

Winter 2017-2018

Cart Wheels

**Miracle
baby:** Meet
a NICU warrior

Teens & vaccines

*When babies need
care before birth*

Finding a CURE for
CYSTIC FIBROSIS



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On the cover: Liam Thomas

The season of giving is upon us once again

With fall on its way out, the patients, families and staff of Norton Children's Hospital are gearing up for a special time of the year. We give thanks for the blessings in our lives, we celebrate family and friends, and we embrace the spirit of giving during the holidays.



As you prepare for the holiday season and all the joys it brings, we ask that you keep close to your heart the children who spend their holidays at Norton Children's Hospital. We are lucky to have wonderful providers who take great care of kids who are hospitalized during this time. They lift their spirits with holiday cheer, costumes and special visitors.

There are lots of ways to support Norton Children's Hospital during the holidays to ensure children in our region have access to great care year-round. This year, we are focusing on the neonatal intensive care unit (NICU). Each year, more than 1,400 critically ill and premature infants from throughout Kentucky, Southern Indiana and beyond come to the Norton Children's Hospital Level IV NICU, which offers the highest level of care available.

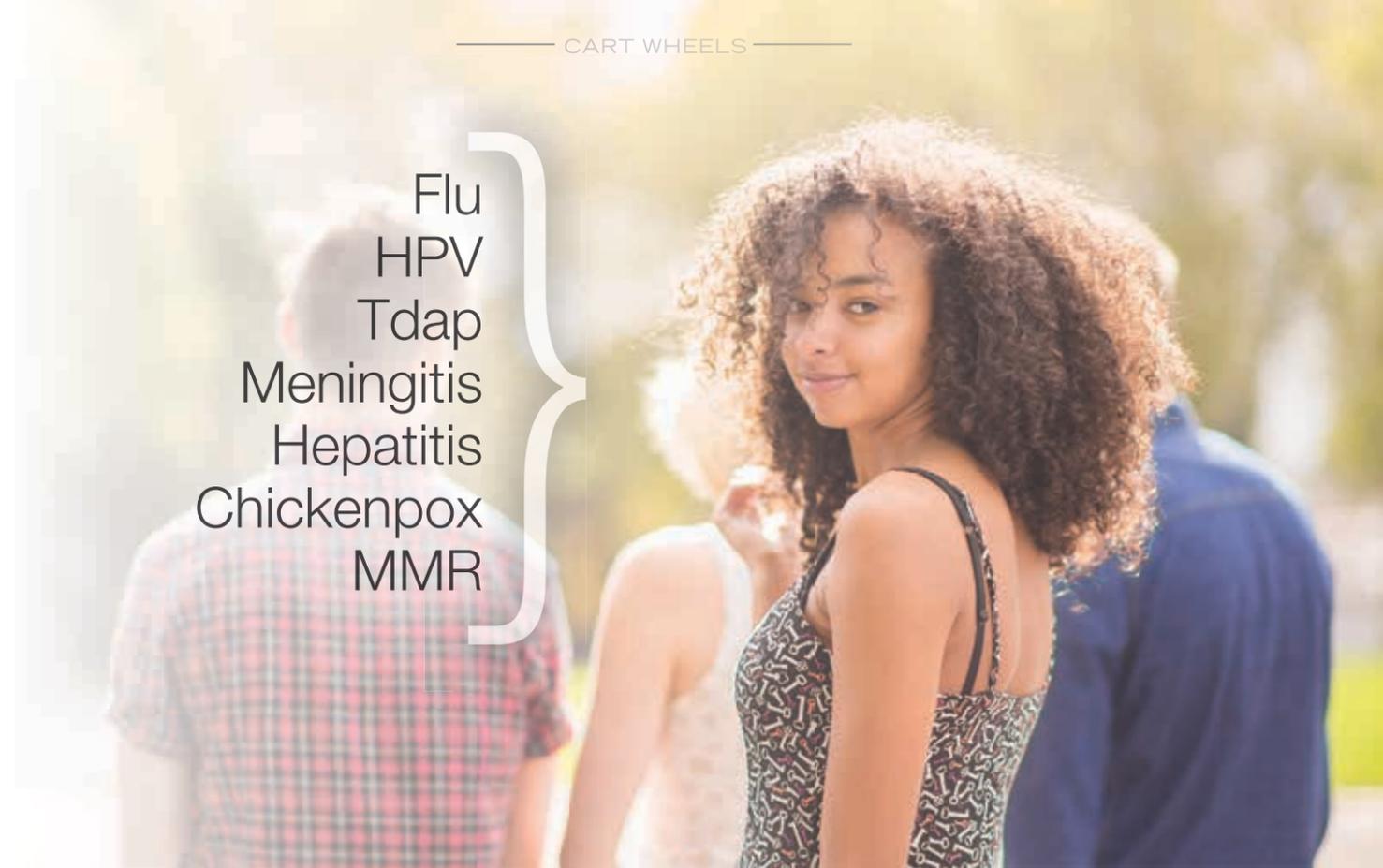
To help support our tiniest patients, don't miss the annual Festival of Trees & Lights, Nov. 10 to 12 at Louisville Slugger Field. This affordable event is fun for the entire family. Start a tradition by viewing and purchasing beautifully decorated trees, wreaths and holiday décor. The event also features Louisville's first visit from Santa!

The annual Snow Ball also is approaching quickly. This year's gala, on Nov. 18, will support the NICU's final phase of renovation and expansion. We will draw the winners of the 2017 Home & BMW Raffle during the Snow Ball. Get your ticket now for your chance to win a new home in Norton Commons built by the Ramage Company and a 2017 BMW convertible from BMW of Louisville plus \$10,000 cash.

On behalf of everyone at Norton Children's Hospital, thank you for your continued support of our mission. We wish you and your loved ones a holiday season filled with hope and joy!

Thomas D. Kmetz
President
Norton Children's Hospital

Lynn Meyer, Ed.D., R.N., CFRE
Senior Vice President
Chief Development Officer
Norton Healthcare



- Flu
- HPV
- Tdap
- Meningitis
- Hepatitis
- Chickenpox
- MMR

What vaccines do teens need? National poll finds many parents don't know

Is your teen up-to-date on vaccines? If you don't know, you're not alone.

According to a recent poll, more than one-third of teens' parents don't know when their child's next vaccine is due. Even more troubling, 90 percent of parents thought their teen had received all shots recommended for their age. In reality, vaccination rates for things like meningitis, human papillomavirus (HPV) and even the flu are well below public health targets.

"As children get older, families are less likely to schedule yearly checkups," said Selma Winner, M.D., pediatrician with Norton Children's Medical Associates – Springhurst. "Many teens may be missing out on important vaccines because families aren't always aware it's time for one. Vaccination is the best way to make sure our children are healthy and protected from preventable diseases."

Researchers say the lack of awareness may be the result of constantly changing vaccine guidelines. Additionally, parents may be less informed about recommended vaccinations for teens. This is because fewer states have vaccine requirements for high schoolers compared with kindergartners and middle school students.

Dr. Winner advises the best way to make sure your child is properly vaccinated, regardless of age, is to schedule a yearly wellness visit with their pediatrician.

"Your doctor is the best person to advise you which vaccines your child needs and to discuss any questions or concerns," she said.

—Joe Hall

It's flu shot season!

The flu shot is one vaccine just about everyone needs, every year. Now's the time to get your family protected from the flu. If your child is a current Norton Children's Medical Associates patient, schedule an appointment online through MyNortonChart, or call your pediatrician's office.



Carter Alvey has sights on U.S. Paralympic Soccer Team



Carter Alvey of Mt. Washington, Kentucky

It is a hot July day in Bardstown, Kentucky, and Carter Alvey is working up a sweat on the Bethlehem High School soccer field. Of course, Carter, a senior goalie, has always had to work harder than his teammates.

Carter was born with cerebral palsy, a neurological disorder that primarily affects body movement and muscle coordination.

By the time he was 6 years old, Carter had already had two major surgeries. One was a selective dorsal rhizotomy, which relieves certain types of abnormal muscle tone. The other was a procedure involving tendons in the lower leg and lengthening the Achilles tendons.

Laura K. Jacks, M.D., pediatric orthopedic surgeon with Norton Children's Orthopedics of Louisville, performed the surgery on Carter's tendons. She has been his orthopedist ever since.

"The ankle surgery takes half of an overly tight tendon that pulls the ankle inward and moves it to the outside of the ankle to pull it outward," Dr. Jacks said. "At the same time, we lengthened Carter's Achilles tendons to help his heels come down to the floor. He wore casts after the surgery for a month and then required a lot of rehab."

By the time of his surgery, however, Carter had already fallen in love with soccer.

"Carter started playing soccer at the YMCA when he was about 4," said his mom, Kandi Alvey. "He loved it from the first practice. He even played with two casts and braces on his legs following his surgery."

"I played other sports, but I always liked soccer the most," Carter said. "I guess my love for the game drove me to work harder at it, and I excelled for someone with my limitations. I've never skipped a season."

Cerebral palsy no match for this

SOCCER PHENOM

Fast-forward more than a decade. Carter has continued to dedicate himself to soccer and has made the varsity team.

In October of his junior year, Carter saw a recruitment ad for players for a possible U.S. Youth Paralympic Soccer Team. After talking to his mom, Carter emailed the coach, Stuart Sharp, and almost immediately received a reply asking for a scouting video and other information.

Within two weeks, Carter was at the first Paralympic soccer camp in California.

"Camp was incredible," Carter said. "I haven't been around many other people my age that are like me — that understand the challenges. At camp, there were athletes from 14 to 20 and from all over the country who had to work just as hard as I do. It was cool to see how everyone there handled their issues. There are four or five of us who still keep in touch."

"My teammates and friends at home have always been accepting and supportive, but they can't truly understand what my life is like."

Upon returning home to Kentucky, opportunities continued to present themselves. Carter was connected to Clemson University, which has a leading Paralympic soccer club.

"If I'm accepted," Carter said, "I may be able to play soccer for one of the best collegiate clubs out there."



Rachel Waters at Dean Lavenison Photography

Inspirational relationships

Where does Carter get his drive?

He credits his parents, Kandi and Dennis, for always encouraging him to pursue his dreams. He also is grateful for his high school soccer coach, Jody Spalding, who has boosted his confidence by never treating him any differently than any other player.

He is especially grateful for Dr. Jacks — not just for her surgical assistance, but for her belief in him.

"I always look forward to my physicals," Carter said. "I like telling her what I'm doing, and she doesn't act amazed that I can do any of it. It is like she knew I could all along. It's like she knows what you're capable of, so she expects it from you."

Dr. Jacks' admiration for Carter is equally lofty.

"Carter is more than just a surgical success and more than just a good soccer player," she said. "He is a terrific person with an internal force driving him that will never stop. He will have success at everything he does. There is no end in sight to what he can accomplish."

—Kathy Keadle

Specialized care for congenital orthopedic conditions

Cerebral palsy is just one of many congenital or hereditary conditions that affect muscles, bones and joints in kids. Others include muscular dystrophy, clubfoot, developmental dysplasia and limb deformities. Many of these require a team approach to care that includes pediatric orthopedic specialists, neurologists, physical and occupational therapists, respiratory therapists and more. Norton Children's network of pediatric specialists and outpatient clinics makes getting multidisciplinary expertise seamless and convenient for families. To learn more, call (502) 629-KIDS.

Norton Children's Medical Center

It's more than just an emergency department



8

Miles from Southern Indiana thanks to Lewis & Clark Bridge



Let's look inside!

Convenient diagnostic testing and lab: MRIs, CT scans, X-rays, lab work and more



Never fear!

Emergency department is a scare-free zone



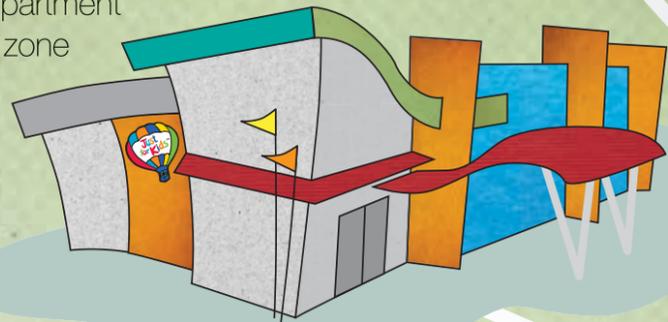
You're in good hands!

The same pediatric specialists rotate between here and Norton Children's Hospital



Walk this way!

Special entrance just for kids



Norton Children's Medical Center



It's the little things!

Interactive TV network, games and personalized services make the medical experience more positive



No more tears!

Child life therapists to help ease fears and stress



Just for kids!

Full-service pediatric outpatient surgery with anesthesiologists trained to care for kids



A tiny NICU warrior

Liam's story and how his family is channeling grief into gratitude

Liam Thomas is just beginning to walk. His legs are a little wobbly, so when he's on the move, he reaches out for sturdy objects to help keep his balance. He has a curious mind — a sponge to soak up all kinds of new information, like how to say “dada” and call for his pet cat, Gabe, whom he's nicknamed “Gaga.”

Liam is thriving, but about 1½ years ago, he was fighting for his life — a small warrior with an army of doctors and nurses behind him.

>> Continued from previous page

Miracles happen in the NICU



Megan Thomas with Liam at 10 days old

Megan Thomas and her husband, Alex, were filled with so much joy the day they learned they were expecting identical twin boys. They had decorated their nursery with matching cribs. Letters spelling out “Noah” and “Liam” hung above each crib.

Their journey of a lifetime turned into an emotional rollercoaster the day they learned of complications with the pregnancy. An issue with the placenta, called twin-to-twin transfusion syndrome (TTTS), meant their sons’ lives were at risk.

“With TTTS, one twin gets all of the nutrients and the other is basically starved,” Megan said. “An ultrasound showed Noah had a large amount of fluid in his sac, and Liam didn’t have a drop.”

Noah was showing signs of heart failure, and Liam was extremely sick. The only way to give the boys a chance was to do an emergency cesarean section. Noah and Liam were delivered 15 weeks early at Norton Hospital — each weighing a little more than 1 pound.

The babies were stabilized and quickly transported across the pedway to the Norton Children’s Hospital neonatal intensive care unit (NICU). From there the goal was to keep them stable and oxygenated while trying to recreate the womb as much as possible.

“Nothing could have ever prepared us for what it was like to see them for the first time,” Megan said. “They were so tiny and their little bodies were covered with tubes and wires. Their skin was translucent, so we could only lay a finger on them.”

Noah lived for two days. His condition was just too severe for his tiny body to overcome.

“It’s hard to think about losing Noah, but we are still grateful, because while we only had two days with Noah, that’s more than what a lot of people get to have,” Alex said.

“I don’t think Liam would still be here if it weren’t for this hospital,” Megan said during a visit to Norton Children’s Hospital.

She was there to see Maggie Flowers, a NICU nurse with whom the Thomas family has developed a special bond.

“She was Noah’s nurse the day he passed away, so she was with us on our darkest day,” Megan said. “She is an amazing nurse, and it brought me peace knowing that Noah was loved by her in his final hours.”

The Thomases call Liam their “miracle boy.” He has risen above so many challenges during the five months he spent in the NICU.

“There were several times that doctors didn’t think he would make it through the night and he did,” Megan said as she fought back tears.



Liam Thomas at 1½ months old

Liam would not be here if it wasn’t for the knowledge and perseverance of [the doctors at Norton Children’s Hospital] trying literally everything they could. We spent all day, every day in the NICU for 5 months. The doctors and nurses became our family. They cried with us on the hard days and celebrated with us on the good days.”

—Megan Thomas

Liam was so tiny his parents could slide their wedding rings over his hand and up his arm to his shoulder. His size, they say, was comparable to a Barbie doll.

As Liam grew in the NICU and began to look like a more developed baby on the outside, on the inside his organs still had a lot of catching up to do.

He developed a hole in his bowel when he was 1 month old. This potentially deadly condition took three surgeries to repair. He also overcame kidney failure. He had stage 3 retinopathy of prematurity, which can cause blindness. Thankfully, he kept his sight but will need glasses for the rest of his life. He developed rickets, which put him at risk for broken bones, and suffered a fractured femur before he even weighed

3 pounds. Something as simple as changing his diaper could cause a fracture. And he was not able to totally breathe on his own for about four months, among other hurdles he fought through.

“Liam’s doctors teased that some babies take the road less traveled, but Liam would take the road never traveled,” Megan said.

In all seriousness, doctors were in Liam’s room every hour and did not give up on him no matter how grim the outlook was.

“Liam would not be here if it wasn’t for the knowledge and perseverance of those doctors trying literally everything they could,” Megan said. “We spent all day, every day in the NICU for 5 months. The doctors and nurses became our family. They cried with us on the hard days and celebrated with us on the good days.”

Channeling grief into gratitude

Not a day goes by that the Thomases don’t think of Noah. They’ve chosen to channel their grief into gratitude for their miracle boy, who is now at home and healthy.

“Just knowing that so many times we almost lost Liam, I’m always reminded to have gratitude,” she said. “I have learned what takes some people a lot longer to learn, about what really matters — to appreciate the smallest things.”

And that gratitude especially will be felt this holiday season as the Thomases experience the joy of Christmas through the lens of a toddler who beat all odds.

—Erica Coghill



Megan, Alex and Liam Thomas

Rachel Waters at Dean Lavenson Photography

The Festival of Trees & Lights

The Norton Children’s Hospital NICU is a place where miracles happen every day. Premature babies can spend months there — usually at least as long as it takes to reach their original due date. Premies have a much harder time learning the “suck, swallow, breathe” concept, so it can take a long time to get them to a point where they can be fed by bottle. Serious health conditions that come with being a preemie keep many babies there even longer.

You can help ensure lifesaving, specialized care is always available to the tiniest patients by attending the 28th annual Festival of Trees & Lights, benefiting the Norton Children’s Hospital NICU.

Bring the family and marvel at hundreds of beautifully decorated trees, wreaths and décor; enjoy pictures with Santa, children’s crafts, holiday entertainment and Hanukkah activities; visit the outdoor Elf Town; and get a start on holiday shopping at the Sweet Shop and Gift Shop. Presented by Republic Bank.

Friday, Nov. 10, to Sunday, Nov. 12
Louisville Slugger Field

Get tickets and details at FestivalOfTreesAndLights.org.



Rachel Waters at Dean Lavenson Photography

When babies need care before birth

Medical advances and skilled specialists make it possible to treat life-threatening issues before a baby is born

We

With a baby on the way, Ni'Eshia Andrews and her family were overjoyed. The family planned to welcome a baby girl, joining her big brother in summer 2017. Everything was going as planned until they hit a bump in the road.

During a 28-week fetal ultrasound, Andrews' obstetrician discovered she had too much amniotic fluid volume and the baby was showing abnormal kidney function. This discovery led to a chain of events that would eventually land Andrews and her unborn baby in the hospital for a rare and risky intrauterine blood transfusion.

Andrews was reluctant to undergo percutaneous umbilical blood sampling, which involves taking a blood sample from the umbilical cord. She agreed to amniocentesis, a less risky procedure that takes a sample of the amniotic fluid. That test indicated that the baby was anemic, according to Mureena A. Turnquest Wells, M.D., maternal-fetal medicine specialist with Norton Children's Maternal-Fetal Medicine.

Fetal anemia occurs when there are not enough red blood cells or there is an abnormality with the blood cells. The blood cells play a vital role in fetal development because they carry oxygen to cells and organs. Anemia can lead to many complications in the fetus, including heart failure and death.

Andrews, 28, had a normal pregnancy with her first child and was overwhelmed with concern when she was faced with the choices ahead of her.

"It was during a doctor's appointment that I was told I needed to be admitted to the hospital immediately so they could monitor the baby. From there, I was given the option of having the blood transfusion or not, and Dr. Turnquest Wells explained the risks," Andrews said. "I was scared, but the doctors and nurses gave me time to think it over and to answer my questions."

Andrews was faced with the choice of having the procedure, which carries about a 1 percent risk of fetal loss, versus not having it, which could lead to the baby developing congestive heart failure, hydrops fetalis (severe swelling with fluid), premature birth, the baby being born anemic and needing a transfusion immediately following delivery, or death.

At 30 weeks' gestation, Andrews and her baby underwent the intrauterine blood transfusion at Norton Hospital. Performed with guidance from an ultrasound, Dr. Turnquest Wells and colleague Vance Cuthrell, M.D., injected compatible red blood cells through the umbilical vein into the baby.

According to Dr. Turnquest Wells, the transfusion is the best medical option to prevent further complications in a situation such as fetal anemia. Once a transfusion is complete, the mother and baby have to be monitored frequently until delivery.

Andrews continued to see the maternal-fetal medicine specialist multiple times per week until her delivery at 37 weeks. On Aug. 28, Rose Chanel was born weighing 6 pounds, 10 ounces. Other than some fast and labored breathing, the baby girl was healthy and was not anemic at delivery. She went home with mom and big brother, Kerion, just four days later.

Although there are several potential causes for fetal anemia, most cases occur when the baby has a difference in blood antigens or proteins from the mother. The cause of Rose's fetal anemia was unknown, but her mother is relieved it was discovered and treated.

"Our family is very thankful to have a healthy and happy baby girl," Andrews said.

Maternal-fetal medicine physicians specialize in high-risk pregnancies like Andrews', as well as women carrying multiples or who have certain health conditions. They partner with obstetricians to care for women with conditions as common as high blood pressure or diabetes to more serious issues that require advanced monitoring.

— Lynne Choate



Mureena A. Turnquest Wells, M.D., with Ni'Eshia and Rose Andrews

Expert care for mom and baby

The team of Norton Children's maternal-fetal medicine providers draws from years of experience in diagnosing and caring for women during pregnancy. Our specialists have a network of referral centers across the region, along with two Louisville locations, to provide care without patients having to make a long drive. Patients must have a referral from a physician. Learn more at NortonChildrens.com or call (502) 629-7181.

Meet Ann Muth, nurse practitioner with Norton Children's Urology

Ann Muth, APRN, is the newest addition to the Norton Children's Urology practice. We sat down to learn a little bit more about her and what she's passionate about.

A Louisville native, Muth knows the River City just about as well as she knows pediatric urology. She grew up here and attended Mercy Academy before enrolling in Bellarmine University, where she earned a degree in biology. She went on to attend Spalding University in order to begin her career as a nurse practitioner. After graduating from Bellarmine, she began to take care of her mother, who was dealing with sickness. In hindsight, Muth believes that caring for her mother helped her realize that she wanted a job where she could help others.

Starting off at Norton Children's Hospital, Muth has worked in many different environments and has received a great amount of experience collaborating with a variety of doctors. She spent seven years in oncology, and then 10 years in the operating room. Muth knew she wanted to focus on a specific field and became interested in pediatric urology when an opportunity in a practice presented itself. She quickly fell in love with caring for children.

"Kids are resilient," she said. "They also say the funniest things."

Her passion is being able to see kids with stigmatizing issues, such as bedwetting, come back to see her with their issues resolved.

Spina bifida has been an important focus for Muth for 14 years. The birth defect affects the way the bladder works.

"Spina bifida used to be life-threatening because kids couldn't empty their bladders," she said. "The introduction of catheters meant that babies with spina bifida could overcome the urinary system challenges."

Urology is a vital component of spina bifida treatment, and Muth loves helping her patients get on a healthy path.

One of Muth's most interesting hobbies is Olympic weightlifting. In her free time, she works on lifts such as the clean and jerk, snatch and power clean. She has participated in several weightlifting competitions and can deadlift over 300 pounds! Muth also enjoys traveling. She's vacationed in Puerto Rico and is currently looking forward to a trip to the Baltic Sea.

Muth's one health tip is to maintain a healthy body weight. Many health issues are a direct result of poor weight management, so it's very important to eat well and exercise.

—Christian Cox

Ann Muth, APRN

Lifting kids up from health challenges



So your child wets the bed. Should you be concerned?

Bedwetting can be frustrating, embarrassing and uncomfortable for you and your child. But for most families, it's a common part of childhood.

What causes bedwetting?

Kids may wet the bed for various reasons. Young children are still developing bladder control. In many cases, bedwetting runs in families — about 70 percent of children who wet the bed have at least one parent who wet the bed as a child. For most children, bedwetting (nocturnal enuresis) has no anatomical or physiological cause.

When should I seek help for my child?

Most of the time, the issue will resolve itself, usually by the time a child is about 7 years old. If your child is age 7 or older and still wetting the bed, a pediatric urologist can step in to provide a treatment plan. This age is a good time for beginning treatment because the child will be mature enough to have the desire and motivation to stop wetting the bed.

What does treatment look like?

Treatment is based on the individual needs of the child. Depending on the situation, a pediatric urologist may treat bedwetting using a behavior modification schedule. In some cases, a bedwetting alarm, medication, bladder control retraining or a combination of treatments may be needed.

What should I say to my child who wets the bed?

Children do not do this on purpose. It is important not to ridicule or punish your child for wetting the bed. The most important thing to understand about bedwetting in children is that there is no "quick fix." The best practice is to be patient and consistently follow the treatment plan developed for your child.

Muth and her team with Norton Children's Urology offer consultations and specialized care for children and teens with a variety of urological conditions. To learn more, call **(502) 559-1670** or visit **NortonChildrens.com**.

Rachel Waters at Dean Lavenson Photography

In their own words

Families touched by cancer share their stories for 'Give for Good Louisville'



On Sept. 14, the Children's Hospital Foundation participated in "Give for Good Louisville," a day of online giving hosted by the Community Foundation of Louisville. In honor of Childhood Cancer Awareness Month, the community had an opportunity to donate to help children fighting cancer at Norton Children's Cancer Institute, affiliated with the University of Louisville.

During the 24-hour campaign, Norton Children's shared stories of courageous cancer patients on social media, as told by their family members, to show the reality of what this disease really looks like and to showcase the strength of kids and teens fighting cancer. Below are some of their stories.



HOLLY

When Holly was diagnosed with cancer, her parents struggled to cope. Holly's mom shares the reality of what it's like to receive that kind of diagnosis and recounts the amazing strength of children.

"Our first night in the hospital after just learning Holly's diagnosis, the nurse we had was like a guardian angel sent to us. I had stepped outside of the room for a moment and became overwhelmed with emotions. I was sliding down the wall in tears when I felt these arms lift me up and embrace me. I had no idea at the time who it was. This stranger was holding me as I wept for my little girl. That first night she treated us with such care. We were all exhausted and mentally and emotionally anguished that we could barely speak. Her love and care saved us that night.

"During our time, we met many nurses and stayed many nights, but we did not see that nurse again until during our final week of treatments after Holly had received a positive prognosis. It was as if we had come full circle. I wept when I saw her again. She was there at the beginning of our journey, and at the end.

"The day [Holly] had her scan after her last treatment, there was no evidence of disease. This was my happiest moment: seeing her being a kid again. She was doing simple things that I took for granted before she had cancer. But now we struggle dealing with our new norm. Things never will be like they were. Every time she gets sick, I worry.

"After ... I was having a conversation with [Holly's] Nan. Her Nan said in passing that she was just ready to give up. Holly spoke up and told her, 'Nan, you never give up, no matter what it is! I had cancer, but I never gave up! You find the love in your heart to keep going and you just do it!' That is how she faced cancer. That is how she won."

end-of-year donation, volunteering your time or making a planned gift to benefit kids who seek lifesaving care.

Visit HelpNortonChildrens.com or call (502) 629-8060 to learn more.

It's not too late to give!

Your donation means the world to the more than 170,000 children from throughout Kentucky and Southern Indiana who receive care at Norton Children's Hospital facilities each year. Consider making an



T.J.

Living with cancer at any age is difficult, but experiencing it as a teen is especially difficult when you're trying to be "normal." T.J.'s sister opens up about her late brother's incredible strength throughout his journey.

"In August 2013, T.J. had to go for an MRI to make sure everything still looked good. It seemed like we waited for days to hear the results because we were so nervous. A few days later Mom got the call and it's one we will never forget. His tumor was back and had grown larger. We were once again heartbroken and just couldn't understand. Without our faith in the Lord we would have never made it this far. It was back to Louisville for them to discuss what was going to happen next. T.J. was fixing to go into his junior year of high school — the best times of our lives for most. He struggled once again that he couldn't be a normal teenager.

"The chemo took a huge toll on his body mentally and physically. Until you've seen someone go through chemotherapy and the process, you really can't imagine what it's like. T.J. pretty much lived on Ensure and PowerAde. He was weak and just aggravated that he couldn't be a normal teenager like all his friends. I remember them bringing the chemo bags in. They were in black bags. I asked why they were in those bags and it's because the sunlight from the windows can't get through them. I was blown away. T.J. got really depressed and didn't want anyone to come see him like that. This was hard for all of us to watch. He was always so happy and had a big smile on his face. As a child T.J. was so loving, full of energy and kept us on our toes."



Photos courtesy of their families

MICHAEL

Michael was diagnosed with cancer at age 5. His mom recounts the challenges, speed bumps and her son's faith throughout this journey.

"He was very thrilled to be at the hospital because he thought it was a hotel. He was only 5 at the time so he had the beautiful innocence of a child. Michael was so young that he didn't really realize what was ahead. He started treatment in March 2015 and doesn't end treatment until July 2018.

"Treatment has been very rough. Michael has spent more than 110 days in the hospital since diagnosis. He has had countless spinal taps, blood transfusions, fevers, two surgeries and most recently was diagnosed with an adrenal insufficiency disorder. The toughest times are when he is admitted for two weeks at a time for fever. He has missed tons of school due to the effects of treatment and that has been very tough.

"But he has been so resilient during his fight; he truly has faith. His great outlook keeps all of us going and looking ahead to the end of treatment. Michael's faith is beautiful to witness. I feel he has the best personality to fight this journey."



Photos courtesy of the family

Jessica, Emma, Luke and Joseph Klausing

Working to find a cure for cystic fibrosis

Gift sets stage for more comprehensive program at Norton Children's Hospital

In an effort to boost care for children in our region with cystic fibrosis (CF), Cure CF Inc. has announced a gift of \$300,000 to Norton Children's Hospital through the Children's Hospital Foundation.

The funding will bring additional clinical research trials to Norton Children's Hospital in collaboration with specialists from University of Louisville Physicians and support additional specialists, including a specialized nutritionist and pharmacist to address the special needs of CF patients.

"Cure CF is cognizant of the need to better the care of CF patients and families in Kentuckiana," said Joseph Klausing, executive director of Cure CF, who has a son with the disease. "We are hopeful that the cure for CF will be found through our pledge, as access to state-of-the-art research, clinicians and clinical trials will now be available to our local patients."

"Cure CF is setting the stage for a long-term vision of the care we can provide to children with cystic fibrosis and other respiratory issues," said Lynn Meyer, Ed.D., R.N., CFRE, chief development officer, Norton Healthcare. "This truly is a foundational gift, and Cure CF is showing great leadership in recognizing some of the issues our children face."

The Children's Hospital Foundation has committed an additional \$400,000 in support of this project, bringing the total amount for CF support to \$700,000.

The gift is part of a long-term vision for the hospital and the University of Louisville to create a more comprehensive program to treat CF and respiratory issues, including establishing a dedicated center, adding respiratory care specialists and expanding research programs.

Respiratory-related issues are the top diagnoses for children who are admitted to Norton Children's Hospital, resulting in 1,600 hospitalizations. These illnesses also cause more than 8,000 outpatient visits at Norton Children's.

While the top three issues are asthma, bronchiolitis and RSV pneumonia, CF falls within this area and requires often extensive, lifelong treatment. The genetic disease causes recurring lung infections and difficulty breathing. The disease is known for its sticky mucus buildup in the lungs, pancreas and other organs. Patients must use a variety of treatments to loosen mucus and ease breathing, including percussion vests and medication.

"There is no cure for cystic fibrosis, but we can help with symptoms and slow the progression of the disease," said Nemr S. Eid, M.D., pulmonologist with Norton Children's Hospital and division chief of pulmonary pediatric medicine with the University of Louisville School of Medicine Department of Pediatrics. "Bringing additional clinical trials to Louisville provides other options to help children with this disease."

—Maggie Roetker

How you can help

Help the foundation reach its goal and help kids with CF get life-extending care. Donate at HelpNortonChildrens.com or by calling (502) 629-8060. If you are interested in joining a steering committee to form a CF support group, email the Children's Hospital Foundation at foundations@nortonhealthcare.org.



Luke Klausing gets treatment for cystic fibrosis.

What is cystic fibrosis?

CF is caused by a defective gene that tells the body to make thick, sticky mucus in the lungs, pancreas and other organs. The mucus clogs the airways and traps bacteria, which can lead to infections, lung damage and respiratory failure. In the pancreas, the mucus prevents the release of digestive enzymes that allow the body to break down food and absorb nutrients.

According to the Cystic Fibrosis Foundation, about 1,000 kids a year are diagnosed with CF. Current life expectancy is close to 40 years old, a large improvement from 50 years ago when it was just 10. Specialists with UofL Physicians and Norton Children's Hospital closely follow more than 135 CF patients in our area.

CF AFFECTS



Lungs

Pancreas

Liver

Intestines

HOW RESEARCH HELPS

Thanks to advances in screening at birth, most kids are **diagnosed before age 2** and **living longer** because of **new treatments becoming available**.

1960 TO TODAY

10  40+

Life expectancy



Cycling for a cure

On Sept. 9, more than 1,000 cancer survivors, supporters and community members came together for the ninth annual Bike to Beat Cancer, powered by Bryant Heating & Cooling. More than \$450,000 was raised to support Norton Cancer Institute and Norton Children's Cancer Institute, affiliated with the University of Louisville. The event began and ended at Norton Children's Medical Center. More than 800 riders and 450 volunteers took part, including 162 Family Ride participants who cycled around Norton Commons, sponsored by Schnell Contractors Inc. This year, there also was a virtual ride option.



Mason Christensen with the chefs who participated in the 2017 Bourbon & Bowties

Another successful Bourbon & Bowties in the books

The Children's Hospital Foundation raised over \$250,000 at the 2017 Bourbon & Bowties™: A Taste of Corbett's. This year, the event was held in honor of Mason Christensen. In 2013, at age 9, Mason was diagnosed with Type 1 diabetes. He received his insulin pump and the care he needed through the Wendy Novak Diabetes Center at Norton Children's Hospital and the University of Louisville. Presented by Northwestern Mutual, the event featured hors d'oeuvres from 35 of Louisville's top chefs, music and an auction. Since the event's inception in 2010, Bourbon & Bowties has raised more than \$1.5 million to benefit Norton Children's Hospital. Make sure you save the date for next year's event on Thursday, June 7, 2018!



Looking back at 2016

The Children's Hospital Foundation and Norton Healthcare Foundation have just released a joint annual report looking back at the care provided in 2016 across Norton Healthcare at every age, every stage, every step of the way. If you did not receive the 2016 annual report but would like a copy, email us at foundations@nortonhealthcare.org or call (502) 629-8060.



Jamie Rhodes Photos

Walk/run event makes a big splash

August marked the third annual Splash 'n' Dash 5k Walk/Run, presented by Texas Roadhouse, on the Big Four Lawn at Louisville Waterfront Park. More than 800 participants splashed their way through either a 5k course or 1k family fun run. After the race, everyone stayed cool in the "Just for Kids" Zone, sponsored by Hwang's Martial Arts. Over \$35,000 was raised for Norton Children's Hospital. Participants were able to designate their funds raised to the service area of their choice within the hospital.



Tim Furlong Jr. Photo

Last call to get your Home & BMW raffle ticket!

Don't forget to purchase your \$100 ticket now for the 2017 Norton Children's Hospital Home & BMW Raffle! Each ticket is a chance to win a new home in Norton Commons built by Ramage Company and valued at approximately \$600,000, and a 2017 BMW 2 Series convertible from BMW of Louisville, plus \$10,000 cash. Three winners have already been drawn for monthly prizes, which included gas for a year, a curved 4K LED smart TV and free groceries for a year from Walmart. Grand prize and first prize winners will be drawn Nov. 18, 2017, at the annual Snow Ball gala. For details and to buy a ticket, visit HomeAndBMWraffle.com.

Charitable gaming license Children's Hospital Foundation #ORG: 0000851



Enjoy pizza while giving back!

With your help, in 2016 Papa John's donated over \$26,000 to Norton Children's Hospital. Now their fall 2017 campaign has officially begun! Visit PapaJohns.com and use promo code "BALLOON" to receive 20 percent off your order, and 20 percent of your discounted purchase price will be donated to Norton Children's Hospital.

Offer good online only for regular menu price items Nov. 10 through Jan. 1 at participating Papa John's restaurants. Not valid with any other coupons or discounts. Limited delivery area. Delivery fee may apply and is not subject to discount offer. Customer is responsible for all applicable taxes. ©2017 Papa John's International Inc. All Rights Reserved.

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The following individuals in bold were recognized through tribute gifts to the Children's Hospital Foundation from April 1 to Aug. 31, 2017.

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For more information on events listed below, call **(502) 629-8060** or visit **HelpNortonChildrens.com**.

	NOVEMBER	<p>Home & BMW Raffle open houses, every Saturday and Sunday, noon to 6 p.m. through Nov. 12, and Saturday, Nov. 18, noon to 3 p.m., 6119 Mistflower Circle, Prospect, Kentucky. Tour a beautiful new home in Norton Commons valued at approximately \$600,000 that could be yours for just \$100. Purchase a raffle ticket at HomeAndBMWraffle.com.</p>
	<p>Now through Feb. 4, 2018</p>	<p>Hope & Healing: Celebrating 125 Years of Norton Children's Hospital, Frazier History Museum. Exhibit explores our rich history through interesting and interactive displays for kids and adults. COUPON ON BACK!</p>
	<p>10 to 12</p>	<p>Festival of Trees & Lights, Louisville Slugger Field. Visit a winter wonderland of trees, lights and holiday accents available for purchase to benefit our tiniest patients in the neonatal intensive care unit. Enjoy a Hanukkah display, sweet treats, free children's crafts, holiday entertainment and Louisville's first appearance of Santa. Presented by Republic Bank. Visit FestivalOfTreesAndLights.org for details. COUPON ON BACK!</p>
	<p>16 and 17</p>	<p>Norton Children's Hospital Radiothon, 6 a.m. to 7 p.m., Norton Children's Hospital lobby. Listen live on Alpha Media stations B96.5, 99.7 DJX, Magic 101.3, 102.3 Jack FM and G105.1 as local families share their hospital experiences. Pledge your support by calling the Horseshoe Southern Indiana Phone Bank at (877) 335-KIDS.</p>

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Follow us on Facebook, Twitter, Snapchat and Instagram to stay up-to-date on events and happenings around Norton Children's. Feel free to drop us a note or share your experience!



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Norton Children's maintains an unwavering dedication to the children of our community and region by offering pediatric specialists at Norton Children's Hospital, Norton Women's & Children's Hospital, Norton Children's Medical Center and Norton Children's Medical Associates pediatric practices throughout Kentucky and Southern Indiana. To learn more about our programs and services, visit NortonChildrens.com.

The Children's Hospital Foundation raises funds exclusively for Norton Children's Hospital and its sister facilities, providing support for facilities, equipment, new technologies, clinical research, child advocacy and health education for patients, parents, physicians, staff members and the community. For more information about charitable contributions that help children, call (502) 629-8060 or visit HelpNortonChildrens.com. To learn more about volunteer opportunities at Norton Children's Hospital, call (502) 629-6122.

Winter 2017-2018

Cart Wheels

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