



A New Model for Autism Care

*Levine Autism Center
set to open this Spring*

***An inside look:
Developmental and
Behavioral Pediatrics***

- ▶ Nina Schor to Step Down as Pediatrician-in-Chief
- ▶ Feeding Disorders Program Helps Kids with Developmental Disabilities
- ▶ Renovated NICU Adds Capacity, Technology

Dear Friends



Many years ago, when our ambulatory clinic space was designed and created, the needs and desires of developmentally typical children with physical ailments – strep throat, ear infec-

tions, rashes – were foremost in the minds of the interior decorators. The space is brightly colored, built to house lots of children and families in one waiting room, noisy, and busy, with interactive exhibits on the walls and toys on the chairs and floor. Little did our predecessors know how large would be the representation of children with behavioral, intellectual, and mental health challenges in our clinics 10 or 20 years later. Our colorful, noisy, hectic space still serves behaviorally typical children well, but it is exactly the opposite of what we would want to create for children with developmental and behavioral challenges. Luckily for us and the children and families we serve, our friends at the William and Mildred Levine Family Foundation understand this issue and were willing to

help us overcome it. With a \$1 million grant from them, we are building the perfect space to serve the needs of our region's developmentally and behaviorally challenged children and families right on our own centrally-located and easily-accessed campus. This new clinic space on East River Road will co-locate Developmental & Behavioral Pediatrics, Pediatric Neurology, and Child Psychiatry – all services critically important for these children. How fortunate our community is to have generous donors like the Levines who understand the imperative that we provide outstanding care for all of our children in a space that makes them and their families comfortable and welcome!

Nina F. Schor, M.D., Ph.D.
Pediatrician-in-Chief,
Golisano Children's Hospital
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NICU Renovation Enhances Patient Care, Increases Privacy for Families



The Strong Memorial Hospital (SMH) neonatal intensive care unit (NICU), a state-of-the-art facility that helps provide care for 1,200 newborns in the Finger Lakes region, officially reopened in January.

The renovated SMH NICU, an expansion of the Golisano Children's Hospital's Gosnell NICU, houses 24 beds that are predominately single family spaces. Along with the 44 beds in the new children's hospital tower, Golisano Children's Hospital's NICU now boasts 68 beds and is the only Level IV NICU in upstate New York.

The renovated space will house 16 private rooms and a transitional care nursery with eight beds. The transitional care nursery will focus on care for babies who need intense observation and monitoring, but whose mothers are inpatient. The private rooms will not only allow for more space, but also support infection control and enable parents to more actively participate in their child's care.

NICU graduates from past and present attended a special ribbon cutting held on Dec. 14, 2016.



“Our NICU has the latest design elements and the best innovative technology that is available to make it the safest, most advanced NICU for patient care,” said Carl D’Angio, Chief of the Division of Neonatology at Golisano Children’s Hospital. “This renovation not only provides parents with more privacy, but our neonatologists more space to care for the babies we see.”

Along with the newly refurbished unit, the SMH NICU features top-of-the-line technology. Just like in the new tower, a variety of beds, warmers, incubators and cribs are available to the baby. Parents can also utilize omnibeds (Giraffe beds), which function as incubators and warmers so the more fragile babies don’t have to be moved between the two. Babies will also be able to be weighed on a built-in scale. With dimmer light capabilities and a device to monitor sound level, the new rooms provide the optimal environment for babies’ hearing, growth, and overall development.

The new NICU is also equipped to take bedside digital x-rays, ultrasounds, electroencephalograms (EEGs), and pulmonary function tests. Those images and tracings are available online to doctors in other parts of the hospital or at home.

Designated a Level IV NICU — the highest classification – Golisano Children’s Hospital’s NICU is capable of caring for the tiniest and sickest patients in the Finger Lakes region.

Phase II: *Just around the corner!*



Phase II of the new Golisano Children’s Hospital will allow us to provide the most advanced care for the region’s sickest children – while supporting our amazing surgeons with the technology they need. It will also help us to attract more of the best pediatricians and pediatric surgical specialists in the nation.

The fourth and sixth floors will house a Surgical Suite, with six new operating rooms, 23 pre- and post-op recovery rooms, a GI suite and catheterization/electrophysiology lab, and a new Pediatric Intensive Care Unit. Stay tuned for an announcement later this year!



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MEDICINE of THE HIGHEST



A Decade Well-Spent

Nina Schor, who is stepping down from her post as the Golisano Children's Hospital pediatrician-in-chief in June, reflects on the latest milestone in her career.

They called it a “lab,” but it wasn’t a lab, or much of anything, really, when Nina Schor walked in. Just a drab, tweed-carpeted, 300-square-foot room with a few benches in it.

The nearest source of distilled water — an essential for medical research — was in the Department of Pathology, across a bridge. You’ll need to clean your own glassware, she was told. And we don’t have that laminar flow hood you wanted — maybe you can fund it through one of your grants?

So began Schor’s research career at the University of Pittsburgh School of Medicine in 1986.

“It was like doing research in a log cabin,” said Schor, who spent 20 years in Pittsburgh before her appointment as pediatrician-in-chief at UR Medicine’s Golisano Children’s Hospital. “And you know what? I absolutely loved it.”

Two decades later, Pittsburgh’s once-fledgling pediatric laboratory research program — which began with Schor and just three other physician-scientists — had grown into a nationally-recognized powerhouse. And Schor herself had been promoted to Associate Dean of Medical Student Research, as well as Chief of Pittsburgh’s Division of Pediatric Neurology, which had grown from six faculty members to 21 during her tenure.

With both her university and her division thriving, Schor began looking around for her next challenge.

Meanwhile, the University of Rochester Medical Center had recently received a gift from local businessman and philanthropist B. Thomas Golisano, who had given \$14 million to support their children’s health programs.

The facility was called “Golisano Children’s Hospital,” but it wasn’t a children’s hospital, really. Just a collection of pediatric services and specialists, largely confined to the fourth floor of its parent, Strong Memorial Hospital, and its community partners. But Golisano’s gift had provided a spark. After decades of hoping, the Department of Pediatrics was beginning to realize that their vision of a standalone children’s hospital was, for the first time, actually in sight. Like the log-cabin lab in Pittsburgh, it just needed someone to help turn the dream into reality.

Becoming a physician

Schor grew up in New York City alongside a father who always liked to describe himself as one of the first male suffragettes.

“He had two daughters and told us the sky was the limit,” said Schor. “He lived to see us go to Yale — which was all-male when he was a graduate student there — and he was always a champion for women’s rights.”

Having graduated high school early, Schor made it to the university at age 16, where she studied biochemistry and music theory. She’d leave Yale early, too, graduating in just three years, and then became the first woman accepted to the M.D.-Ph.D. program at Cornell/Rockefeller, now known as the Tri-Institutional M.D.-Ph.D. program.

Of course, accomplishments like this always seemed a bigger deal to those around her than to Schor herself.

“It was always funny to me what a big fuss they made about things like that,” she said. “I had gone to public school, and was in co-educational classes all the way through, and nobody ever made much of a distinction. To me, it never seemed like a big deal whether you were a boy or a girl, a man or a woman.”

By 1980, she had her Ph.D. from Rockefeller University, and the following year, she earned her M.D. from Cornell. She then headed to her residency at Boston Children’s Hospital, the teaching affiliate of Harvard Medical School, where she spent two years in pediatrics, and three more in child neurology.

For seven months, she was the only chief resident. This, during a time when there were no restrictions on duty hours.

“I was on every night, every weekend, every holiday,” said Schor. “It was insane, but when I went to Boston, I had my M.D., and by the end of my internship I had actually become a physician.”

Boston asked her to stay, but Schor wanted to pursue her research. That’s when Pittsburgh came calling, offering to support her full-time research for three years in the hopes she could earn her own government grants during that span.

“Two years in, I had myself fully funded,” said Schor. “But had they not given me a chance, I don’t think I could have done what I did.”

More than a building

After 20 years in Pittsburgh, Schor came to Rochester, and in 2006 became URM’s seventh Chair of the Department of Pediatrics. Another staggering gift from Tom Golisano followed — this time, it was \$20 million — and a multi-year campaign was launched to generate the remaining funding. Throughout the campaign, Schor was always out front, educating the community on the importance of a standalone children’s hospital: Children and families would be more comfortable in their own space. Top-tier pediatricians and medical students, drawn by the promise of a brand-new facility, would come to Rochester to work and study. Care would improve. Outcomes would improve.

As time passed, she became the face of an organization that needed the community’s support, all the while leading the Department of Pediatrics through a period of strong growth despite diminishing federal research funding.

Finally, in 2015, Golisano Children’s Hospital had its new building. An 8-floor, \$190 million hallmark of children’s health, the hospital overlooks Crittenden Boulevard and sits right next door to its old home base in Strong Memorial Hospital.

It remains a remarkable achievement, and a testament to both the community that made it a priority, and the leader that willed it into existence. But as Schor considers her legacy, the fact that the new hospital building will be inextricably linked with her tenure in Rochester gives her pause.

“There will be a great many people who say ‘Nina Schor built that building over there,’” said Schor. “And I

“Nina truly ensured that every detail of the new building was designed with patients and families in mind. She has been the face of the children’s hospital and inspired trust in our families, physicians, and donors at a time when we very much needed the community’s support.”

-Mark Taubman, M.D., URM CEO and Dean of the School of Medicine and Dentistry

don't want to downplay the significance of that. But the building is not important in and of itself. It's what we do *inside* of it and *because* of it that's so important."

Instead, the accomplishments Schor will carry with her are centered on the people she influenced — either through early career support or by cajoling them into braving the sleet and snow and moving to join her team in Rochester.

The Department of Pediatrics grew from 110 faculty members to more than 170 during her tenure. New divisions were created in palliative care, sleep medicine, allergy, and hospitalist medicine. Research centers that focused on premature infants, translational molecular programs, and red blood cell development also took root and flourished under Schor's leadership.

And Schor never forgot the early support she received as a young researcher in Pittsburgh, paying it forward to her more junior colleagues whenever possible.

"Nina has been incredibly supportive of the faculty and researchers who are trying to establish themselves," said Laurie Steiner, M.D., assistant professor of Pediatrics and Neonatology. "She's very approachable and has gone out of her way to include me and others in certain opportunities."

Schor hasn't yet decided on her next destination. A research institution may be a good fit; despite all her responsibilities here, she's continued to conduct groundbreaking studies into neuroblastoma, the most common childhood cancer. (In the past six months alone, she won the 2017 Hower Award from the Child Neurology Society, and was named Fellow of the American Association for the Advancement of Science.)

She also may stay in Rochester, where she can return to her lab full-time, while also acting as mentor to future pediatric leaders, passing the torch in a similar manner to her own mentor and predecessor, Elizabeth McAnarney. But regardless of where she ends up, one thing can be certain: Like Rochester and Pittsburgh before it, Schor will leave her next home a better place than she found it.



"One of her accomplishments that is striking — and may be less evident than our magnificent new children's hospital — is the sustained increase of extramural research funding to the department, including the funding of physician scientists, during a time when the availability of all research and training funding has diminished."

-Elizabeth McAnarney, M.D., Chair Emerita of the Department of Pediatrics

"Whether it's the clinical, research, or education mission, Nina has been an exceptionally strong advocate for her Faculty. She thinks critically about strategic goals for our department as well as the tactics necessary to make them happen."

-Timothy Stevens, M.D., Medical Director of the Neonatal Intensive Care Unit

Pediatric Feeding Disorders Program's Inventive Approach Allows Families to Thrive

Interdisciplinary collaboration allows for comprehensive care



Kennedy works with Dr. Kimberly Brown during an appointment in January.

Kennedy Wolf is a 6-year-old with Down syndrome who has always had trouble gaining and maintaining weight. Kennedy's mother, Tammy, says it dates back to her stay in the neonatal intensive care unit at Golisano Children's Hospital. In her first 72 days, she had gained just three ounces of weight.

Six years later, Kennedy is still facing eating challenges.

"Kennedy isn't particularly a picky eater. Rather, she gets tired of chewing and tries to swallow everything she eats before it's fully chewed," said Tammy. "She'll eat anything. How can we make sure she doesn't choke on it?"

Picky eating and building proper eating habits has long been called a "normal rite of passage" for most toddlers. Structuring a child's eating routine so that they are getting proper nutrients is tough enough for the average baby, but for families that have a child with a developmental disability, it can be much more difficult.

Nearly 75 percent of children diagnosed with a developmental disability have some type of feeding disorder. Most children with Autism Spectrum Disorders, Down syndrome, and other developmental disorders who have problems feeding fear new foods and often have a preference for certain brands. Children who are extremely selective run the risk of having nutrient deficiencies. Selective eating that is not treated can remain a lifelong challenge.

Five years ago, the Feeding Disorders Program — part of the division of Developmental and Behavioral Pediatrics — was started at Golisano Children's Hospital as a way to help children and families evaluate their child's nutrition, feeding behaviors and chewing/swallowing skills, and help them get on the path to eating in an age-appropriate way. They see children ages 1-10 years old who have feeding problems such as very selective eating, refusing certain foods or liquids, disruptive mealtime behavior, difficulty chewing or swallowing, or fear of choking. They also see children with complex medical conditions. These are all areas the team in the Pediatric Feeding Disorders Program aims to help.

"The interdisciplinary nature of our clinic allows for collaboration between our dietitian, speech therapist, social worker, nurses, and doctors," said Kimberly Brown, Ph.D., director of the Pediatric Feeding Disorders Program. "We provide a full nutritional analysis for patients and provide an individualized plan for parents to teach their children better eating habits."

The Pediatric Feeding Disorders Program is typically six to eight weeks of weekly or biweekly appointments, where families practice sitting for a meal and go through many of the interactions associated with eating. If a child has a really hard time trying new foods, they may begin by teaching the child to learn to interact with new foods before committing to eating it.

Kennedy started attending the Feeding Disorders Clinic about eight months ago. She has worked with Dr. Brown, speech therapist Katherine Maruska, and registered dietitian Brianne Schmidt. Katherine assisted in identifying safe and appropriate textures that Kennedy could eat, monitoring her chewing and swallowing skills while assisting with her self-feeding.

"The overall goal was to realize what she could safely eat and how to introduce new foods into her diet," said Tammy.

The team at the Pediatric Feeding Disorders Clinic ran blood work on Kennedy to see what nutrients she was lacking in her current diet. When Tammy and Brianne went over the results, they discovered that Kennedy was lacking Vitamin D and iron, so she is now on supplements for those nutrients.

"Every visit, I had a homework assignment to bring in a different food to evaluate and see how Kennedy was maneuvering with her food," Tammy said. "The overall nature of the clinic allowed us to see multiple



specialists per visit, so the collaborative nature really benefited Kennedy."

And that collaboration is about to get better. When the Pediatric Feeding Disorders Program makes their move to the new space on East River Road, providers from Developmental and Behavioral Pediatrics, Child Neurology, and Psychiatry will be co-located. The clinic will have a fully stocked kitchen, which will allow families to be comfortable in an environment that looks more like their own home.

"We want kids engaged in cooking and meal prep," Brown said. "The new area will have two rooms directly next to each other, each with observation areas. Our ultimate goal is to make home life be similar to their appointments in our clinic."

Patients will also benefit from having other providers sharing clinic space in addition to their developmental pediatrics team.

The Feeding Disorders Clinic will begin seeing patients in the Neuromedicine and Behavioral Health center in early April.



The Levine Autism Clinic: A New Model for Care

The clinic, which opens this spring, provides a sensory-friendly environment for children with autism spectrum disorder and other developmental disabilities.

It's hard to say who is more enthusiastic about the opening of the new William and Mildred Levine Autism Clinic: the patients and families who will come for care or the clinical staff who will provide it.

Both groups have reason to be excited and proud: the clinic team, patients and families helped design the space together. And they'll define a new approach to care together: this will be the region's first stand-alone clinic to integrate care of autism with pediatric neuromedicine and child and adolescent psychiatry services.

For the first time in our area, specialists in autism, child and adolescent psychiatry and neuromedicine services will work in the same space, offering multidisciplinary care to children and teens. Patients who need to see one or more providers can find them in the same clinic, and those providers can collaborate and consult more easily on the patients they share.

Clinicians in the Levine Autism Clinic will offer care in a child-friendly environment that meets the unique physical, sensory and environmental needs of children who need those services. For example, many patients with autism spectrum disorders become anxious and uncomfortable in loud, busy places, so caregivers have helped designers plan a quiet, soothing place for appointments. Clinical teams as well as patients and their families had input on the design of the clinic. Families recommended attention to lighting and noise reduction and creation of a family support and sibling care area known as the Kids Club.

"Children and families thrive when they receive care where they feel safe, calm, and comfortable," said Pediatrician-in-Chief Nina Schor, M.D. Ph.D., of the Golisano Children's Hospital. "We are proud to be a leader in patient-centric care and provide this model to all of our patients and families."

The project was supported by a \$1 million gift from the William and Mildred Levine Foundation. Todd Levine, president of his family's foundation and Alleson Athletic, and his wife, Julie, recognize the importance of easy access to high-quality autism care at Golisano Children's Hospital.



Lynn Cole, director of clinical services for the Division of Developmental and Behavioral Pediatrics, stands in a patient room at the Levine Autism Clinic.

“Helping create a stand-alone clinic where children with developmental disabilities can receive comprehensive care will allow us to reach for new heights, ensuring everyone receives the best services and care possible,” he said.

In the past year, more than 500 children in our region were diagnosed with autism spectrum disorder, leading to more than 3,500 visits. The new clinic will accommodate the growing need for diagnosis and treatment.

The clinic is housed in a 90,000-square-foot, three-story building that also brings our area a new, state-of-the-art outpatient Imaging Center. The project relocates these vital services from the University of Rochester Medical Center campus to an easily accessible location along East River Road and the I-390 corridor. The building’s top floor will be home to the Levine Autism Clinic.

The Developmental and Behavioral Pediatrics team will be co-located with neurology, behavioral and mental health programs, which is convenient for families that see specialists in each of those programs. The physical proximity of the programs will foster greater collaboration among the multidisciplinary caregivers and will benefit patients and families.

“We’re looking forward to the collaboration between programs and the ability to give patients a more convenient, accessible place to receive care,” said Lynn Cole, MS, PNP, Director of Clinical Services in the Division of Developmental and Behavioral Pediatrics. “Having all the resources patients will need in one spot will be much simpler for families. We’ve been talking a lot with patients and families — they are really excited about our move.”

After years of envisioning what this clinic could be, and seeing it through to completion, the staff is excited for the building to open too — so much so, they’re planning *two* open houses for patients, their families and the community.

“We’re hosting an event for families, community pediatricians, and schools — anyone who wants to come,” Cole said. “But we’re also offering a sensory-friendly, quieter and calmer open house because many of our patients struggle with change and doing new things differently. We want to give them a chance to experience the new clinic in a way that’s comfortable for them.”

Someone who knows what we're feeling

Family Navigator program supports families with guidance and empathy

Lisa Latten will never forget the woman's face.

She'd just spent about two hours in the office of Susan Hyman, M.D., with her 3-year-old son, Ian. Hyman had watched as Ian played, communicated, and responded to various questions and commands. Then, Hyman made her diagnosis:

Autism Spectrum Disorder.

Latten left the office in a haze as the news sank in. As she walked back into the waiting room, her gaze fell upon a woman across from her, holding a boy the same age as her own and quietly sobbing. Their eyes met, and a feeling of mutual desperation passed between them.

"I wish I could go back to that moment," said Latten. "You hear 'autism' and that's all you can think about. But I want to go back and tell her that it's not terrible. It's not awful. It doesn't mean your child won't be happy or won't have a place in the world. That feeling that you're all by yourself — it's not true. It's just that your reality will be a little bit different now."

Today, that's exactly what Latten tells people. She still sees that look on parents' faces when they walk out of the doctor's office after getting the diagnosis for the first time. But now, she's there, ready to offer her guidance and empathy. And most importantly, to show people they're not alone.

Of the 13 different sites in the Autism Treatment Network — a network of hospitals throughout the country aimed at improving the treatment of indi-

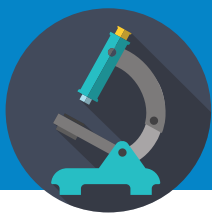


viduals with autism — Golisano Children's Hospital is the only one with a full-time Family Navigator devoted exclusively to working with families of children with autism and other developmental disabilities. Latten, who is on hand at the Developmental and Behavioral Pediatrics clinics to consult with parents and caretakers following an autism diagnosis, has served in the role since 2015.

"It was such a relief to see someone who had been in our shoes and knows what we're feeling," said Caitlin Legros, of Rochester, whose son was recently diagnosed with Autism Spectrum Disorder. "The physicians are wonderful, but there's a part that they can't necessarily speak to in terms of the day-to-day activities."

"Once Lisa came in and started working with the kids, it was just a whole different experience," said Carol Marcellette, of Rochester, who has a grandson with Autism Spectrum Disorder. "She calmed the kids right down — she was like a child whisperer. She definitely knows what you're going through and has been through the same thing that you have."

Latten's work at Golisano Children's Hospital is supported by AutismUp, a Rochester organization that supports individuals with Autism Spectrum Disorder. Now with over 2,000 members, AutismUp provides support and education to individuals, families, and professional service providers. An additional gift from Jean Warren will soon allow the Family Navigator team to expand.



Research Round Up

URMC receives \$1.9M to study Acute Lung Injury



Fabeha Fazal, Ph.D., assistant professor of Pediatrics and Neonatology at UR Medicine's Golisano Children's Hospital, has received a 4-year, \$1.9M grant to identify viable therapies that will limit acute lung injury (ALI). ALI, a major cause of respiratory failure in critically ill patients, is responsible for approximately 75,000 deaths annually. ALI occurs when capillary-alveolar barriers in the lung are disrupted, resulting in a variety of dangerous symptoms that can lead to respiratory failure. Currently, there is no treatment for ALI, which has a mortality rate between 25 and 40 percent.

However, Fazal's research has shown that the endoplasmic reticulum chaperone protein BiP

(binding immunoglobulin protein) and mitochondrial chaperone mortalin play a role in ALI due to their ability to promote inflammation and capillary barrier disruption and that inhibiting both proteins in tandem can protect against ALI. Fazal's current study aims to understand how BiP and mortalin control the proinflammatory and leaky phenotype of the lung, and potentially understand and develop a therapy that targets these proteins. Early results have shown promise.

Her research team includes co-principal investigator Arshad Rahman, Ph.D., and co investigators David Dean, Ph.D., Michael O'Reilly, Ph.D., Minsoo Kim, Ph.D., and David Yule, Ph.D.

RE/MAX Associates Eclipses Fundraising Goals, Continues Support of Golisano Children's Hospital

RE/MAX realtors are extremely devoted to making a difference in the lives of children in our community. As a Children's Miracle Network Hospitals (CMNH) sponsor, they've gone above and beyond to support Golisano Children's Hospital. Last year alone, the RE/MAX Plus and RE/MAX Realty Group raised close to \$50,000 for the children's hospital.

"RE/MAX's dedication to helping our children really is praiseworthy," said Betsy Findlay, director of Advancement at Golisano Children's Hospital. "When we opened the new tower, they committed to naming a room, which further exemplifies how dedicated the associates and brokers are to helping our community's children. We are incredibly grateful for their enthusiastic support of the hospital."

The 5th annual RE/MAX Plus Charity Golf Tournament, held on Aug. 15, 2016, raised \$16,618 and brought their total to more than \$95,000 through the tournament's history.

As part of the Miracle Home Program, RE/MAX realtors have the opportunity to make a donation for every transaction they make. Through this initiative, RE/MAX realtors raised over \$20,000 for the hospital in 2016. RE/MAX realtors also help the hospital through their annual balloon sales promotion, and they have sponsored Golisano Children's Hospital's Gala and Stroll for Strong Kids.



**Children's
Miracle Network
Hospitals**

Community Events Eclipse \$1 Million Raised in 2016



“Every penny counts.” It’s a phrase that’s said a lot. The new Golisano Children’s Hospital was built from donations, all of which fueled the construction of the new tower. Almost one-third of the donations that funded construction came from community-organized events that benefited Golisano Children’s Hospital.

One year after the opening of the new hospital, community events exceeded \$1 million raised for Golisano Children’s Hospital. From lemonade stands, bake sales and concerts to festivals and discos, for the first time in our history, these events have combined to reach this momentous number.

“It’s absolutely incredible that we’ve hit this milestone,” said Stephanie Sheets, assistant director of community affairs at Golisano Children’s Hospital. “In 2016, there were more than 250 events that benefited our kids, and we cannot stress how grateful we are to be the recipients of so many wonderful events.”

At Golisano Children’s Hospital, every gift we receive brings someone joy, fulfills a great need, or makes wonderful new things possible.

“The Rochester community, along with the surrounding region, has been so generous to us,” said Wendy Lane, Child Life Coordinator at Golisano Children’s Hospital. “Many of the play areas we utilize and the activities we offer have been graciously donated by the community.”

To organize a community event to benefit the kids at Golisano Children’s Hospital in 2017, email Stephanie Sheets at Stephanie.sheets@rochester.edu or by phone at 585-275-5268.



Autism research at URM C means quicker adoption of new therapies, and better outcomes for patients

If you're really good — and a little bit lucky — it can happen in about a decade. That's how long it takes promising clinical research to turn into widely-accepted medical treatment.

There are good reasons for this, of course. Clinical trials take years, and publishing research data in a medical journal usually requires several rounds of revisions and editing to ensure the data's quality. Then, once the information is out there, it takes a while for the majority of the medical community to adopt a new practice.

All of this serves to show why the Behavioral Interventions for Families (BIF) clinic, which launched in 2011, was so remarkable. Only two years had passed since Tristram Smith, Ph.D., joined with several researchers from universities across the nation to embark on a clinical trial that would test whether children with Autism Spectrum Disorder could benefit if their parents underwent rigorous training designed to manage their behavior.

But early results were so successful that the

department moved quickly to turn the research methods into clinical practice. While clinics such as BIF still may not reach other areas for years, families in the Rochester community are already benefiting.

Research has long been a cornerstone of the Division of Developmental and Behavioral Pediatrics, and early adoption of programs such as BIF are among the benefits. Even treatments that aren't developed in Rochester can reach our community early because our faculty are so closely plugged in to various national research efforts.

That means earlier results for patients. Daniel Deyo, a 2016 Miracle Kid, was among those to benefit from BIF. Daniel, who has Autism Spectrum Disorder, struggled through his early years, throwing tantrums that his mother, Fauna, struggled to control. But after Fauna began implementing some of the methods she learned in BIF, Daniel's behavior improved tremendously — to the point where he was able to return to elementary school.

"It changed our lives," said Fauna Deyo.



Tops Markets Continues Tradition of Supporting Golisano Children's Hospital



Tops Friendly Markets has deep roots in the Upstate New York community and has long believed in giving back locally. Through numerous fundraising events, volunteerism, and their support through the Children's Miracle Network Hospitals (CMNH), Tops' outstanding support continues to leave its mark at Golisano Children's Hospital.

Since becoming a CMNH sponsor in 2005, the company has raised almost \$1 million for Golisano Children's Hospital. More important than the money, however, is the unwavering commitment that Tops has made in helping the children in our region.

"We're so thrilled to partner with Golisano Children's Hospital and support kids in our community," said Andrew Brocato, director of community and public relations at Tops. "Our entire staff gets excited to get involved and rallies together to raise money for the hospital."

Tops goes above and beyond to support the children's hospital, providing volunteers and food for events, holding promotions and shopping sprees at its stores, sponsoring the annual Drive for Miracles Radiothon, and hosting its own fundraising events like Monte Carlo Night, as well as their annual golf tournaments.

"They're an organization that I know I can always count on," said Betsy Findlay, director of advancement for Golisano Children's Hospital. "They are always so enthusiastic and willing to get behind our cause."

Tops associates recognize the importance of giving back to the communities they live and work in, especially when they see what a difference Golisano Children's Hospital makes to this community. It was natural for Tops to join the CMNH for just that reason. The network, which includes 170 children's hospitals nationwide, is a wonderfully wide-spanning institution that forges bonds between children's hospitals and the corporations like Tops that want to help them. The special connection between Tops and the hospital goes even deeper because one of Tops' associates, Eric Czekanski, has a personal connection with the hospital. Eric is not only a manager at Tops, but also a grateful parent.

Eric's son Bryce has a rare genetic disorder called Hurler-Scheie syndrome, which brings Bryce and Eric to Golisano Children's Hospital every week for synthetic enzyme-replacement therapy. Bryce has gotten to know the hospital very well over the 13 years he's been receiving his weekly IV therapy, which lasts eight hours each session.

Bryce has created artwork for the Monte Carlo Night invitations and Kards for Kids, while he and his dad have shared their story at children's hospital events like Radiothon. The Czekanskis' dedication has inspired employees at the 19 Tops stores that support Golisano Children's Hospital to be enthusiastic advocates for the hospital.

RADIOTHON

A SMASHING SUCCESS



The Drive for Miracles Radiothon to benefit Golisano Children's Hospital raised an astounding \$197,500 on Feb. 9 and 10.

Once again, WHAM1180, 100.5 The Drive, and 13WHAM-TV joined forces to broadcast from the Strong Memorial Hospital lobby, sharing stories from our inspiring children and families. Our thanks to the thousands of people who made donations throughout the two-day event.

Wisteria Flowers and Gifts, a longtime children's hospital partner, donated colorful floral arrangements that were delivered to patients' bedsides.

A huge thank you to The Drive's Julie DePasquale, J.P. Hastings, Bill Moran, Mayor Pete Kennedy, and Scott Brooks; WHAM's Bob Lonsberry, Pauly Guglielmo, and Deanna King; and 13WHAM's Jennifer Johnson. We are so grateful for your continued support!

We would also like to thank our families who gave their time to come and support our efforts and share their story of how important the Children's Hospital is to them. Without the support of our community and events like the Radiothon, the hospital would not be able to provide world-class care in a state-of-the-art facility.

Presenting Sponsor: Tops Friendly Markets and Garber Honda

Miracle Moment Sponsors: Pettis Pools & Patio and Advantage Federal Credit Union

Special Thanks: Tops Friendly Markets, Walmart, RE/MAX Plus, Champps Sports Bar and Grill, Schramrocks Irish Pub, McDonald's, Tim Horton's, Consiliarium Group, Frontier Abstract and Research Services, the Golisano Children's Hospital nurses, and the University of Rochester men's and women's tennis teams.

thank you



Thank you to our wonderful community supporters!

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Mrs. Metzger
Midlakes Middle School 6th Grade Science Students
Barb Halbert & her knitting class

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 Stephanie Sheets at: stephanie.sheets@rochester.edu.

Upcoming Community Events

March 24, SMILE Dinner Norman Howard School

Head to the Norman Howard School, located at 275 Pinnacle Road in Rochester N.Y., from 5:30 to 7:30 p.m. for a pasta dinner to benefit the Cleft and Craniofacial Anomalies Center at Golisano Children's Hospital. Takeout meals are available for \$6. For more information contact mtobin9@naz.edu.

April 1, Ugly Disco Rochester Riverside Convention Center

Come get your groove on from 8 p.m. to 1 a.m. at this '70's celebration. The Ugly Disco is a night of fun that features live music, Twister, and more. For more information, visit www.uglydisco.com.

April 8, Daniel's Race Churchville Chili Middle School

Register online at www.daniels5k.com for the race on April 8, 2017. Walk-in registrations open at 8:30 a.m. and the race starts promptly at 9:30 a.m. Come to Churchville Chili Middle School Cafeteria. The race is a road race that ends on the outdoor track. Thank you for helping us to support families with children fighting a life-threatening illness. For more information, visit www.daniels5k.com.

May 7, Beat Brain Cancer East Rochester High School

This is the second annual 5K and 1-mile walk in memory of Desiree Stockholm. Desiree passed away on 11/21/2014 after a courageous battle with brain cancer. This event is to bring awareness to brain cancer, and all proceeds will be donated to Golisano Children's Hospital for a plaque dedicated in Desiree's honor. For more information, visit www.beatbraincancer5k.com.

June 3, Stroll for Strong Kids & 5K Genesee Valley Park, 1000 East River Road The 5K race begins at 8:30 a.m., followed by the walk at 10:30 a.m.

The event will continue until 1 p.m., with family-friendly activities, including over a dozen bounce houses, carnival games, photo booths, and much more! The event is presented by Abbott's Frozen Custard. Register, create a team, and fundraise on the Stroll for Strong Kids. www.givetokids.urmc.edu/stroll.

June 10, Team Ali-Gaiter Clambake 321 Monroe St., Honeoye Falls Honeoye Falls Fireman's Training Grounds from 2 p.m. to 7 p.m.

Attendees will enjoy clams, pulled pork, hot dogs, salads, desserts, and drinks. There will also be live music, raffles, bounce houses, costume characters and pony rides. Tickets are available in advance and at the door. For more details, please contact Jackie Klube at 585.704.4124.

Save the Date 2017

August 19 – GCH Gran Fondo

August 25-26 – Fairport Music Festival

August 28 – Golisano Children's Hospital Golf Classic

October 21 – Golisano Children's Hospital Gala

Golisano Children's Hospital Advancement Office

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