

GOLISANO CHILDREN'S HOSPITAL AT THE UNIVERSITY OF ROCHESTER MEDICAL CENTER

STRONG KIDS NEWS



2012 VOL. IV



Tom Golisano applauds the efforts of former patients at the Golisano Children's Hospital groundbreaking.

— CAMPAIGN UPDATE —

Breaking ground on a new era of children's health for our region

After five years of planning, including substantial input from children and families, the University of Rochester made history Sept. 10 as it broke ground on its largest capital project ever – the new Golisano Children's Hospital.

University President Joel Seligman, University of Rochester Medical Center CEO Bradford C. Berk, M.D., Ph.D., and Paychex founder and hospital namesake B. Thomas Golisano took part in the groundbreaking ceremony, along with several children who have benefitted from the hospital's care.

"This is a proud day, when we can start building a world-class children's

hospital for our region's children and families," Seligman said during the ceremony. "We have already been delivering outstanding patient care, and this new facility is going to make Rochester a destination for pediatric care across upstate New York and the nation."

The new \$145 million building, to be located on Crittenden Boulevard and attached to the Medical Center and Strong Memorial Hospital, will have eight floors and approximately 245,000 square feet of space dedicated to children and their families. The new hospital features 52 private, patient rooms, a greatly expanded Neonatal Intensive Care Unit,

Continued on page 5

Gosnells give NICU naming gift

| New building's interior design revealed

| Rare genetic disease too common for one family



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DEAR FRIENDS —

What an incredible whirlwind this past summer has been! Together, we have made our way through the external structure and the layout and the interior decoration plans for our new Golisano Children's Hospital at URMC.

We have begun to orchestrate how water, heat, air conditioning, electricity, medical gases, people and everything else everyone needs get from where they are now to where our new hospital will be safely, economically, and efficiently. Now what?

Now comes what may be our only outstanding chance to optimize the most important part of a children's hospital enterprise – the seamless interactions and innovative practices of the people who make it what it is. In the coming months, teams of us – physicians, nurses, therapists, social workers, dieticians, child life specialists, parents, patients – will be thinking through every aspect of the experiences of patients, families, and employees within our hospital. From things as simple as helping a family feel welcome and secure in their path as they go from the lobby to the admitting office to their child's hospital room to things as complex as easing the way for a blind father to visit, first his wife, and then his new baby in the NICU, will all be "walked through" a dozen times in the minds of our different constituencies to optimize them. It will make no difference how beautiful our new hospital is if it takes navigating a circuitous route to take patient meals from the Strong Memorial Hospital kitchen to the Golisano Children's Hospital patient rooms.

If keeping our floors and walls and bathrooms clean requires different skills or schedules than is the case for Strong, it is up to us to identify ahead of time those employees who choose to work with kids and families and to give them the training they will need and the kudos and pride they will earn before and after the building opens. And because our new building will initially make the hospital somewhat separate from the rest of the medical center, we will need to create events, venues, and circumstances that bring together the students and trainees, researchers and referring pediatricians into our new hospital so that the connections we have enjoyed and benefitted from for decades are enriched rather than squelched.

It would be so tempting, now that the building plans are nearly finished, to sit back and let our colleagues from LeChase do the rest. But to make our new house our community's home for children, families, and all the people who care for them in so many ways, we must continue to work and strive for innovation, for sustainable funding, and for recognition of and collective pride in the many different skill sets and people it takes to keep children healthy.

Sincerely,

Nina F. Schor, M.D., Ph.D.

Pediatrician-in-chief,

Golisano Children's Hospital,

William H. Eilinger Chair of Pediatrics



Howie Jacobson helps Bryce Czekanski choose a winner of the Tops Friendly Markets grocery giveaway.



Aerial Artistry performers entertained guests during the cocktail hour.

25th Anniversary Gala

Almost 900 elegantly-dressed guests gathered at the Rochester Riverside Convention Center on Saturday, Oct. 20, for the 25th annual Golisano Children's Hospital Gala. The storybook-themed evening focused on the history of the children's hospital and Department of Pediatrics, honoring five of the department's chairs – the late David Smith, M.D., Robert J. Haggerty, M.D., Robert A. Hoekelman, M.D., Elizabeth R. McAnarney, M.D., and Nina F. Schor, M.D., Ph.D. – for their medical achievements in pediatric medical care, both regionally and nationally.

The event kicked-off with a 6 p.m. cocktail hour and continued into the night with a fairy-tale-like dinner program. Keeping with the storybook-theme, the program was emceed by 'Little Miss Muffet,' otherwise known as Howie Jacobson, children's hospital board vice chair. Howie, in a dress and bonnet, sat on a tuffet and told the magical tale of the children's hospital and Department of Pediatrics. Attendees listened while surrounded by popular storybook characters, including Curious George, the Cat in the Hat, the Very Hungry Caterpillar, Eloise, and Wilbur.

Although this year's Gala focused on remembering the past, it also encouraged guests to look ahead to the future. The live and silent auctions of the night allowed them to contribute to the story and play their own role in a "happily ever after" ending. The about \$820,000 raised will greatly impact the new children's hospital, in addition to many of its programs.

The funds raised on Saturday are part of Golisano Children's Hospital's \$100 million campaign. The campaign was launched publicly in October 2011 and supports major enhancements to several pediatric programs. The effort is part of the University of Rochester Medical Center's \$650 million campaign and the overall \$1.2 billion goal of *The Meliora Challenge: The Campaign for the University of Rochester*.

Special thanks to our major Gala sponsors:

Presenting Sponsor The Cabot Group

Diamond Sponsors Tops Markets and William & Mildred Levine Foundation

Platinum Plus Sponsors Hammer Packaging and Rainaldi Brothers, Inc.

Platinum Sponsors Abbott's Frozen Custard, DGA Builders, Jackson Welding Supply Co., Inc., and LeChase Construction

Gold Sponsors John W. Danforth Company, JT Mauro Co., MVP Healthcare, and O'Connell Electric



Howie Jacobson looks on as Zachary Slade plays piano



Mark Siewert, Robert Haggerty, Kathy Wissler, Nina Schor, M.D., Ph.D., Elizabeth McAnarney, M.D.



Robin Lohkamp, Joyce Sudak, Rob Tortorella, Erin Cunningham, Christopher Carretta, Jake Scherer



— CAMPAIGN UPDATE —

Golisano Children's Hospital NICU receives naming gift from Gosnells

GEORGIA GOSNELL AND HER LATE HUSBAND, THOMAS, HAVE A LONG HISTORY OF GIVING IN THE ROCHESTER AREA, AND THE COUPLE'S LATEST GIFT WILL LEAVE AN INDELIBLE MARK ON THE HEALTH OF THE REGION'S MOST VULNERABLE CHILDREN. MRS. GOSNELL HAS COMMITTED \$5 MILLION TO NAME THE NEONATAL INTENSIVE CARE UNIT (NICU) IN THE NEW GOLISANO CHILDREN'S HOSPITAL AT THE UNIVERSITY OF ROCHESTER MEDICAL CENTER (URMC).

The \$5 million commitment, announced early in September, will help fund the hospital's new Gosnell Neonatal Intensive Care Unit, which will include 60 beds both in the new building and in the current NICU space on the third floor of Strong Memorial Hospital. The Gosnell NICU in the new building will provide intensive care to the region's sickest babies in private rooms. Renovations will be made to the current NICU space to deliver highly specialized care for babies who need less acute treatment.

"There are few ways to make a greater impact on a community's future health than by ensuring babies the best start they can have in life, and the Gosnells' gift is going to help us do just that," said Bradford C. Berk, M.D., Ph.D., URMC CEO.

It was this intensive care needed by 1,200 newborns in the region each year that inspired Mrs. Gosnell to make her gift. Her two girls were born very small almost 60 years ago at Strong Memorial before the NICU existed. One of them, Elizabeth Gosnell Miller, gave the family—and the physicians—quite a scare when she was born in 1962.

"Her heartbeat had stopped, so they did an emergency Caesarian," Mrs. Gosnell recalled. "She had the umbilical cord around her neck six times, which was a record." Both girls recovered.

Mrs. Gosnell's gift is one of the largest the Golisano Children's Hospital's \$100 million campaign has received since its public launch in

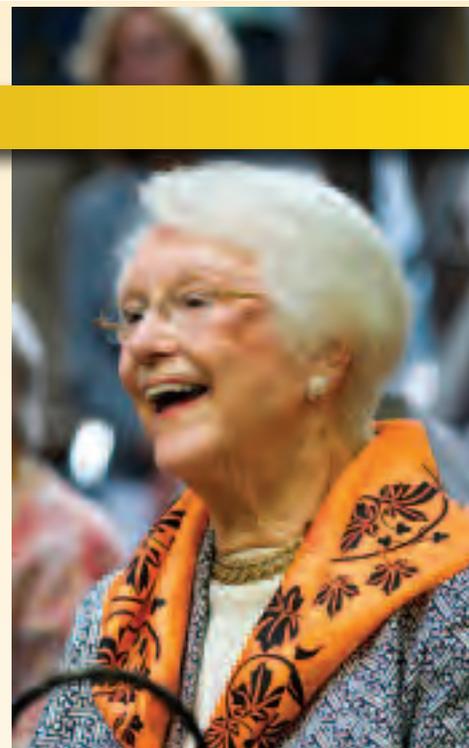
October 2011, supporting both a new children's hospital and major enhancements to pediatric programs. The campaign is part of the URMC's \$650 million campaign and the overall \$1.2 billion goal of *The Meliora Challenge: The Campaign for the University of Rochester*.

The new \$145-million Golisano Children's Hospital, which is the largest single capital project in the history of the University, will be located on Crittenden Boulevard and attached to the Medical Center and Strong Memorial Hospital. The new building will be eight floors and approximately 245,000 square feet of space dedicated to children and their families. The groundbreaking is planned for Sept. 10, 2012, with an expected opening in 2015. It is being financed through a combination of equity, loans, and a comprehensive fundraising effort.

"Without forward-thinking philanthropists like Georgia and Tom Gosnell, we wouldn't be breaking ground on a new children's hospital tailored to the needs of families of today and tomorrow," said Nina F. Schor, M.D., Ph.D., William H. Eilinger Chair of Pediatrics and pediatrician-in-chief of Golisano Children's Hospital. "Grateful" doesn't begin to describe how we feel about Georgia's generosity to our region's most fragile babies."

Gosnell philanthropic history

The Gosnell family is one of Rochester's most generous families, having supported URMC,



Rochester Institute of Technology, Rochester Museum & Science Center, Rochester Philharmonic Orchestra, Al Sigl Center, Genesee Land Trust, and the Memorial Art Gallery, among other important Rochester institutions. In fact, the Gosnells left visible marks on the community, having been instrumental in the restoration of the George Eastman House and the wing-footed Mercury statue on the top of the Aqueduct Building along the river in downtown Rochester.

Mr. Gosnell, who died three years ago, was chairman emeritus of RIT's Board of Trustees and was a major force behind that school's Access to the Future fundraising campaign that raised more than \$120 million. He served in the U.S. Navy during World War II and earned many honors during his service, including a Purple Heart. He then went on to earn his bachelor's degree from Yale and worked his way up in the Lawyers Co-Op publishing firm from elevator operator to become the fourth generation of his family to run the company.

Mr. and Mrs. Gosnell met after World War II and shared a common love of sailing. Their love of sailing persisted and the couple's name graces RIT's Boathouse. Mrs. Gosnell has loaned out the couple's yacht, the *Timoneer*, to bring educational aid to isolated communities around the world.





Be a part of this history — make a gift today! Visit www.givetokids.urmc.edu or call (585) 273-5948.

Breaking ground

Continued from cover
and various spaces designed to meet the needs of children and their families.

“This new hospital has given us a chance to take our goal of patient- and family-centered care to a whole new level,” Berk said. “Having the space to accommodate a patient’s family means they can truly be part of their child’s care team. Children heal faster and more comfortably when they have their families with them while they are hospitalized.”

The project is being financed through a combination of equity, loans, and a comprehensive fundraising effort. In addition to the new building, Golisano Children’s Hospital’s \$100 million campaign, supports major

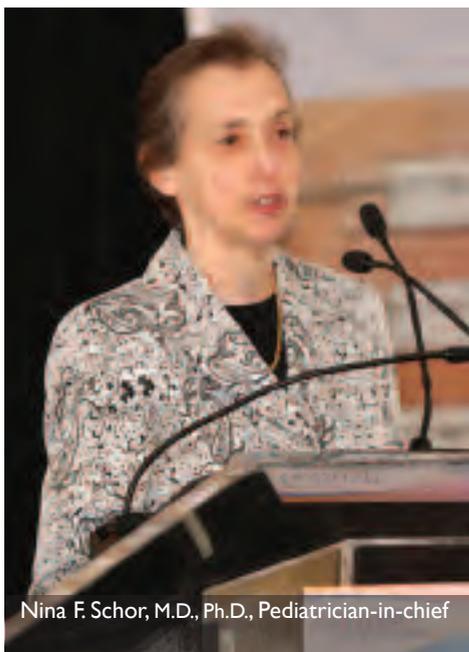
enhancements to several pediatric programs. The effort is part of the University of Rochester Medical Center’s \$650 million campaign and the overall \$1.2 billion goal of *The Meliora Challenge: The Campaign for the University of Rochester*.

Not only will the new building give pediatric patients and their families private rooms, it will also include a new hospitality suite that parents can use to shower, prepare and eat home-cooked meals as a family, or even run a load of laundry.

“This is truly the community’s children’s hospital. The children and families of the Greater Rochester region have been our partners, literally at the table, in designing this hospital to meet their needs, as well as those of

the staff who care for them,” said Nina F. Schor, M.D., Ph.D., William H. Eilinger Chair of Pediatrics and pediatrician-in-chief of Golisano Children’s Hospital. “While we are more than halfway there in funding this critical project, we have a long way to go before we can open the doors in 2015.”

The building has been designed by Ballinger Architects, a Philadelphia-based firm that specializes in health care facilities. Construction manager LeChase Construction, LLC, will oversee the three-year project, which the Center for Governmental Research calculates will create 1,066 construction jobs.



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



Patients Jamie White and Cory Milburn



Fina, Israel and Nico Santiago



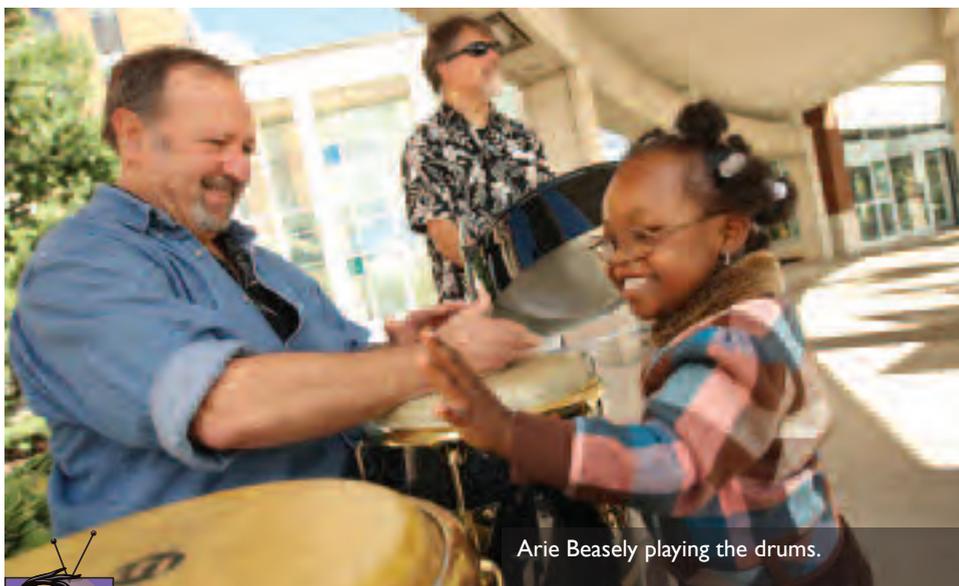
Robert Latella, Robert Witmer, Sue Bezek, Elizabeth McAnarney, M.D., and Michael Smith



Tom Golisano and Robert Witmer



Jennifer Johnson, parent of Miracle Kid Grace Esposito.



Arie Beasley playing the drums.

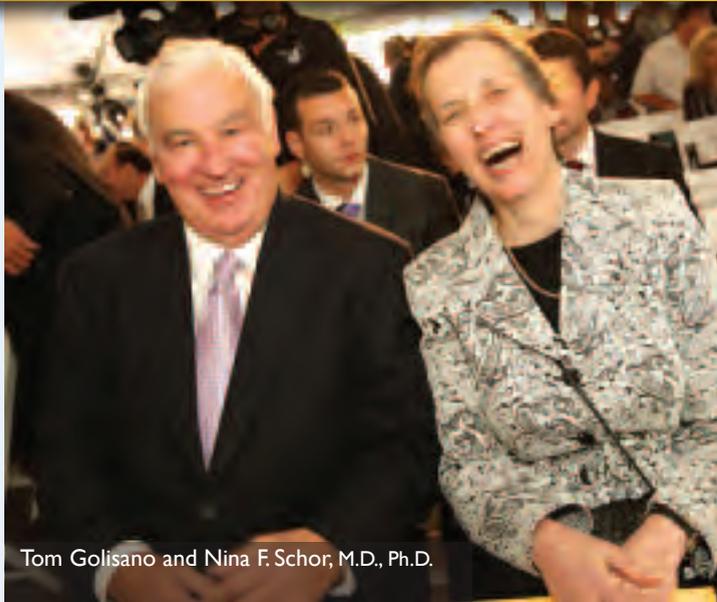


For a video of the event, visit <http://bit.ly/GCHgroundbreaking>, or for a video about families who helped us design the new hospital, visit: <http://bit.ly/GCHparents>





— CAMPAIGN UPDATE —



Tom Golisano and Nina F. Schor, M.D., Ph.D.



Heather Goetzman, N.P., and Mason Mitchell

Building donors* to date

\$5 million – 20 million

B. Thomas Golisano
Georgia Gosnell

\$1 million – 4.9 million

Mike & Alice Smith
Walmart Stores and Sam's Clubs

\$250,000 – 999,999

B&L Wholesale Supply Co. Inc.
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Sue Bezek
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 Jean Meier

* List does not include our generous donors after Nov. 1 or to programs supported by the children's hospital campaign. Watch future issues of the *Strong Kids Newsletter* for recognition of those important donors.



To explore the building and naming opportunities online, visit www.givetokids.urmc.edu and click on "Explore Our New Building."

We need your help to put patients and families first!

The new Golisano Children's Hospital at URMC will focus on providing a world-class facility to match the immense talent and incredible hearts of the doctors, nurses, social workers, child life specialists, and so many others.

Be part of our team to make the dream of the new hospital a reality:



Join 'Sandy's Friends'

This group of amazing friends provides support by volunteering at our events. Please visit <http://bit.ly/GCHVolunteer> for more information.



Attend an Event

Enjoy a great benefit event and help kids in the process! Please visit <http://bit.ly/GCHevents> and join in the fun!



Hold a Community Fundraising Event

Every dollar raised goes to Golisano Children's Hospital. You can support a specific program or our effort to build the new hospital, including pledging enough to name spaces throughout the new building. Events have been as varied as dance marathons, golf tournaments, benefit dinners and sporting events. Contact Michael Fahy at (585) 276-5176 or michael.fahy@rochester.edu for info.



Spread the Word

Tell everyone you know about the new Golisano Children's Hospital and about all the wonderful programs and patient- and family-centered initiatives that will help us exceptional care to kids.

We hope you'll join us on our journey to provide every child with the best care possible.



— CAMPAIGN UPDATE —



Interior design to be soothing, engaging

New building celebrates New York's landscapes while entertaining and educating

The new Golisano Children's Hospital at the University of Rochester Medical Center will be a place of healing and a place to celebrate who our patients, families, faculty and staff are. Ballinger architects and hospital staff are hard at work, refining the interior of the new hospital. The design includes graphic elements, décor, art and architectural features that will showcase the many beautiful landscapes of upstate New York.

Each floor will have a different theme, such as, waterways, meadows, gardens and parks, with an icon to represent it. The icon will help families remember which floor they're on and find their way back to it, and the floor's theme will provide creative opportunities to engage

with children of all ages in interactive ways. For example, on the Lake floor, children may be able to push buttons to cause bubbles to rise up through tubes in a wall. Other ways the theme will be incorporated into the building are more subtle. On the Park floor, glass in patient rooms may be frosted with leaves that will cast shadows along the floor with a linoleum park path in it.

"We want very ill children to feel soothed but we want children who aren't as sick to be as engaged as possible, exploring interactive wall art and kicking leaf shadows down the path of their unit," said Elizabeth Lattimore, chief administrative officer. "We have also been careful to make the design appealing to young children

while also making it interesting to teenagers and caregivers, so our older patients and their families know this is their hospital, too."

The new \$145-million building, located on Crittenden Boulevard and attached to the Medical Center and Strong Memorial Hospital, will be eight floors and approximately 245,000 square feet of space dedicated to children and their families. The groundbreaking is planned for next month with an expected opening in 2015. It is being financed through a combination of equity, loans, and a comprehensive fundraising effort.

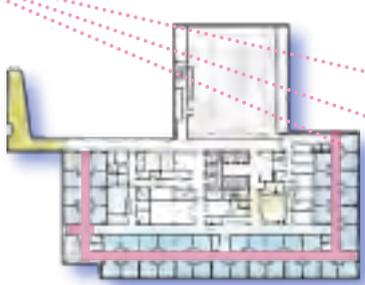
Lattimore said she hopes to incorporate local history displays through the hospital that would rotate out to provide families with an

Ground Floor





Patient hallways Family lounges Patient rooms



Third Floor (NICU)



Seventh Floor



Eighth Floor

additional educational opportunity – or source of community pride – while they are here. The displays would also give upstate communities a way to help brighten children’s experiences while they’re inpatients. (As programs like this are developed for the new building over the next three years, information on how to contribute will be available on www.givetokids.urmc.edu.)

“The new building represents an enormous opportunity to design and configure the space to best serve the way we practice medicine and celebrate health in the 21st century;” said Nina F. Schor, M.D., Ph.D., William H. Eilinger Chair of Pediatrics and pediatrician-in-chief of Golisano Children’s Hospital. “We’re not only

providing the space for parents to participate in the healing process; we’re also giving them the tools they will need to keep their children healthy once they leave the hospital. We’re not only providing the equipment our staff needs to do their jobs; we’re also giving them an environment that will welcome them each morning and remind them of what an important part of the Upstate landscape they and the healthy habits they foster are.”

| Floor themes | |
|--------------------------|---------------------------|
| Ground Floor (Imaging) | – Lake |
| 1st floor (Lobby) | – All New York landscapes |
| 3rd floor (NICU) | – Meadow |
| 4th floor (future OR) | – TBD |
| 6th floor (future PICU) | – Gardens |
| 7th floor (General Care) | – Park |
| 8th floor (General Care) | – City |

First Floor



To explore the building and naming opportunities online, visit www.givetokids.urmc.edu and click on “Explore Our New Building.”



COMMUNITY FUNDRAISING

Festival aims for high-quality event for children's hospital

Rob Burch and Andy McDermott don't have any harrowing stories of their children needing the experts at Golisano Children's Hospital at the University of Rochester Medical Center. But they don't need a personal experience to appreciate the high-quality care the hospital brings to the region's children and families. They use that high-quality care as inspiration to create a high-quality event – the Fairport Music and Food Festival.

"Golisano Children's Hospital represents quality care, quality medicine," McDermott said. "What's important is we have a quality event and we represent the hospital well!"

The pair point out that they don't run the festival like a business, that they focus on ensuring that the event is a success from the point of view of the people attending. They figure that the festival can only be a successful fundraiser if it's a success at being fun for everyone who comes.

And it's obvious they are right.

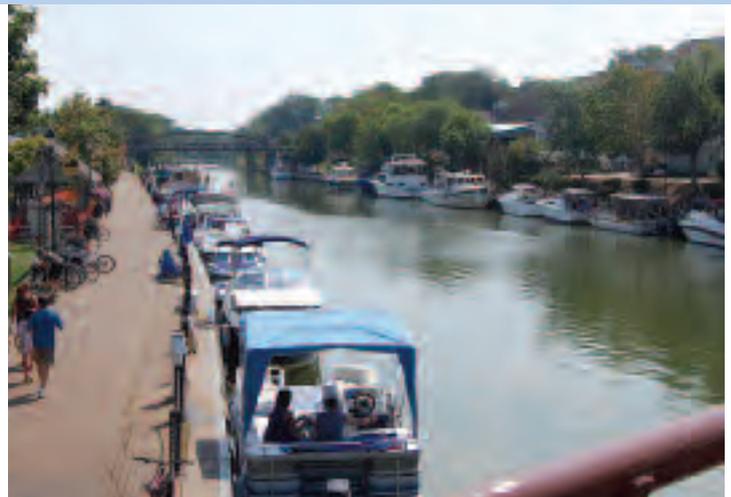
The first year, they raised an impressive \$13,700. Four years later, in 2008, they had quadrupled that amount. This year, they raised \$100,824 and broke the \$500,000 mark for fundraising for the hospital.

The festival has committed \$200,000 to funding a patient room and a nursing station in the new hospital (see pages 8 and 9 for more information on the new building). They're already almost done fundraising for it, and they're not ready to stop. "Andy and Rob are two of our most dedicated supporters," said Mike Fahy, assistant director of Community Affairs at Golisano Children's Hospital. "They've created an amazingly fun event that has become a hallmark for the town of Fairport and has had an immeasurable impact for the kids we serve at the Children's Hospital."

Next, they've set their sights on helping even more with the new hospital. In addition to funding a patient room and a large nurse's station, they decided to fund something that fits the personality of their festival, of their 295 volunteers and of themselves – the playroom. As one of three spaces dedicated entirely to fostering play in our patients, it's a fitting choice for a couple of guys who can find fun in any task and in any conversation with anyone.

Over the seven years the festival has been running, McDermott and Burch have chosen to use its proceeds to fund the hospital's education and entertainment system Get Well Network, a pediatric anesthesia machine, two Giraffe Omnibed incubators and the playroom in the B&L Wholesale Outpatient Pediatric Treatment Center. It has also supported the Pediatric Social Work program and given to the hospital's unrestricted fund, which offsets costs of un- and under-funded care.

"The explosive growth of the Fairport Music and Food Festival is a perfect example of what dedicated community members can do to help our region's children," Fahy said.



Feeling in the holiday mood? Give to Kids!

The giving spirit is almost as pervasive as tinsel this time of year and we hope you will consider directing some of that holiday generosity toward the Finger Lakes region's only hospital dedicated to children and their families. It could impact your taxes and impact the life of a child.

Still need some convincing? Visit www.givetokids.urmc.edu and click through the "Meet Our Patient" section of the website. Incredible children like Grace Esposito, who fought almost insurmountable odds to survive a devastating congenital defect, would not be here if it weren't for Golisano Children's Hospital.

Children in need of cardiac surgery – like Charlie Levin – would have to travel across state lines to get the care they need, if it weren't for Golisano Children's Hospital.

Without Golisano Children's Hospital, what would Arie Beasley's family have done when she was diagnosed with cancer?

Consider giving to in honor of a loved one this holiday season. What better gift can you give than one that could save lives like those of Charlie, Grace and Arie?

Visit www.givetokids.urmc.edu and click on "Make a Gift."





Spotlight on CMN Hospitals Sponsors

RE/MAX Plus holds first golf tournament

It's common knowledge that RE/MAX Plus has an ambitious group of realtors, so it should come as no surprise that for its first golf tournament Aug. 13, they sold out Locust Hill! With 144 golfers, RE/MAX Plus raised more than \$21,000 for Golisano Children's Hospital. Former RE/MAX employee Erin Sackett and her daughter, Karleigh, attended the impressive \$21,251 check presentation Oct. 16.

When Karleigh was 11 months old, she suddenly stopped crawling and standing to "cruise" along the furniture. After taking her to a neurologist, Erin learned Karleigh had a tumor pressing against her spine. Following surgery and chemotherapy, Karleigh is recovering well and back to keeping her mother on her toes.

Thank you, RE/MAX Plus, for all your support of Golisano Children's Hospital!

Realtor's "feat" raises big bucks for kids

Bob Kirby of RE/MAX Realty Group put his pedals to the pavement and rode his bicycle 400 miles from Rochester to New York City to raise money for the new Golisano Children's Hospital. This incredible feat was inspired by the work his wife, 4-1600 Nurse Manager Jeanne Kirby, and her colleagues do on behalf of our region's sick and injured children. Bob raised \$4,800. Thank you!



Double win for Tops Friendly Markets promotions

Rochester area Tops Friendly Markets didn't stop after raising \$28,000 for Golisano Children's Hospital through its annual balloon sales in June. It went on to hold a sweepstakes to benefit Golisano Children's Hospital. At the checkout, shoppers could donate \$1 and in return they were entered into a raffle to win a year's worth of groceries. The promotion raised more than \$30,000! The winner was drawn at the 25th annual Children's Hospital Gala Oct. 20 at the Rochester Riverside Convention Center. Congratulations, Jeanne Herbert of Hilton!

Giving credit to our credit unions

Credit Unions for Kids (CU4Kids) is a non-profit collaboration of credit unions across the country, including many of our generous local credit unions. CU4Kids raises money for Children's Miracle Network Hospitals, so all the money raised by our local credit unions benefits Golisano Children's Hospital. Our local credit unions always get creative with their fundraisers.

This year, our friends at WIT Federal Credit Union raised \$5,000 for Golisano Children's Hospital! Advantage Federal Credit Union donates \$25 for every double the Red Wings get during home games. That promotion raised \$2,700 this year. And together, the Pittsford Federal Credit Union and Summit Federal Credit Union raised \$4,000 through their participation in the Credit Union Cherry Blossom Ten Mile run in Washington, D.C. A big thank you to our credit unions for going the extra mile for kids!

Save the Date

The Drive for Miracles RADIOTHON

to benefit Golisano Children's Hospital

Save the date for "The Drive for Miracles Radiothon" to be held Feb. 14 & 15, 2013 presented by Clear Channel's 100.5 The Drive and WHAM 1180.

Hear miraculous stories of healing and hope from Golisano Children's Hospital families and call in with your pledge of support!



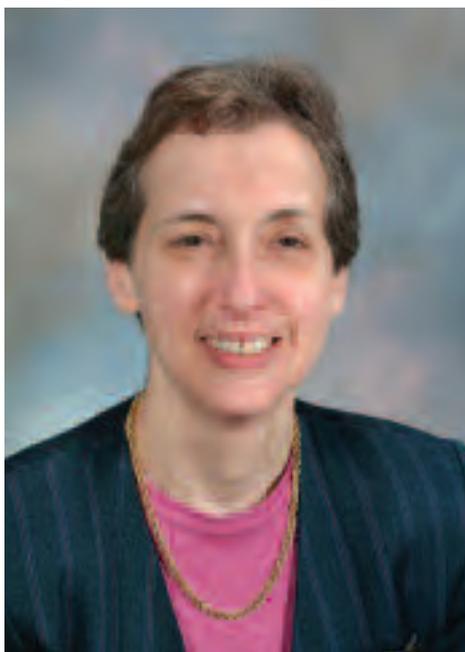


GOLISANO CHIEF NAMED PRESIDENT OF CHILD NEUROLOGY SOCIETY

GOLISANO CHILDREN'S HOSPITAL'S PEDIATRICIAN-IN-CHIEF HAS BEEN ELECTED PRESIDENT OF THE NATION'S LARGEST ORGANIZATION OF CHILD NEUROLOGISTS.

Nina F. Schor, M.D., Ph.D., William H. Eilinger chair of Pediatrics at the University of Rochester Medical Center and pediatrician-in-chief of Golisano Children's Hospital, was voted into the presidency by fellow pediatric neurologists from around the world and became President-elect following the annual meeting of the Child Neurology Society in November.

The Child Neurology Society is a non-profit professional association of 1,300 pediatric neurologists in the United States, Canada, and worldwide who are devoted to fostering the discipline of child neurology and promoting the optimal care and welfare of



children with neurological and neurodevelopmental disorders.

"This position represents an enormous

opportunity to champion internationally the cause of children and families with neurological and neurodevelopmental disorders and to enhance the ability of the health care community to meet their needs," Schor said. "It will grant me the honor of facilitating education and communication on behalf of these children, families, and health care professionals."

Before coming to Rochester, Schor held the Carol Ann Craumer Endowed Chair for Pediatric Research at Children's Hospital of Pittsburgh of the University of Pittsburgh Medical Center and was chief of the Division of Child Neurology, director of the Pediatric Center for Neuroscience, and associate dean for Medical Student Research at the University of Pittsburgh School of Medicine.

Schor is nationally recognized for her research on neuroblastoma and the role of oxygen radical damage in degenerative disease of the nervous system. She has spent the past two decades pursuing potential treatments for neuroblastoma, a frequently fatal cancer of childhood that grows from immature nerve cells.

GOLISANO GENETICIST WINS NATIONAL HUMANISM AWARD

CHIN-TO FONG, M.D., DOESN'T JUST TEACH UNIVERSITY OF ROCHESTER MEDICINE AND DENTISTRY MEDICAL STUDENTS THE FOUNDATION OF GENETICS AND MOLECULES DURING THEIR FIRST YEARS OF TRAINING.

Fong teaches students the very foundation of practicing medicine: that their patients – and they, themselves – are human beings, first and foremost. He believes it's important to connect on that level to be effective physicians.

That teaching and Fong's ability to form those connections are why he is the 2012 AAMC Arnold P. Gold Foundation Humanism in Medicine Award recipient. Fong, chief of Pediatric Genetics at Golisano Children's Hospital, received the award Nov. 3 at the organization's annual meeting in San Francisco.

UR medical students nominated Fong



because they felt he exemplifies the qualities of a caring and compassionate mentor in the teaching and advising of medical students. They also said that he doesn't just

teach them to be caring physicians, he is an example of one.

"I have witnessed his interaction with patients, his calm demeanor and compassion, as well as his credentials and extensive knowledge of genetics that make him an exceptional physician," Judy Liu, a former medical student, said in Fong's nomination.

Fong's connection to his patients is evident to students when he brings families into classes to talk about what it's like to have a child with a difficult genetic disorder. He aims to show his students – early in their education – the impact these disorders have on families and how resilient the human spirit is.

Fong said he doesn't ever remember talking, specifically, about humanism in his classes, and yet this isn't the first time UR medical students have nominated him for the humanism award.

"The very simple thing is, you have to actually care about the people you care for," Fong said.

(See page 13 for an example of a family cared for by pediatric geneticists.)



RARE GENETIC DISORDER ALL TOO COMMON IN ONE FAMILY



AS NEW PARENTS, BRIAN AND LAURA KLEINHANS WEREN'T SURE WHAT TO EXPECT WHEN THEY BROUGHT THEIR DAUGHTER HOME FROM THE HOSPITAL IN OCTOBER 2008. SO THEY TRIED TO TAKE IT IN STRIDE WHEN MADELYN SPENT MOST OF HER TIME ASLEEP AND ATE VERY LITTLE. MADELYN CRIED EVERY HOUR AND WOULD TRY TO NURSE UNTIL SHE PASSED OUT.

Laura wanted to succeed at breastfeeding and didn't want to introduce a bottle too early, so she pressed on. But when Brian's sister-in-law, Erin, saw Laura struggling, she encouraged the couple to trust their instincts and give Madelyn a bottle with breast milk in it.

Doctors believe that Madelyn wouldn't have made it to the morning if they hadn't.

"That's something as a parent that you never want to hear about your kid," said Brian.

Three days later, the family pediatrician called them to his office to receive the results of Madelyn's newborn screening.

Madelyn was born with a rare genetic disorder of the metabolism that affects roughly one out of every 12,000 to 17,000 children called medium-chain acyl-CoA dehydrogenase, or MCAD, deficiency. Because of her disorder, Madelyn is deficient in an enzyme needed to convert fat from her body and her food into energy. If she doesn't eat



every four hours, her body attempts to use fat for energy and her blood sugar drops very quickly, which can progress to metabolic shock, then eventually coma and even death. The bottle-feeding saved her life.

"At first we were devastated," Brian said, "but after sitting down and talking to our doctors we understood this wasn't the end of the world. We did have a long road to

understanding the disorder and how we, as a family, would come to deal with it, but we knew we were in good hands."

"Madelyn only has four to six emergency visits a year," Brian said. "But whenever we come in to the hospital the staff talks with us, asks us how we're dealing with things, what our routines are and what we could do better."

The Kleinhans family has worked closely with the Genetics Division at Golisano Children's Hospital at the University of Rochester Medical Center to learn more about her disease and to streamline her treatment when she gets sick. The first night the Kleinhans family brought Madelyn to the emergency department, they were sent to the waiting room because Madelyn wasn't visibly ill. Because of MCAD deficiency's rarity, many medical professionals don't realize how severely it can progress. After an hour in the waiting room, Madelyn's blood sugar numbers crashed.

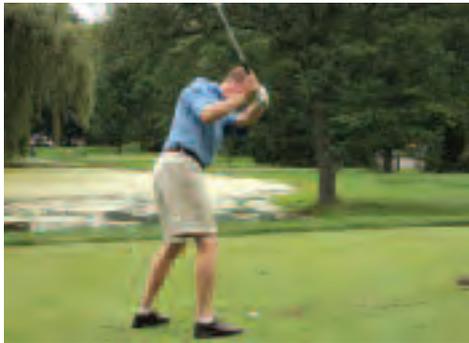
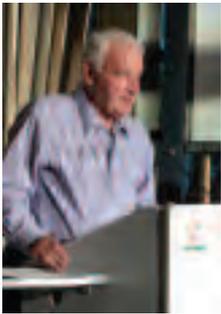
"We were on the verge of a really bad crisis," Brian recalled.

This episode became a learning experience for everyone. Since Madelyn's first hospitalization, Madelyn's trips to the ED have gotten much quicker. "We call the geneticist before we are about to leave for the hospital so that they'll have everything ready when we get there. From the time we call, to the time when Madelyn is hooked up to her IV and getting the nutrients she needs, is less than half an hour, including the drive," Brian said.

But what's really helped to empower the Kleinhans family in their endeavor is that the hospital gives them the power to make the call on what to do when Madelyn isn't feeling well. "When they call to say there is an issue, it's usually pretty serious," said Elaina Howell MS, PNP-BC, one of Madelyn's metabolic providers. "You need to take into consideration that parents are the experts on their children. They know when something isn't right."

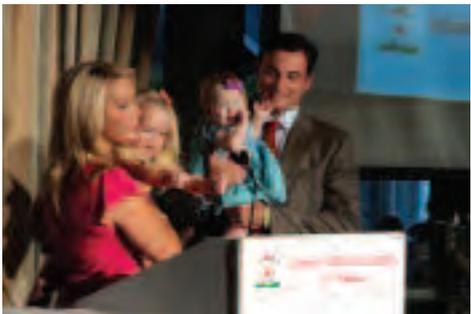
Because of this empowerment and the closeness that the Kleinhans family has developed with the hospital, when Colin Kleinhans was born on March 13, 2012, and was subsequently diagnosed with MCAD deficiency, the family was able to take it in stride. "We're sharp in our routines and we understand the road ahead of us," Brian said. "We know we're in good hands."

How can a round of golf get any better?



The place to be on Aug. 27 was clearly the 16th annual Children’s Hospital Golf Classic.

After outgrowing the Monroe Country Club, the Country Club of Rochester and the Oak Hill Country Club’s west course, Golisano Children’s Hospital added on a morning round at Monroe Country Club to fit all the golfers aiming their drives at helping the Finger Lakes region’s only children’s hospital. If the tournament isn’t already the largest in the Rochester area, its 456 golfers this year had to break the record! The event raised an incredible \$436,080.



The exciting day ended with dinner and Pediatrician-in-Chief Nina F. Schor’s updates on the progress of the new Golisano Children’s Hospital. 13WHAM Anchor Jennifer Johnson and her husband Vinnie Esposito shared their family’s remarkable journey with their daughter, Grace, who was born with a congenital diaphragmatic hernia and was given a slim chance of survival. The “Amazing” Grace celebrated her first birthday less than a month later, thanks to Golisano Children’s Hospital, her dedicated family and her fighting spirit.

Special thanks to all of the sponsors of this year’s tournament and especially to our major sponsors:



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Upcoming Community Events

Dec. 1, Talent for Tots & Teens Holiday Showcase

Alumni & Advancement Center Auditorium, 300 East River Road, 5 p.m.

A diverse group of young dancers showcase their talents in the theme of the holiday season. Please contact Ms. Ida Wheeler at iwheeler@alumni.rochester.edu for additional information.

Dec. 21, Rainbow Classic

The heated rivalry between Pittsford Mendon and Pittsford Sutherland always makes for great entertainment. Every penny from admission and commemorative program sales from this year’s event will support the Adolescent Eating Disorders program at Golisano Children’s Hospital at URM. The girls tip-off at 6 p.m. followed by the boys at 7:45 p.m. For information about tickets, please call the Pittsford Athletics Office at (585) 267-1062.

Jan. 15 and Feb. 12, Battle of the Beaks

St. John Fisher and Nazareth College Cross-Street rivals Nazareth and St. John Fisher battle in Men’s and Women’s Basketball with all proceeds from ticket sales, prize raffles, and commemorative t-shirt sales benefitting the kids at Golisano Children’s Hospital. The game on Jan 15th will be held at St. John Fisher’s Manning & Napier Gymnasium, while the Feb 12th contest will be held at Nazareth College’s Kidera Gymnasium in the Otto Shults Center. For more information, please contact Becky Fahy at rfahy6@zimbra.naz.edu or by calling (585) 389-2735.

Feb. 2, Cycle for Hope

Participating fitness centers Local fitness clubs help support the kids at Golisano Children’s Hospital at URM and Camp Good Days & Special Times one revolution at a time with this spinning event,

which benefits both organizations. Donations of \$20 per hour are requested from 8am to 2pm at participating locations. Join us and receive a commemorative gift! Please visit www.campgooddays.org/CFH/CFHmain.htm for more information, or call (585) 276-5176.

Feb. 10, Winter Walk for Strong Kids

Shults Center at Nazareth College This family-friendly event has something for everyone. The event includes indoor activities such as a bounce house, snow cone making, carnival games, craft stations, manicures, face-painting, and much more! A brief, brisk walk around the Nazareth Campus is followed by more fun. Contact Becky Fahy at rfahy6@zimbra.naz.edu or by calling (585) 389-2735.

Special Thanks

Many thanks to these and all generous supporters and event organizers that benefit Golisano Children's Hospital!

If you are interested in hosting a fundraiser please contact Michael Fahy at: michael.fahy@rochester.edu or 585-276-5176.

- We appreciate the incredible generosity of the Gough Family for supporting the Neonatal Intensive Care Unit at Golisano Children's Hospital at URMIC in honor of their twin boys, Maxwell & Aiden, who celebrated their first birthday. These NICU graduates donated \$1,100 to support the hospital – thank you!
- Thanks go out to the Pittsford Crew team for their continued support through their annual Row for Strong Kids event, which raised \$4,000 this year!
- We appreciate the support Cheshire A/V provides the Andrew J. Kirch Center for Developmental Disabilities through their annual golf tournament. This year's Cheshire A/V Golf Classic raised \$4,167 for the Center – thank you all!
- Our appreciation goes to everyone associated with the 2nd annual Jordan's Journey benefit event, which raised \$781 this year. We can't thank you enough for all you put into this year's casino-themed event.
- Special thanks to everyone at Mulconry's Irish Pub & Restaurant and Lauren's Legacy for your donation of \$2,000 from the Mulconry's Charity Golf Tournament and Chicken Barbeque events. We truly appreciate this support!
- Thanks so much to Olivia & Aleena for their donation in lieu of gifts from their birthday celebrations. Family and friends donated \$1,035 to the girls, who gave the funds to Golisano Children's Hospital!
- We can't thank everyone associated with the Rich Struzzi Memorial Golf Tournament enough for their support of Pediatric Pulmonology. This year's tournament raised \$10,424, and will help purchase a state-of-the-art diagnostic machine to help evaluate our youngest patients.
- Thank you very much to the Davis Family for holding the first annual Love Through Lemonade fundraiser. This event helped raise \$535 for Golisano Children's Hospital, and will go a long way to helping us care for our region's sick and injured children!
- The Photo City Browns Backers once again supported Golisano Children's Hospital through a generous donation of \$200. We appreciate this generous support, and wish the group the best of luck enjoying this year's football season.
- We cannot express our appreciation enough to the Hardter family for holding a golf tournament to support the Pediatric Cardiac Intensive Care Unit. The time and energy the family put into the tournament helped raise \$2,000 this year – thanks so much!
- Many thanks go to Steve Clough, who raised \$1,580 from the inaugural Kayak for Kids event, where he asked for sponsorships for a 32-mile round-trip kayaking adventure on Canandaigua Lake.
- Our friends from Panera Bread recently donated \$5,860 to Golisano Children's Hospital. Thank you all for this incredible support!
- Jimmy LeChase hosted 'A Night of Too Many Hardee-Har-Hars,' a comedy show that supported the Kirch Center. We appreciate this support and the \$640 donation from this first-time event!
- Team Ali-Gaiters 9th annual Clambake was an enormous success! Thanks to everyone for the amazing donation of nearly \$20,000 from the Clambake and for your commitment to supporting our efforts to build the new Golisano Children's Hospital!
- Our close friend Aiden helped raise \$1,000 by asking for donations in honor of his close friend Andrew, a cancer patient at Golisano Children's Hospital, in lieu of gifts for his birthday. We can't thank you enough Aiden!
- We can't thank everyone at the Harley School enough for the energy they put into inviting the U of R's Yellowjackets to the school for a concert. They raised an incredible \$3,114.30 for our region's sick and injured children – thank you so much!
- Our sincere appreciation goes to everyone at the Garden Factory for holding their Fall Family Fun event to benefit the Children's Hospital. Thank you for all your hard work and for the terrific \$8,927 donation from this wonderful event!

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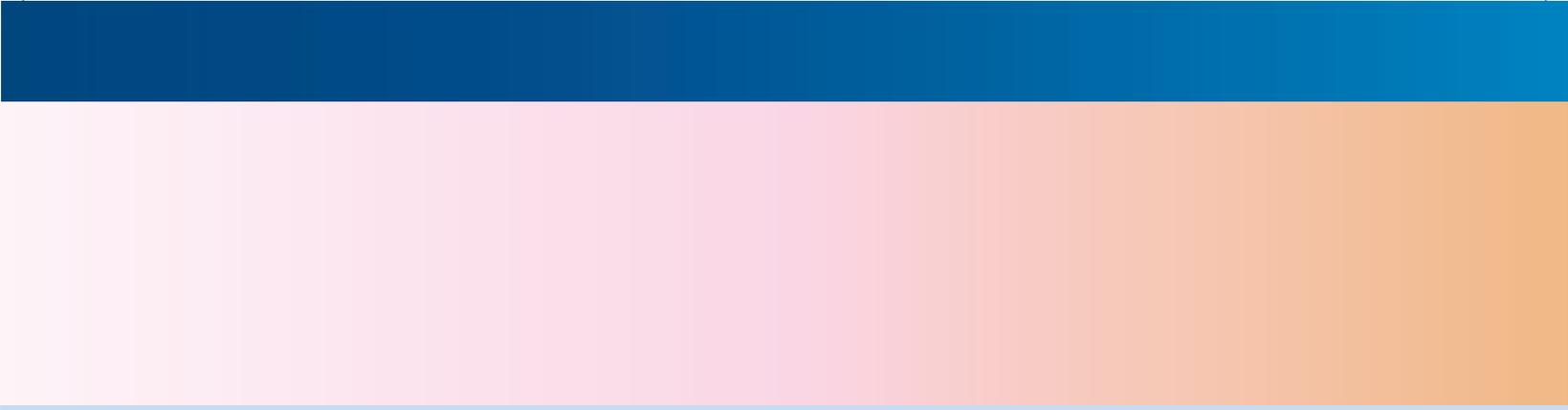
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