

UR MEDICINE'S GOLISANO CHILDREN'S HOSPITAL

STRINGKIDS

NEWS



2016 VOL. III



2016 Fairport Music Fest is ready to rock

Cleft and Craniofacial Center
uses team approach

| Treating Duchenne
Muscular Dystrophy

| Complex Care Center opens

DEAR FRIENDS —



Nina F. Schor

*Nina F. Schor, M.D., Ph.D.
Pediatrician-in-Chief,
Golisano Children's Hospital,
William H. Eilinger Chair of Pediatrics*

It has been 30 years since I finished my residencies in Pediatrics and Child Neurology. But in that time, many childhood diseases that frequently required hospitalization - epilepsy, diabetes, cystic fibrosis, asthma - became predominantly outpatient diseases. And other diseases that filled hospital beds - rheumatic heart disease, H. flu meningitis - occur only rarely today. This is wonderful news. Most ill children are treated at home with their families in an environment that is private, less threatening, and less disruptive to everyday life. But what this also means is that the small fraction of ill children who need to be hospitalized, many of whom would have succumbed to their illness in years past, have diseases that are more complex and more chronic than anything we were called upon to treat 30 years ago. This issue of our newsletter illustrates that Golisano Children's Hospital is at the forefront of making the lives of children with complex, chronic disorders longer, more comfortable, and more productive.

In the pages that follow, you will learn about a new way to get genes into the lungs of newborns that

enable them to bring oxygen into their bloodstream. You will find out about new studies aimed at enhancing and prolonging muscle (including heart) function in children with Duchenne muscular dystrophy. You will read about the multidisciplinary team that cares for children who are born with craniofacial abnormalities like cleft lip and cleft palate. And you will see how our innovative new center for young adults with complex disorders provides care that helps these adults with childhood-onset health conditions remain healthy and become as self-reliant as possible in caring for their own health.

None of this would be possible without the steadfast support of you and others like you. Take, for instance, our dedicated friends from the Fairport Music Festival, who have been there for us so many times in the past and have now made a \$750,000 commitment to building and equipping our new pediatric cardiac operating room. We are so very fortunate to live in a community that puts the health and well-being of its youngest and most fragile members first!

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Gala continues drive toward Phase 2

Grace Esposito was born in September 2011 with a congenital diaphragmatic hernia pushing her heart out of place and leaving little room for her lungs to grow and form. “Amazing Grace” fought on for a year and a half, enduring five surgeries and spending a week on a heart-lung bypass machine, before losing her fight in February 2013.

Long before she was born, Grace’s parents, Jennifer Johnson and Vinnie Esposito, had given back to Golisano Children’s Hospital. And this year, they will serve as honorary chairs of the 29th Annual Golisano Children’s Hospital Gala at the Rochester Riverside Convention Center on Oct. 22.

During their time at the children’s hospital, Jennifer, Vinnie, and Jennifer’s colleagues at 13WHAM led the creation of Grace’s Garden, committing \$350,000 to the outdoor garden, that provides patients a healing change of scenery during their

stay at the children’s hospital. They also fulfilled a \$100,000 pledge along with Rochester-area Kiwanis clubs for a NICU room in Grace’s name. Jennifer, who serves on the children’s hospital’s Board of Directors in addition to her role as a reporter and anchor at 13WHAM, has also joined several other local media members to host the children’s hospital radiothon, which annually raises several hundred thousand dollars for the care of children.

The presenting sponsor of this year’s Gala is The Cabot Group. Company owner Mike Smith has been a member of the children’s hospital Board of Directors for six years, and his company has been the presenting sponsor of the Gala since 2008. The Cabot Group was a 2010 Miracle Maker

recipient for Outstanding Commitment by a Corporation, and the company has consistently supported other children’s hospital initiatives, including the annual Golf Classic.

The event, themed “A Royal Celebration,” features a live and silent auction, dinner and entertainment featuring Steve Augeri, former lead singer of Journey; Wally Palmar, The Romantics, and Terri Nunn from The Berlins. Sponsorships are available starting at \$1,000 and tickets are \$200 per person. Proceeds from the gala will support Phase II construction at Golisano Children’s Hospital.

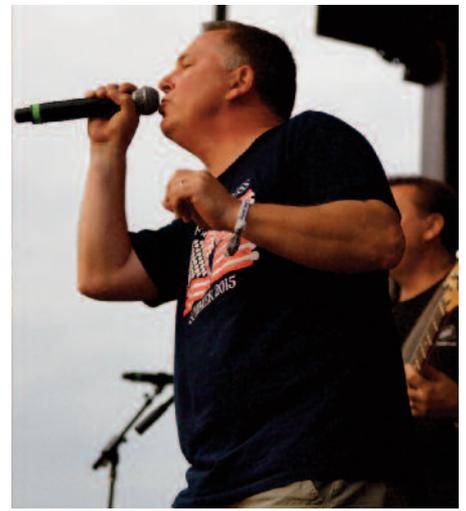
For tickets, sponsorships, or to donate auction items, please contact Betsy Findlay at 585-273-5933 or bfindlay@admin.rochester.edu.

Vinnie Esposito and Jennifer Johnson, from 2012 with Avery and Grace.



Fairport Music Festival an Instrument of Hope





The noise you're hearing from the Fairport Music Festival isn't just great music. It's the sound of thousands of people coming together in support of the region's only children's hospital. The beat goes on – to the tune of \$923,328 in 11 years, and organizers Rob Burch and Andy McDermott don't plan on slowing down any time soon.

"The children's hospital benefits so many in Western New York," said McDermott. "It's important to help when the hospital means so much to the community."

Started in 2005, the Fairport Music Festival has grown exponentially and become one of the most anticipated community fundraisers of the year. With dozens of bands, food vendors galore and numerous activities for kids culminating at the end of the summer along the Erie Canal, many have it bookmarked on their calendar months in advance. This year's 12th annual Fairport Music Festival will take place on Friday, August 26 and Saturday, August 27, 2016 along Liftbridge Lane.

"We strive for excellence in the festival with the idea that the money will flow to the children's hospital from that," said McDermott.

Fairport Music Festival will kick off on Friday at 5 p.m. with three bands playing on the festival's Railroad Stage. The fun will continue Saturday from noon to 10 p.m. and will feature music on four different stages, with more than 30 bands performing. Guests will enjoy a variety of food offerings, with favorites from local food trucks and nearby Fairport eateries. With entertainment for everyone in the family, the day will also feature kids' activities from noon to

6 p.m. including bounce houses, arts and crafts, and more!

"The Fairport Music Festival is one of the largest community events that supports Golisano Children's Hospital, and it's also one of the most well-run, enjoyable events of the summer," said Stephanie Sheets, assistant director of community affairs at Golisano Children's Hospital. "If you ask anyone who has been to the festival, they'll tell you they never want to miss it, and that's a testament to the work that Andy McDermott, Rob Burch, and their committee do, not only for the festival, but for the community as well."

With the support of children's hospital advocates and the Fairport community, last year's festival raised \$154,827.16. In addition to funding multiple items in the old children's hospital, funds from the event have also supported the 7th floor Play Room, a large Nurse Manager station, two giraffe omnibeds for the neonatal intensive care unit, a pediatric anesthesia machine, and many more furnishings in the new children's hospital.

"It's a hobby for us, so it really doesn't seem like work," explained Burch. "One would be hard-pressed to find a more worthwhile hobby than helping the children in our community."

Buy your tickets online now until August 25 for the special price of \$15. Tickets will be sold at the gate for \$20 on Friday and Saturday. One ticket gets you event access for both nights. Kids ages 12 and under are free. Discounted tickets are available with sponsorships.

To learn more about the event and to purchase tickets, visit www.fairportmusicfestival.com.



The courage, blessings of children, families on display

Stroll for Strong Kids raises close to \$400,000 for Golisano Children's Hospital

The Stroll for Strong Kids and 5K Run has evolved into a true community event showcasing the inspiring children treated at UR Medicine's Golisano Children's Hospital. Twenty years of community involvement have made the Stroll what it is today, an annual Rochester tradition. Each shirt worn by a team during the Stroll tells a story. Each team honors a child.

Over 10,000 people filled Genesee Valley Park for the 20th annual Stroll for Strong Kids on June 4 to carry on legacies, honor their miracles and raise hundreds of thousands of dollars to support the critical research, patient care and the community health programs of Golisano Children's Hospital. The event - which was themed "Royal Fun" - featured thousands of people, including children's hospital staff and area community pediatricians, dressed in a child's favorite color or character.

"The Stroll is a picnic with 10,000 of our closest friends," said Steve Terrigino, Chairperson of the Stroll for Strong Kids. "We had another beautiful day and yet another record-breaking year in terms of attendance."

"It's a great family event and a great way to give back to the children's hospital," said Matt Elliot, a Grateful Parent and captain of Team Addy. Matt's daughter, Addy, was diagnosed with three congenital heart defects at just four days old. "Addy had open heart surgery at just 14 days old. The hospital literally saved her life. The Stroll is a big deal and our way to pay it forward, just like so many did before us."

The sun was shining down as 5K runners took their marks to kick off the day at 8:30 a.m. and it continued throughout the walk and into the afternoon as families enjoyed food and more than a dozen activities. Abbott's Frozen Custard, the event's presenting sponsor for the fifth consecutive year, provided runners and strollers with chocolate and vanilla frozen custard. Subway, a Stroll favorite, provided more than 6,000 sandwiches for participants and Zweigle's offered plenty of its appetizing samples. Families munched on more goodies, including KP's Kettle Corn, as they made their way through the activity tents and bounce houses. AP Enterprises provided bulldozers, tractors, and more.

With a total of \$23,605 raised at this year's event, Lauren's Legacy was the top fundraising team for the fifth year in a row. Other top teams included Mia's Marchers (\$13,862), Team Addy (\$12,416), Craig's Cookie Monsters (\$11,916), and Honoring Owen (\$9,175).

"The Stroll is made up of individuals and teams, both large and small, who are all strolling for a reason - for a child," said Stephanie Sheets, assistant director of community affairs at Golisano Children's Hospital. "The event allows families and friends to give back to the hospital that has cared for or is caring for their loved one. Thank you to our participants, volunteers, sponsors, and the Stroll committee who make this an outstanding event for our families, year after year."



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Innovative Approach Team

Pediatric Cleft and Craniofacial Center's team approach simplifies care for complex problems – using a multidisciplinary team of medical subspecialties to provide optimal care

Jodi and Frank Gleichauf didn't know what to do when they were told their baby would be born with cleft lip and palate. Their daughter, Laila, had a bilateral facial cleft that would require surgery to repair after her birth. A cleft, or separation of the upper lip and/or roof of the mouth, occurs very early in development of a fetus. Although cleft lip and palate is the most common anomaly of the head and face, it occurs in only one of every 1,000 births. In addition to her cleft, Laila was also diagnosed with a rare congenital facial condition called Goldenhar syndrome.

"It was scary," said Jodi, a resident of Naples, NY. "Frank and I were very nervous. The doctors did prep us on what to expect, but nothing can prepare you for the journey."

Laila's condition required a two week stay in the neonatal intensive care unit (NICU) at UR Medicine's Golisano Children's Hospital where she required special feeding therapy to make her discharge safe.

In the first year of life, Laila required two reconstructive surgeries by the pediatric plastic surgery team; her cleft lip was repaired at 5 months and her cleft palate was repaired at 10 months of age. Both surgeries took their toll on Laila and required Jodi to be constantly monitoring her so that she did not rupture the areas that were repaired. Laila's cleft lip and palate were repaired, but her journey is still not over.

The Cleft and Craniofacial Team

The Pediatric Cleft and Craniofacial Center at Golisano Children's Hospital cares for more than 500 patients a year with various facial differences. Cleft lip and palate is the most common surgery performed at the Cleft and Craniofacial Center, and the treatment requires the involvement of experts from many subspecialties.

Cleft and craniofacial patients are evaluated and treated by as many as 10 subspecialists including: plastic/craniofacial surgeon, pediatric neurosurgeon, orthodontist, pediatric dentist, sleep specialist, speech and language pathologist, otolaryngologist, audiologist, ophthalmologist, genetic counselor, social worker, psychologist, and a nurse



team coordinator. The comprehensive nature of the cleft and craniofacial team allows patients to receive optimal care from a diverse group of medical professionals.

"Our team does a great job exemplifying a model of multidisciplinary care for the University," said Clinton Morrison, M.D., Director of the Cleft and Craniofacial Center. "We are able to get all our subspecialists into one place at one time to meet the needs of our families without them having to come to multiple visits. We're able to put our heads together."

Benefiting from a Team Approach

The Gleichauffs drive over an hour to Laila's appointments at Golisano Children's Hospital. Laila, now 5 years old, just graduated from kindergarten.

She, like all the other patients of the Cleft and Craniofacial Center, is followed on an annual basis. During her appointment she meets with all of the relevant providers caring for her complicated condition who then formulate a treatment plan for the coming year.

"It's tremendous. If we didn't have the craniofacial team, I don't know where we would be," said Jodi. "I try my best to do everything to help her through it, but I'm so glad they are that close to us so that we can get all the care that she needs. We'd be lost without them."

"Getting all of these doctors in one room after clinic allows for the most comprehensive single visit possible," said Morrison. "After seeing patients, each provider gives their recommendations for each child. Then, our nurse team coordinator works with the family to ensure they understand and have no issues implementing their child's treatment plan."

Communication is one of the team's most important goals. "We recognize the importance of making sure that children and their families stay in close touch with our team members," said Melisande McCheyne, N.P., team coordinator of the Cleft and Craniofacial Center. "It's critical for our patients and families to have all the information they need so they aren't surprised during any part of the journey."



Dr. Clinton Morrison checks a child's jaw line as a part of a routine evaluation.



Erin Shope, DMD, of Eastman Institute of Oral Health, meets with patients to provide nasoalveolar molding prior to their surgeries, and follows up with them yearly.



Nurse practitioner Melisandre McCheyne acts as liaison between patients, families and the craniofacial team.

If you have questions about the Pediatric Cleft and Craniofacial Center and how it may be beneficial to a child, contact the team at 585-275-1000.



Not forgotten

hospital physicians work to treat, study the rarest of diseases

In the beginning, the nurse could find his veins. She'd squeeze his arm and flick his skin and watch the lines of blue and purple push to the surface.

But this never lasts forever. Over time, veins get harder to find, and smaller ones can collapse from overuse.

This isn't an issue if you only need a single injection. But when you need 92 of them — one each week for nearly two years — then you need another option.

Since April 2015, Nicholas O'Neill has traveled nearly three hours by car every week from southeast of Syracuse to Golisano Children's Hospital. Here, in the confines of the Clinical Research Center, he sits in his wheelchair for a few more hours while nurses administer an injection to treat his Duchenne Muscular Dystrophy (DMD), a genetic disease that results in severe muscle degeneration and a life expectancy of 25 years old.

These injections are part of a brand new research study. Doctors are testing a new drug that they hope will aid them in the fight against DMD. And for the first time, children who have already lost the ability to walk were invited to apply.

It's winter time, and this particular Tuesday marks Nick's 30th visit. He now has a port installed on the left side of his chest, so nurses can easily give him injections without searching for a vein. It's a quick procedure, but Nick must remain for several hours so nurses can monitor his vital signs and responses to the drug.

Nick, 13, of Norwich, Chenango County, gazes up at the television above him. There's a long list of shows that he names as his favorites: *Ellen*, *Jimmy Fallon*, *Agents of SHIELD*, *Gotham*. He just finished the entire *Friends* series on DVD.



Today, a sci-fi film has captured his interest.

His big eyes shift downward to the applesauce in front of him. He lowers his head to just above the container, to give his arm the shortest possible route from table to mouth.

His mother, Allison, watches quietly as he looks back up at the television.

A lonely diagnosis

The National Organization for Rare Disorders has a threshold for the diseases that qualify for its official classification of "rare." To earn that designation, a disease has to affect fewer than 200,000 people at any given time.

DMD is only found in 15,000 children and young adults at any given time.

"It's the most common muscular dystrophy in children, but still a very rare disease overall, so, the best care is



“It’s the most common muscular dystrophy in children, but still a very rare disease overall, so, the best care is available only in a few special centers.” – Emma Ciafaloni, M.D.

available only in a few special centers,” said Emma Ciafaloni, M.D., professor of Neurology and Pediatrics at the University of Rochester Medical Center, who treats Nick O’Neill and is among the researchers running the clinical trial.

A disease of this rarity and sophistication can’t be properly treated by a pediatrician, or even a single specialist.

In addition to Ciafaloni, patients with DMD at Golisano Children’s Hospital also see pediatric pulmonologist Karen Voter, M.D., for the breathing issues that tend to develop in late childhood. Pediatric endocrinologist David Weber, M.D., sees them for growth and bone management issues. And they go to pediatric cardiologist Carol Wittlieb-Weber, M.D., who monitors their hearts, which can become weaker due to DMD.

“If you have Duchenne’s and you live in the northeast, you come here, or Cincinnati, or Pittsburgh, or New York City, and that’s it,” said Ciafaloni. “It really does take a village to care for these kids, and that’s a very difficult thing to have unless you are an institution of this caliber.”

DMD is among several rare diseases that are studied within the hospital’s Neuromuscular Division and the Division of Child Neurology. Most notably, the division is home to the University of Rochester Batten Center, where physicians treat and study Batten Disease, a fatal disorder of the nervous system that begins in childhood. It is estimated that less than 1,000 people in the United States are living with Batten Disease at any given time.

But while efforts are being made, advances can be slow. There aren’t the same resources available to study diseases such as DMD compared with more common ailments, meaning money for research is scarce and new treatments don’t come along very often.

And even within a disease that is already tremendously

uncommon, there are a variety of different mutations. Nick’s mutation only occurs in 13 percent of DMD patients.

Hope for the future

This means Nick’s affliction represents a rare subset within one of the rarest of rare diseases. But at Golisano Children’s Hospital, these patients are not forgotten.

The clinical trial that Ciafaloni is helping to run focuses on this exact subset of patients. Only 24 children are participating, and to find these patients, doctors had to search all over the country. Nick was one of them.

“We feel so lucky that we’re able to just come here for this – it’s been one of the first positive things we’ve had to focus on in years. We would’ve gone anywhere to participate,” said Allison O’Neill. “This medication, if it works, it’s not going to help him stand or walk again, but we’re hoping that he can eat, and hold his books, and play videogames, and write and draw.”

And on a Wednesday in June – Nick’s 58th visit – there are already several gains from the winter. Instead of lowering his head to the table to eat, he can bring his hand all the way up to his mouth. When he goes to the movies, he doesn’t need to rely on his mother to give him his popcorn any more. If he gets uncomfortable while sitting or in bed, he can more easily shift himself instead of needing to call for help.

“The things they’re doing now with kids who are first diagnosed is much more advanced now than it was a decade ago,” said Allison O’Neill. “I wish we knew some of the things then that we know now, because maybe Nick would still be walking.”

But Allison O’Neill keeps sending her son back for treatment every week. Both for his sake, and for all the Nicholas O’Neills of the future.





Dean receives \$3M to study electroporation and ARDS

David Dean, Ph.D., professor of Pediatrics and Neonatology at the University of Rochester Medical Center, has received a \$3 million grant to explore a novel method of gene therapy delivery that could greatly benefit patients with acute respiratory distress syndrome (ARDS).



The syndrome, which occurs after trauma such as an injury or pneumonia, causes alveoli (tiny air sacs in the lungs) to take on too much water and prevents the lungs from efficiently processing oxygen. It affects about 150,000 people each year, and there is no cure — about 40 percent of people who are diagnosed die as a result.

Dean's approach attempts to influence the affected alveoli from the inside out by using gene therapy to communicate with the cells' nuclei and decision-making

centers. Using a carefully-devised DNA compound, the treatment compels lung cells to release their extra water, allowing them to function properly again. Using a process called electroporation, Dean delivers a measured shock of electricity that causes the cells in a target area to briefly open, allowing DNA inside.

Electroporation is a burgeoning science in the field of gene therapy and there is minimal literature on its use across the chest and lungs. The four-year grant, from the National Institutes of Health, will allow Dean to continue to test its safety and efficacy.

"Our research has generated very encouraging results thus far," said Dean. "If it continues to show promise, our next step will be a clinical trial."

The grant, which began earlier this year, supports four years of research.

Neonatology renewed for second stint in prestigious research network

The Neonatology Division at UR Medicine's Golisano Children's Hospital has been

renewed for its second consecutive stint as a part of National Institute of Child Health and Human Development (NICHD) Neonatal Research



Network. The University of Rochester Medical Center, in partnership with University at Buffalo, received \$1.2 million from the NICHD and is one of just 15 major U.S. intensive care units that belong to the network. The mission of the network is to join hospitals together to answer questions about the health of newborn babies that cannot be answered by one hospital alone.

"The network is a highly competitive, respected collaborative that performs clinical trials in newborns," said **Carl D'Angio, M.D.**, Chief of the Neonatology Division at Golisano Children's Hospital and principal investigator. "Our joint partnership with University at Buffalo makes clinical trials available to children across Western New York."

Cocktails for a Cause stirs up friendly competition



On March 9th, Golisano Children's Hospital's supporters poured into Grappa for "Cocktails for a Cause."

The event turned into a friendly competition between Golisano Children's Hospital Board members and physicians as they created some special cocktails to serve to the

hundreds of guests who came out to support this event.

Guest bartenders Mike Goonan and Ann Pettinella kicked off the event, Jeff Davis and George Alfieris, M.D., Director of Pediatric Cardiac Surgery, took the middle shift, and Jennifer Johnson and Walter Pegoli, M.D., Chief of Pediatric Surgery, finished the night pouring drinks behind the bar. Together, thanks to a match from the

Del Monte Hotel Group, more than \$3,400 was donated to the children's hospital.

"We are so grateful to Grappa for hosting this wonderful event and supporting such an important cause," said Betsy Findlay, director of Advancement. "This unique event allowed our Board members and physicians to get in the competitive spirit to raise money for kids. We cannot thank everyone who came to the event enough for their support."

Longtime children's hospital supporter raises \$13K through haircutting fundraiser

Joe Franch didn't always used to look like this.

"I've actually always had very short hair, contrary to what people seem to think now," said Franch, a Victor resident.

If you'd met him in the past few years, though, you'd be forgiven for mistaking Franch for a latter-day flower child. He's spent much of the last decade growing his hair out, cutting it, and then growing it out again, for Locks of Love, a nonprofit organization that provides hairpieces to financially disadvantaged children who have lost their hair as the result of cancer treatment.

But Franch's long hair has generated more than just a handful of hairpieces. He's also gotten many questions from friends, colleagues, and neighbors about the change in his hairstyle, and once he starts talking about his reasons for doing it, they ask how they can offer their support.

"That's when I started finding that people were willing to offer



support financially as well," said Franch. "So I thought, 'OK, in addition to donating the hair to Locks of Love, maybe I can generate some monetary donations as well.'"

The first time he cut his hair, a contribution was made to Camp Good Days and Special Times, a free camp for children and families touched by cancer and other life-threatening illnesses. And most

recently, he cut his hair for Golisano Children's Hospital, raising \$13,000.

For Franch, the area director for Subway restaurants, working with Golisano Children's Hospital was an easy choice - he'd already been doing so for nearly 10 years. He's worked with area Subway restaurants to provide free submarine sandwiches to the attendees of the Stroll for Strong Kids and other children's hospital events.

"The people who attend these walks - you see them year after year," said Franch. "Some of them have lost children, but they keep coming back with these big teams to be a part of it. The franchisees, especially the ones that participate and come to hand out sandwiches, we're always just so touched."

And the partnership has been invaluable to Golisano Children's Hospital.

"Joe's support - and that of the various franchisees who supply sandwiches - has helped to make the Stroll for Strong Kids the event that it is," said Stephanie Sheets, assistant director of community affairs for Golisano Children's Hospital. "We're so grateful for his continued support."

*"So I thought,
'OK, in addition to donating
the hair to Locks of Love,
maybe I can generate some
monetary donations as well.'"*

— Joe Franch



Special thanks to all of our sponsors

Tops Friendly Markets campaign soars to a new level

Tops Friendly Markets has been an active supporter of Golisano Children’s Hospital for more than 10 years and continues their dedication to area children. Through various efforts, Tops has named the interior of the new building’s Healthy Eating Kitchen and the Play Pod. In recent months, Tops has engaged in several fundraising efforts, including their annual **Golf Tournament** and the **10th annual Monte Carlo Night**.

Organized by Dan VanAuker, the Tops Golf Tournament has raised close to \$100,000 in the last two years. The event, held at Victor Hills Golf Club, has been a sell out every year.

The 10th annual Monte Carlo Night raised \$13,700. Started in 2006 after Sheryl and Eric Czekanski’s son, Bryce, was diagnosed with a rare disease, the annual Monte Carlo Night has been a way for the family to financially support the hospital that has helped so many in the community, including Bryce. To date, they have donated \$116,300 to the children’s hospital.

Thank you to all of our friends at Tops Friendly Markets for their tremendous support and commitment to our efforts at Golisano Children’s Hospital.



Daniel's Race honors the legacy of 16-year-old with melanoma

Imagine running 5 kilometers.

Now, imagine running 5 kilometers while you're in the midst of fighting for your life against an opponent you can't even see.

That's exactly what Daniel Myslivecek did when he ran in the inaugural Daniel's Race, which took place in 2006, two years after he had been diagnosed with metastatic melanoma at the age of 14. Despite being in the midst of chemotherapy treatment, Daniel, an athletic young man, crossed the finish line in just over 30 minutes.

When medical bills began piling up, friends and family came to the aid of the Mysliveceks, and the idea for the 5 kilometer road race was hatched.

"At that time, Daniel was in the middle of all of his chemotherapy and we were flying all over the country trying to get the latest and greatest treatments that were available," said Dean Myslivecek, Daniel's father. "We were caught up in that, trying to manage his health care and not focus on his finances."

Daniel's Race, which was started by friends and former soccer teammates of Daniel's, honors the courage and strength that the entire Myslivecek family showed while their eldest child and brother was enduring chemotherapy and treatment for his melanoma which ultimately took his life.

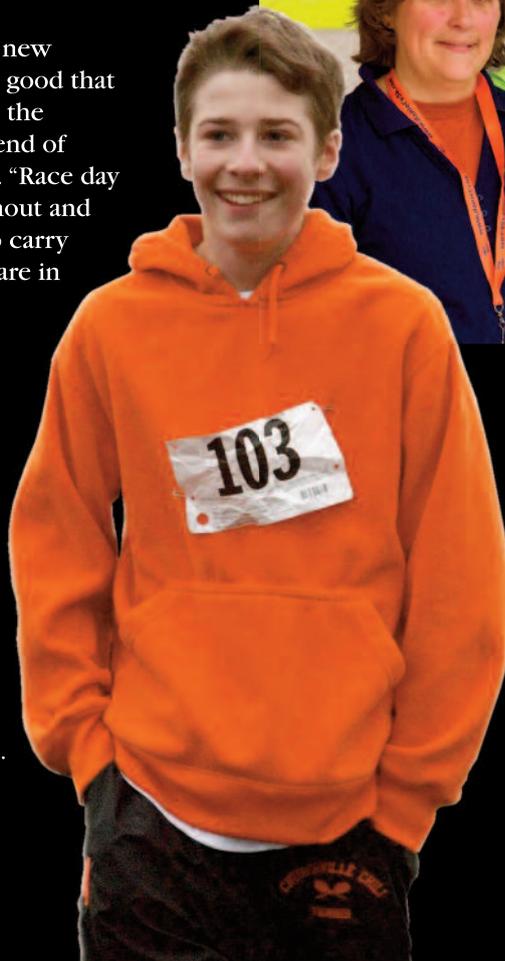
Dean and his wife, Tammie, say that there is no way they could have gotten through this difficult time without the support of Daniel's friends, who organized the race.

The Daniel's Race committee is dedicated to completing a \$25,000 commitment for a caregiver alcove in on the 7th floor of the new children's hospital.

"Being able to see Daniel's name in the new children's hospital has made us realize the good that we are doing, and that it's truly something the community enjoys," said Kevin Bauer, a friend of Daniel's and an active committee member. "Race day is never an easy day for any of us. The turnout and support from the community pushes us to carry on his legacy while helping out kids who are in a similar situation that Daniel was."

"We are really fortunate to have such a wonderful institution here in Rochester," said Dean. "Too many people take for granted what we have or may not know what we have. The hospital not only meets the needs of the children, but the entire family. We are dedicated to supporting the hospital in any way we can."

Daniel's fight against melanoma brought a community together, many of which still trek to Churchville-Chili High School every April to honor his memory. To date, Daniel's 5K has raised over \$100,000 for charities in the Rochester area.





Complex Care Center remaking treatment for adults with childhood diseases

Children with complex, lifelong medical conditions face many challenges; one of the biggest happens when they turn 18 and have to make the transition from pediatric to adult primary care.

A new UR Medicine primary care practice opened in March 2016, and it's a welcoming, warm and comfortable "medical home" for these patients and their families.

The Center is Rochester's first primary care practice dedicated to caring for adults with chronic childhood-onset conditions such as cystic fibrosis, sickle cell anemia, childhood cancers, autism, and intellectual and developmental disabilities.

A primary care practice devoted to adults with childhood diseases is not only new in Rochester: across the nation, only a few such centers exist, but demand for this type of care is rising as the patient population grows. Thanks to medical advances, more than 90 percent of children with special health care needs now reach adulthood, and for some conditions, adult patients outnumber children.

"As the leader in complex pediatric care for the region, families rely on the Golisano Children's Hospital when their children need advanced medical care, and they also turn to our system for help as their children become adults," said Mark Taubman, M.D., CEO of the University of Rochester Medical Center and Dean of the University of Rochester School of Medicine and Dentistry. "Our new Complex Care Center marks a significant commitment by UR Medicine to improve health transitions and address the special needs of these patients throughout their lives."

The Center offers specialized outpatient services to

better meet the needs of patients who often have multiple, severe conditions that require close management, and who face disparities in accessing health care. Patients who graduate from pediatric focused care often have a combination of challenges moving to an adult primary care setting. They may have difficulty finding a provider, and lack of reliable access to outpatient care often results in preventable Emergency Department visits and hospital stays.

"We developed the Complex Care Center model over the past several years by really listening to our patients and families," said Tiffany Pulcino, M.D., M.P.H., the Center's director. "We know the challenges they face, and our entire team is passionate about making health care better for them. We want to provide them a medical 'home' in the truest sense of the word - a place where they can come and feel welcome, cared for, and supported."

The Complex Care Center adds to the array of programs and services UR Medicine provides patients with intellectual and developmental disabilities (IDD). Margy Mattison, mother of two sons with MECP2 Duplication Syndrome, a rare neurodevelopmental disorder, will rely on the Center to help manage care for Tyler, 21, and Josh, 19. She credits Pulcino for helping her and her family transition from pediatric primary care to the adult setting - which has been especially challenging during her sons' frequent hospitalizations.

"I feel truly blessed to have a doctor, a go-to person, who understands their needs; it is huge to have someone on our side," Mattison said. Providers and care managers will have fewer patients than in a traditional primary care practice, allowing adequate time to work with patients and develop care plans. The care team is geared to helping patients

navigate the health care system to reduce preventable ED visits and hospitalizations. An Inpatient Consult Provider will divide clinical time between the Complex Care Center and UR Medicine-affiliated hospitals to collaborate with hospital providers on inpatient care, and facilitate a smooth transition from hospital to home when a patient is discharged.

In addition to primary care, the new practice will offer other essential services, including nutritional counseling, physical therapy, respiratory therapy, occupational therapy, and a lab draw station, with plans to add mental health services later on.

Access to oral health care is a significant unmet need – particularly for patients with intellectual and developmental disabilities – in large part because there are not enough dentists trained to care for them. The Eastman Institute for Oral Health (EIOH) has three clinic rooms in the Complex Care Center, equipped with handicap-accessible dental chairs, to provide dental care to both adult and pediatric patients. EIOH is also establishing residency training at the center, ensuring future generations of oral health specialists gain experience in treating complex patients. EIOH residency training is made possible through a Health Resources and Services Administration grant.

The Center's concentration of patients with childhood-onset conditions makes it an ideal setting for research on the impact of these conditions on adults and how to optimize their health and functional status. Research scientists from the UR Ernest J. Del Monte Institute for Neuromedicine will have space onsite and seek input from the Center's caregivers as they work to discover more effective therapies and interventions.

"The key to cutting-edge health delivery is a deep understanding of patients' underlying issues and our researchers will benefit from close collaboration with providers and their patients at the Complex Care Center," said John J. Foxe, Ph.D., Director of the Del Monte Neuromedicine Institute. "Research and clinical delivery go hand-in-hand – that's how you get to better treatments and therapies." Through the research enterprise, patients at the Center will have access to advanced diagnostic testing and emerging treatments in clinical trials.

The Complex Care Center team will also explore new approaches to caring for patients with complex needs. Only a generation ago, patients with conditions like sickle cell disease or cystic fibrosis did not survive to adulthood, so medical providers haven't formed consensus on the best approaches to care for adult patients. Resources for providers and patients are in short supply. The center aims to be a resource for primary care providers in Rochester and the region who also see patients with complex conditions by offering them information and support – including phone consultations, educational sessions, and patient care protocols designed for them. A Greater Rochester Health Foundation grant supports the Center's workforce development initiatives, web development, communications, and patient and community engagement.

Several local and national organizations have been instrumental in the center's launch, including the Farash Foundation, which donated the building that houses the Complex Care Center to UR Medicine; the national Cystic Fibrosis Foundation, which provides grant funding for UR Medicine's Cystic Fibrosis Center; and the Loboazzo-Walsh Family Foundation, which donated funding.

Fast Facts

UR Medicine Complex Care Center

Rochester's first primary care practice dedicated to adult patients with childhood-onset diseases and conditions. Eastman Institute of Oral Health delivers greatly needed dental services to adult and pediatric patients here.

The clinic space

Location 905 Culver Road

Area 2500 sq.ft.
currently 8 treatment rooms,
including 3 dental clinic rooms

On-site Many other essential services, including: physical therapy, respiratory therapy, occupational therapy, nutritional counseling, and a lab draw station; mental health services will be added.

Research Scientists from UR's Ernest J. Del Monte Institute for Neuromedicine will be onsite as they work to discover more effective therapies and interventions. Patients at the center will have access to advanced diagnostic testing and emerging treatments in clinical trials.

Design Used input from patients and family:

- Four-foot wide doors for wheelchair access
- Low counters for patients at wheelchair height
- Dental rooms with fully moveable, adjustable chairs so patients with mobility issues can be comfortable during treatment
- A quiet room for patients with sensitivity to light, motion, and noise

Patients

Hundreds of patients from Rochester, Ontario County and the southern tier with childhood-onset conditions, including:

Autism Spectrum Disorder	Metabolic disorders
Cerebral Palsy	Multiple functional difficulties
Childhood cancers	Myotonic Dystrophy
Congenital Heart Disease	Sickle Cell Disease
Cystic Fibrosis	Spina Bifida
Intellectual & developmental disorders	

The care team

Tiffany Pulcino, M.D., M.P.H., Complex Care Center Director; Assist. Prof., Department of Medicine/Pediatrics, URM – internal medicine-pediatrics provider who specializes in patients with complex medical conditions

Steven Scofield, M.D., Assoc. Prof., Department of Medicine, URM – internal medicine-pediatrics provider who specializes in care of cystic fibrosis

Adela Planerova, D.D.S., M.S. (Medical Management) Clinical Assist. Prof., Eastman Institute for Oral Health – dentist who specializes in treating patients with special needs, pediatric patients, and underserved populations.

Plus – a multidisciplinary care team that helps ensure patients are up-to-date with their wellness care, have access to health care resources they need, and can successfully navigate all stages of the health care.

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 or 585-275-2268



- Thank you to St. John Fisher College and Nazareth College for the participation in Battle of the Beaks. Together, they raised \$2,215 to be donated to Golisano Children's Hospital.
- A big thank you to the organizers, clubs, and participants at Cycle for Hope! Cycle for Hope this year was able to donate \$11,180.46 to GCH!
- We are grateful to Jam at the Ridge for holding an amazing Phil Vassar concert and donating a portion of ticket sales to GCH!
- Red Jacket Jr. Hoops held their Hoops for Hope basketball tournament and donated \$4,000 to GCH. Thank you!
- Special thanks to all who attended and organized the Cleft and Craniofacial Pancake Breakfast at Zebb's. They raised \$2,200.
- We appreciate the \$1,500 donation raised through Constellation Brands Corks Against Cancer fundraiser.
- Thanks to Leslie Galusha who held a neighborhood cupcake sale and raised \$122 for the kids of GCH.
- We appreciate LuLaRoe consultant Jennifer Morse for her recent fundraiser that raised \$128. The LuLaRoe Company for matched the \$128 for a total of \$256 for GCH and our kids!
- The 11th Annual Daniel's 5K was run in April, despite the cold the organizers and participants raised \$6,030! Thank you for your donation.
- Thank you to Greece Odyssey Academy whose Color for a Cause fundraiser raised \$100 for the kids of GCH.
- We appreciate Premium Mortgage Corporation which recently held a Game Show fundraiser that benefited GCH. The loser of the game show was able to make a donation to the charity of their choice! We appreciate the \$100 donation!
- Elisia Earle's senior project was to fundraise for Golisano Children's Hospital, our kids, and their families. She raised \$800. Thanks!

- Much appreciation to Andy Creahan and all his friends who attended his recent fundraiser, #MyFriendsWedding, you all raised \$3,160 for our kids!
- Craig Demmin Soccer recently held a 3 vs. 3 tournament that raised \$2,700! Thank you Craig, the Craig Demmin Soccer organization, and all who participated.
- The Aquinas Institute recently held a missions fundraiser and chose GCH as their charity of choice. Thank you for your \$371.94 donation.
- A big thank you to St. Mark's Episcopal Church which recently donated \$500 on behalf of Pennies for Penelope to our building fund!
- Thank you to the Greek Festival and all who attended for the recent \$1,000 to Golisano Children's Hospital and our kids!
- Brownie Troop 60403 recently donated a portion of their cookie sales money to Golisano Children's Hospital. We appreciate your \$100 donation.
- The Nunda Rotary Club recently held a fundraiser in memory of Ms. Rhonda Howard. You all raised \$1,034.50 for the kids at Golisano Children's Hospital. Thanks!
- Thank you to everyone who attended and organized the Coins for Cancer is a fundraiser recently held by the Palmyra-Macedon Intermediate School. You all raised \$627.66 for the kids of Golisano Children's Hospital. Thanks!
- A special thank you to East High's F-Wing Family Groups who recently held a penny drive that raised \$41.33 for Golisano Children's Hospital.
- Much appreciation to West Irondequoit Central School District whose Eagle Charitable Challenge raised \$976.25 this year for our pediatric cardiology fund.
- The Aeneas McDonald PBA of the Geneva Police Department grew mustaches in support of one of their own and our NICU. They raised \$500! Thank you!
- Special thanks to Nazareth College's Class of 2019 for their Valentine's Day Rose and Carnation sale to benefit the kids of GCH, you all raised \$108.
- The freshman class at Brighton High School raised \$100 for Golisano Children's Hospital during the Brighton High Believes in Community Week. Thanks!
- Much appreciation to Owen Scheuer, Isaac Chin, and Samantha Dutt who all participated in the Burger Middle School Practice A Thon. Together they raised \$164.92 for the kids of Golisano Children's Hospital.
- Thank you to the Penfield High School Key Club who raised \$275 for GCH thru their Glove and Hat Sale.
- Webster Schroeder High School's Class of 2017 Warrior Ball donation of \$69.26 is greatly appreciated!!
- The Gananda Sports Boosters Triathlon recently raised \$200 for the kids of Golisano Children's Hospital. Thank you!
- Thank you to the 7th District of NY Sons of The American Legion who recently donated \$700 to GCH.
- Orville's Home Appliance donated \$250 from their mattress sale fundraiser. Thanks!
- Big thanks go out to Fleet Feet for raising \$1,800 at their Spring Fashion Show for the kids and programs of Golisano Children's Hospital.
- Thanks to Jamar Jordan and his Clean Air Bib sales that raised \$153 for GCH.
- Keuka College Community Service Advocates recently held recycling wars and raised \$69.86 for our kids. Thanks!
- Special thanks to North Klem Elementary School which raised \$3,310 through their charity raffles in honor of their classmate, Parker Spencer.
- A big thanks to SUNY Fredonia's Guerrilla's Acapella Group raised \$230 for Golisano Children's Hospital at a recent concert.
- Thanks to Webster Thomas Boys Varsity Basketball Team for their donation of \$800.
- Thank you to all who participated in the Pittsford Central School Districts 'Cupid Classifieds.' You raised \$131 for our kids!
- Sincere appreciation to Peter & Gypsy Grauert for their generous donation to Crosby's Fund at Golisano Children's Hospital for neuroblastoma research.
- Much appreciation to the National Corvette Restorers' Society for their \$225 match of the WNY Corvette Restorers' donation to Golisano Children's Hospital.
- Thank you to William Truesdell for a donation that will allow us to purchase GE Healthcare VScan, which will enhance our diagnostic cardiac imaging capabilities. This pocket-sized diagnostic tool is an ultrasound imaging system that enables the user to see and measure the heart's structures and fluid. It is the first of its kind, combining hand-held portability and outstanding image quality. Mr. Truesdell's gift is given in loving memory of his parents, Charlie and Suzanne Truesdell, and in honor of our Chief Sonographer, Mary Ann Rees, for her many years of dedication and outstanding service to our patients.

Upcoming Community Events

- **Aug. 26 & 27, Fairport Music Fest**

This fun-filled event, located along Fairport's Liftbridge Lane, is great for the whole family! Enjoy two days of good music and food for a great cause. Fairport Music Fest has impacted Golisano Children's Hospital in a number of ways and is committed to supporting a pediatric cardiac operating room in Phase II of the new Golisano Children's Hospital. For more information visit: www.fairportmusicfestival.org

- **Aug. 29, Golisano Children's Hospital Golf Classic**
Monroe Country Club, the Country Club of Rochester, and Oak Hill Country Club's West Course

Golfers from across the Finger Lakes region will come together to play for kids at the 19th annual Golf Classic. Save the date and stay tuned for more information!

- **Now through Sept. 30, Papa John's Pizza for Patients**

Your next pizza order can benefit the patients at Golisano Children's Hospital! Go to www.papajohns.com, enter promo code: GCH, place an online order, enjoy and repeat.

- **Sept. 1 through October 31, Spirit of Children**

The Spirit of Children is a program that brings fun and funding to hospitals at Halloween and all year long. We target hospitals that focus on kids because they need help to make hospital stays less scary for kids and their families. A portion of all sales made will be donated back to Golisano Children's Hospital's Child Life Program. For more information please visit: www.spiritofchildren.com

- **Sept. 24, Running to Remember 5K**

Team Ali-Gaiters' Running to Remember event, dedi"5k"ted to Dante Mastro Simone, is an annual run/walk to raise funds for Golisano Children's Hospital. For information contact Barb Klube-Falso at: 315-576-4529 or bklube@rochester.rr.com

- **Oct. 8, Genesee Valley Hunt Races**

- **3320 Nations Road, Geneseo, NY**

The 88th running of the Genesee Valley Hunt Cup will begin at 10 a.m. and go until 4 p.m. A portion of the proceeds from the event, which features a steeplechase race and fun for the entire family, benefit Golisano Children's Hospital. For more information please visit www.geneseevalleyhunt.org

- **Oct. 22, 29th annual Golisano Children's Hospital Gala, Joseph A. Floreano Rochester Riverside Convention Center**

Join honorary chairs, Jennifer Johnson and Vinnie Esposito, for a "Royal Celebration" featuring a live and silent auction, dinner and entertainment featuring Steve Augeri, former lead singer of Journey; Wally Palmar, The Romantics, and Terri Nunn from The Berlins. Sponsorships available starting at \$1,000 and tickets cost \$200 per person. For more information, visit the website or contact Betsy Findlay, 585-273-5933, bfindlay@admin.rochester.edu.

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