed to children when swallowed. “When multiple high-powered magnets are swallowed, their attraction is so strong they can tear through internal walls, creating holes in the intestines and causing life threatening situations that require surgery,” said Vibha Sood, M.D., pediatric gastroenterology fellow at Golisano Children’s Hospital at University of Rochester Medical Center (URMC). “Any exposure to a magnetic object should be strongly cautioned and avoided.”

The North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN) has stated that warning labels are not enough to prevent children from ingesting magnetic toys. The group released results of a recent survey of more than 1,700 doctors, who reported at least 480 toy magnet ingestions in the past decade, with 204 occurring in the past year. The survey also reported that 50.4 percent of patients are between the ages of 1 and 6, while 33.6 percent are 6 to 12 years old.

Labels that distinguish what is age appropriate are repeatedly disregarded and individuals are often too young or embarrassed to convey what they have swallowed.

As toys become increasingly complex, Anne Brayer, M.D., pediatrician in Emergency Medicine at URMC and director of Injury Free Coalition for Kids of Rochester, offers tips on how to prevent ingestion of toy parts and overall advice as to what consumers should be paying attention to while purchasing safe items for children.

• **Read the Labels** — Always check labels to make sure a toy is right for a child’s age. Consider the child’s temperament, habits, and behavior when picking up a new toy. Use the age and safety recommendations, created by national standards, as a guide. Even if you feel a child can developmentally handle a toy labeled as being appropriate for older individuals, stay on the safe side and do not purchase it.

• **Avoid Toys with Small, Detachable Parts** — Toy parts should be larger than the child’s mouth. Pay attention to the durability of the toy and that it has tightly secured parts. Parents should purchase a Choke Tube Tester, or use the top of a gallon-size milk jug, to examine the safety level of the toy. If a toy can fit in the opening of the tube, or jug, it is a choking hazard for children 3 years of age or younger.

• **Know the Child’s Surroundings** — Consider the ages of all who may have access to the toy. An item that is meant for an older child could get in the hands of younger family members or neighbors and become a choking hazard.

• **Stay Informed and Aware** — After purchasing toys, regularly survey the child’s play area for any small pieces, missing parts or dislodged magnets. Be sure that the child knows how to play with the toy safely.

“Being proactive about toy safety can help prevent emergency situations before it may be too late,” said Brayer.

Check government sites on the Internet, such as the U.S. Consumer Product Safety Commission and www.recalls.gov, to see if the toy being purchased has been recalled.
Ugly Disco celebrates groovy decade of support for kids

Dressed in vibrant bell-bottoms, afros, pink wigs, and platform shoes, Ugly Disco attendees have a history of going all-out to raise money for Golisano Children’s Hospital at the University of Rochester Medical Center (URMC). This year’s 10th anniversary party, held on March 9, was groovin’ from 8 p.m. to 1 a.m., with live tunes from the Atlas Band, The Skycoasters, Fever – The Wrath of Polyester, and a number of DJ-spun hits. Other attractions included Twister, performances by The Village Guys, an appearance by a celebrity guest, and more.

Over the past 10 years, the Ugly Disco has raised thousands of dollars for the children’s hospital. Last year alone, the event raised $28,500 in support of the Pediatric Supportive Care Program and the Bright Eyes Fund, both run by David Korones, M.D., pediatric oncologist at Golisano Children’s Hospital. This year’s event continued that incredible support. Designed to help patients’ pain and symptom management, the Pediatric Supportive Care program provides patient-and family-centered care for those experiencing serious illness. Also focused on improving patient care, the Bright Eyes Pediatric Brain Tumor Research Fund was established to help fund educational and research efforts, and to enhance diagnostic and treatment options for patients with cancerous brain tumors. Both programs are part of Golisano Children’s Hospital’s current $100 million capital campaign.

The Ugly Disco team has also committed a generous $100,000 for the future children’s hospital. $20,000 of the funds raised at this year’s event will go toward fulfilling the pledge, with the remaining resources supporting Korones’ programs.

“Our whole committee enjoys raising money for such a great cause,” said Alan Wood, RE/MAX Plus partner and Ugly Disco co-founder. “The key is – we all have an absolute blast with the planning, promoting, and running of the event.”

Having started out with about 800 attendees, the event now attracts nearly 4,000 people, all of which had Saturday night fever at this popular discothèque.

Upcoming Community Events

- **Children’s Miracle Network Hospitals Spring Balloon Campaign** – Please visit the following CMNH partners area locations and buy a balloon to support a good cause:
  - Sunoco/APlus: March 1 to 31
  - Rite Aid: March 24 to May 1
  - Walmart and Sam’s Club: May 7 to June 21
  - Ollie’s Bargain Outlet: April 1 to 30
- **April 19, SMILE Spaghetti Dinner**, St. John’s Church of Rochester, 8 Wickford Way, Fairport, 5:30 to 7:30 p.m. Benefits the Cleft and Craniofacial Center at Golisano Children’s Hospital.
- **April 20, Talent for Tots & Teens Fundraiser**, Alumni & Advancement Center Auditorium, 300 E. River Road. Contact Ms. Ida Wheeler for additional details at iwheeler@alumni.rochester.edu.
- **May 24 to 27, Roc City Rib Fest**, Lake Ontario Beach Park. The barbecue and music festival hosts more than 100 professional barbequers from across the country who compete to win a portion of more than $22,000 in prizes. Learn more at www.roccityribfest.com.
- **May 31 & June 2, Dance Strong Competition**, Alumni & Advancement Center Auditorium, 300 E. River Road. Contact Ms. Ida Wheeler for additional details at iwheeler@alumni.rochester.edu.
- **June 1, Stroll for Strong Kids Walk & 5K Run**, Genesee Valley Park. On-site registration for the 5K Run is 7:45 to 8:15 a.m., with an 8:30 a.m. kickoff. Walkers can register starting at 8 a.m., with a walk time of 10:30 a.m. The event will continue with family fun and entertainment until 1 p.m.
- **June 2, News 10 NBC Children’s Miracle Network Hospitals Telethon**, WHEC-TV, 10 a.m. to 1 p.m. and 6:30 to 11:30 p.m. Every year, children and families touched by Golisano Children’s Hospital come together to share their remarkable stories at the annual Children’s Miracle Network Hospitals Telethon, presented by Tops Friendly Markets and hosted by News 10 NBC. Cheer on the hospital’s biggest supporters and miraculous children!
- **June 8, 10th Annual Team All-Gaiters Clambake**, Fireman Training Grounds, Honeoye Falls, NY. For more details, contact Jackie Klube at (585)704-4124.
- **July 29, Cheshire A/V Golf Classic**, Deerfield Country Club, Contact Justin Cheshire at justin@cheshireav.com for info.

SAVETHE DATES

- **Aug. 26, Golisano Children’s Hospital Golf Classic**
- **Oct. 19, Golisano Children’s Hospital Gala**, Contact Betsy Findlay at (585) 273-5933 for more information.

Visit our calendar on the web for more details.
Many thanks to these and all generous supporters and event organizers that benefit Golisano Children's Hospital!

• A heartfelt thank you to Heather Amici-VanDeMark and Joyce Amici for their continued support of Golisano Children’s Hospital through their donation from Flowers for Julia. Thanks to their tremendous efforts to help the kids at the hospital, this year’s promotion raised $3,000 – we can’t thank you enough!

• Thank you to the Kleinhans family for holding the 1st annual Kleinhans Kids Golf Tournament, which raised $5,000 for the Division of Pediatric Genetics at the Children’s Hospital.

• We appreciate the efforts of the Yazwinski and Passero families, who held the 100-Inning Festival of Softball again this year. The event raised $12,280 to assist the Children’s Heart Center in serving our young patients and families.

• Team Ali-Gaiters held the inaugural Running to Remember 5K in honor of Dante Mastrimone and Lizzy Spencer. This great race and activity-filled event generated $4,167 toward the team’s goal of $100,000 for naming a room in the new Golisano Children’s Hospital building. Thanks so much!

• Special thanks to Dr. Richard Bloom from Fairport Pediatrics, and all of our pediatricians and pediatric offices throughout the community for their efforts in promoting ROC the Day. Friends of Golisano Children’s Hospital donated a total of $7,600 to support our patients this year – thank you all!

• We can’t thank our autumn golf tournament friends enough for their support – Kittelberger Florist donated $3,500 from their tournament, the WNY Optics/Photonics generated an incredible total of $22,200 from their event, and the BUDDA Association made a nice gift of $1,400 from their annual golf outing. Thanks to everyone for your tremendous support!

• Thanks to the Kids Miracle Making Club for holding a Superhero fundraiser that generated $801 for the children’s hospital – we appreciate all you continue to do!

• Deb Moyer and Jennifer Brush hosted the first-ever TNT Explosion event, which raised nearly $17,000 to help build our new GCH building. Thank you for the time and energy that went into this incredibly fun event!

• The Raytec Group held their annual Carnival of Caring, and the fun-filled week of entertaining activities generated $1,634 to help the kids of our region. Many thanks for this terrific support!

• We appreciate everyone that made this year’s 12th annual Rainbow Classic an enormous success. The Pittsford Schools raised $26,000 from this year’s annual basketball event, which will help support the Child and Adolescent Eating Disorders program at the children’s hospital. Thanks for all you continue to do!

• The Genesee Valley Hunt Races helped to raise $5,000 for the patients and families we serve at the hospital. Many thanks to Austin Wadsworth, Stephanie VonBacho, and everyone involved in this incredible annual event!

• Patrick Booher and Graham Lodge organized the Cruise for a Cause, which benefits Golisano Children’s Hospital each year. This year’s cruise generated $1,295 for the hospital. We truly appreciate the support!

• Held the week of November 12th, the Rochester-area Tim Horton’s once again provided lots of smiles to our community through their very delicious Smile Cookie promotion. The promotion raised $4,500 for our patients. We thank the owners for their very generous support of Golisano Children’s Hospital.

• Thanks so much to the Maloof Family for holding their fundraising event for the hospital this year. The event raised a greatly appreciated $1,050.

• A very special thanks to Jake Wainwright for requesting that donations be made to the children’s hospital in lieu of gifts for his 15th birthday. We can’t thank you enough for your incredible generosity, Jake!

• Thank you to Ms. Ida Wheeler and everyone who helped make this year’s Talent for Tots & Teens Holiday Showcase a reality. This longstanding event raised $3,865 to help the Pediatric Intensive Care Unit at the hospital.

• Odds on Olivia helped to raise $2,700 in honor of Olivia Grace, who is a NICU graduate. Thanks so much for your efforts to support future NICU patients and their families!

• Our appreciation goes to Rene Stewart and Debbie Recchia from Snips Salon for all they did to put together the Beauty at Your Best Winterfest, which raised $964 for the children’s hospital.

• We’d like to thank our friends at Fleming Point in Greece for their incredible support of the kids at the hospital. They raised $507 from a Clambake and Dance Fundraiser to benefit the children and families we serve.