

Spring 2021

Cart Wheels

Caring

FOR THE MOST
VULNERABLE

Kids and COVID-19

Teen talks about mental health

AUTISM CENTER coming soon



A publication of Norton Children's and Norton Children's Hospital Foundation

CART WHEELS
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On the cover: Scott Love, community advocate, at a Norton Children's food pantry

So much to be hopeful for

Here we are — finally — in the season of reawakening, renewal and hope. And there is much to be hopeful for.

Just as the weather finally warmed up, we marked an exciting new beginning at Norton Children's Hospital: the opening of our newly renovated pediatric intensive care unit. This was the final phase of the hospital's \$78 million capital campaign to improve critical care services and expand a family-centered approach to caring for our region's sickest kids.

Also opening in time for spring, the hospital's healing garden got a facelift and is now available to patients and families who need a breath of fresh air and some sunshine.



As we see the end of the pandemic in our sights, our health care heroes continue to persevere — those caring for COVID-19 patients and those caring for the things that don't stop for a pandemic: cancer, heart conditions and other serious health issues.

We count among our heroes caregivers fighting on the front lines to heal children from complications of COVID-19 and other infectious diseases, and givers who care deeply about making things better for our community's families. You'll read about some of these heroes, and more, inside.

It is also with hope that we can begin to once again plan for some fun in-person events, like Bourbon & Bowties, which was put on hold last year. We are thrilled to say it will make a comeback in August of this year, in person with safety precautions in place. We are so excited to come together again and celebrate the kids cared for at Norton Children's Hospital.

On behalf of everyone at Norton Children's, thank you for your continued support during these challenging months. We can't wait to see you face to face soon!

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

Jennifer C. Evans, M.D., MPH
System Vice President
Pediatric Services
Norton Healthcare

Emmett C. Ramser
Chief Administrative Officer
Norton Children's Hospital

All photos were taken either prior to the pandemic or following CDC guidelines for proper use of masking and social distancing.



How **VAPING** and **E-CIGARETTES** affect **TEEN HEALTH**

In 2019, before the coronavirus descended on the world, experts at the Centers for Disease Control and Prevention began sounding an alarm about a different kind of health emergency: the growing number of deaths and hospitalizations among teens who vape.

Attracted by cool gadgets and youth-oriented flavors like bubble gum, mango and cotton candy, 38% of high school students and 20% of middle school students say they vape or use e-cigarettes at least 20 days a month. That's according to the 2020 National Youth Tobacco Survey.

Research suggests that teenagers may be the largest share of the market for vaping products and e-cigarettes. Although it's illegal to sell vaping products to minors, many brands continue to market to a younger demographic. Teens easily circumvent the law by buying products online.

Despite warnings from parents, physicians and health experts, many teens regard vaping as a safe alternative to smoking tobacco, and some think it will help them quit an existing tobacco habit. Neither is true, according to Ronald L. Morton, M.D., pediatric pulmonologist with Norton Children's Pulmonology, affiliated with the UofL School of Medicine.

"A lot of teens are coming to us with acute lung injury from what we call EVALI syndrome after e-cigarette use and vaping," Dr. Morton said. EVALI is an acronym for e-cigarette or vaping use-associated lung injury.

With higher levels of nicotine than tobacco products, e-cigarettes may actually increase the likelihood of future addiction. One popular brand has a product that delivers the nicotine equivalent of a pack of cigarettes in a single pod.

"Teens may be fooled into thinking they can avoid or break a smoking habit, but it doesn't work that way," Dr. Morton said.

It's true that some vaping liquids are free of nicotine, but these products are sometimes laced with dangerous additives such as vitamin E acetate, an agent that can cause permanent lung damage and other health consequences. Scientists found e-cigarette users are more likely to have gum disease, dental issues and bone loss. Dr. Morton said vaping has an inflammatory effect on the body, and it can alter the oral microbiome, the normal bacterial distribution in the mouth.

"We want to work with families and teens to persuade them to quit vaping, in hopes of preventing irreversible changes to their health," he said.

—Crystal Hammon

Stop-smoking classes just for teens

Norton Children's is offering a free American Lung Association class called N-O-T (Not on Tobacco) just for ages 14 to 19. The evidence-based program is designed specifically for teens to help them quit using tobacco products, including vapes, cigarettes and other forms of tobacco. Approximately 90% of teens who participated in a N-O-T program either quit or cut back on their use of tobacco products.

Group sessions meet once weekly via Zoom to learn tools to prepare for tough moments and support each other on their journey to quitting.

Find dates and register at NortonChildrens.com/Classes-Events.

38% OF HIGH SCHOOL STUDENTS
20% OF MIDDLE SCHOOL STUDENTS
USE 20 DAYS A MONTH

Leading the charge against COVID-19 in kids

Touched by the story of a pioneering infant heart transplant, a young medical writer shifted gears to become a physician

When she graduated from college, Kristina A. Bryant, M.D., didn't plan on becoming a doctor. She'd majored in French and political science. Her first job out of school was working as a medical writer for the University of Louisville.

Her career goals changed dramatically when she was assigned to help CNN do a series about an infant heart transplant patient in Louisville. Then known publicly as "Baby Calvin," Robbie Cardin became the first infant to get a heart transplant in Kentucky, and Norton Children's Hospital was just the second site in the U.S. to complete the complex operation.

"I was inspired by Robbie Cardin and his family and the transplant program," Dr. Bryant said.

At the end of her first day on the story, she decided she didn't want to write about medicine. She wanted to do medicine.

Dr. Bryant's career has come full circle. She's now a pediatric infectious diseases specialist with Norton Children's Infectious Diseases, affiliated with the UofL School of Medicine. Dr. Bryant treats children like Robbie who undergo organ or bone marrow transplants and have compromised immune systems, making them more vulnerable to infection.

A leader in pediatric response

During the coronavirus pandemic, Dr. Bryant has served as an expert voice for the medical community, working with a multidisciplinary team of physicians to stay on top of COVID-19 treatment information. They share it with health care providers at Norton Healthcare and Norton Children's as well as with physicians and others in Louisville and across the commonwealth.

Dr. Bryant also works with doctors and nurses at Norton Children's Hospital and Norton Children's Medical Group, affiliated with the UofL School of Medicine, to develop the best treatment and testing protocols for COVID-19.

Every day has brought new challenges.

This is a virus we've only known about for [about] a year, and what we know today may not be what we know next week or next month."

—Kristina A. Bryant, M.D.

Preventing and fighting infections

"My clinical work is very much like that of a detective," Dr. Bryant said. "Who has the child been around? Where have they traveled? Have they had contact with animals? Where have they eaten? All of these can pose a risk for infection. The most important test we have is talking to patients and their parents. Often the history gives us the most important clue what the issue might be."

In addition, Dr. Bryant helps keep hospitalized children free of infections from intravenous lines, catheters and other medical devices. Her research efforts include prevention of hospital infections, and she serves on a national committee advising the Centers for Disease Control and Prevention on infection prevention.

Dr. Bryant also has done vaccine research. She was the local lead investigator on one of the earliest clinical trials for Prevnar 13, a vaccine that prevents serious bacterial infections. According to Dr. Bryant, the research would not have been possible without the help of local families.

"By participating, a number of local families showed the vaccine was safe and effective," she said.

A national leader in fighting infections

A Louisville native, Dr. Bryant attended the University of Louisville for college and medical school. She also did her medical training and a pediatric infectious diseases fellowship at the University of Louisville.

Now, Dr. Bryant is a professor of pediatrics in the UofL School of Medicine Division of Pediatric Infectious Diseases. Between 2008 and 2019, she directed the Pediatric Infectious Diseases Fellowship Program at UofL.

In addition, Dr. Bryant is president of the Pediatric Infectious Diseases Society, the world's largest organization of professionals dedicated to the treatment, control and eradication of infectious diseases affecting children.

—David Steen Martin

Find COVID-19 resources related to kids, from testing to seeing a provider to visiting Norton Children's facilities and more, at [NortonChildrens.com/COVID-19](https://www.nortonchildrens.com/COVID-19).



Jamie Rhodes Photo

Kristina A. Bryant, M.D.

CARING FOR KIDS WITH LONG-TERM COVID-19 EFFECTS

In most children, COVID-19 is mild and they fully recover without the need for ongoing treatment. However, some kids and teens experience symptoms after the usual recovery period.

Norton Children's Infectious Diseases offers a COVID-19 Follow-up Clinic for children and teens who continue to feel unwell beyond 10 days past their first symptoms or a positive test. Children can be seen by a pediatric infectious diseases specialist as soon as the day after receiving a physician referral to the COVID-19 Follow-up Clinic.

Norton Children's also offers a Pediatric MIS-C Multidisciplinary Clinic for follow-up of children discharged from the hospital after a multisystem inflammatory syndrome in children (MIS-C) diagnosis.

For more information about either clinic, speak with your child's pediatrician. Information also is available at [NortonChildrens.com/Covid-Clinic](https://www.NortonChildrens.com/Covid-Clinic) and [NortonChildrens.com/MIS-C](https://www.NortonChildrens.com/MIS-C).

Being a part of **THE SOLUTION**

One man sets out to help meet basic needs in West Louisville

Long before the coronavirus pandemic brought food insecurity into the national spotlight, it's been a heartbreaking reality for too many local families, particularly those in West Louisville. It's not just about job loss or temporary tough times. It's about equitable access to nutritious food and health care.

Scott Love, vice president of CRA and community development for BB&T, now Truist, has spent his career in West Louisville and knows the struggles of families in its nine neighborhoods — an area considered a food desert, where access to fresh and healthy foods is scarce.

Nutritious food is a basic health need, particularly for children's growth, development and success in school. It's the foundation for a healthy and fruitful adulthood.

To address the lifelong implications of child hunger and the barriers families face, in 2016, the Norton Children's Hospital Foundation added food pantries to six Norton Children's Medical Group practices, affiliated with the UofL School of Medicine. They are run with help from Norton Children's Prevention & Wellness.

Having a food pantry within a medical office allows pediatricians to identify families who may need help. As part of all wellness visits, patients are asked a couple of basic questions to determine if they have food insecurities.

While Scott recognized the great benefit of the food pantries, he knew they needed to be stocked with more — diapers, formula and baby food — items that many families struggle to afford.

Through the BB&T, now Truist Foundation and its community development department, Scott set out to ensure these items are available in Norton Children's five food pantries closest to underserved parts of the city.

"At BB&T, now Truist, our charge is to improve the lives of folks in those communities," he said. "Providing essential community services to meet health needs is one way we can ensure families are living a healthy lifestyle and children are set up for a successful life."

Scott's passion turned into \$70,000 from BB&T, now Truist to the Norton Children's Hospital Foundation to fund food and baby essentials in the food pantries.



Dean Lavenson Photo

Scott Love visits the food pantry at Norton Children's Medical Group – Broadway

"The job of our providers is to care for the whole patient, and that is so much more complex than looking after their physical health," said Lynn Meyer, Ed.D., R.N., CFRE, senior vice president and chief development officer, Norton Healthcare. "We are so grateful for community members like Scott and Truist for stepping up to help us fulfill our mission to respond to the needs of our community."

"It brings me great joy to be a part of the solution," Scott said. "Being able to make a difference — it's just the right thing to do."

In 2020, Norton Children's 21 food pantries gave out nearly 66,000 pounds of food to more than 10,000 patients and families.

Norton Children's Prevention & Wellness is piloting a pantry in the Norton Children's Hospital emergency department and a voucher system for patients to pick up fresh produce at a mobile food pantry in the West End. Another pantry is coming soon to the Russell neighborhood.



Food insecurity is a health inequity

The Norton Children's food pantries are part of a larger commitment by Norton Healthcare to address inequalities in our community. In June 2020, Russell F. Cox, president and CEO, Norton Healthcare, announced the creation of the Institute for Health Equity, a Part of Norton Healthcare, as one of five organizational imperatives.

The primary focus of the institute is to identify and remove obstacles that prevent people in underserved areas from receiving the health care they deserve and to eliminate disparities in care.

"The premise of the institute is that health equity can only be achieved when every person has a fair opportunity to achieve their full health potential," said Kelly C. McCants, M.D., executive director, Institute for Health Equity. "We are working to make that a reality by being an advocate and convener for community-based services. Food pantries are just the start."

The **other four imperatives** are:

- 1 Ensuring access to primary care for everyone
- 2 Committing to mirror our community within the Norton Healthcare leadership team
- 3 Providing more education and advocacy for its workforce on health policy issues
- 4 Investing an additional \$20 million over five years to address health needs in underserved areas

Help be the change

You can help the Institute for Health Equity make change for the better in Louisville by donating at **HelpNortonChildrens.com** and designating your gift to the institute. Some recent initiatives include a \$1.2 million commitment to Simmons College of Kentucky for facility improvements and an institute headquarters opening in June in the Russell neighborhood that will provide access to a variety of community health services.

—Jennifer Reynolds

In my own words

It's time we face teens' mental health

If you look up *community* in the dictionary, you'll find one definition is "joint ownership." As a community we need to recognize — and own — suicide prevention and mental health in teens.

Looking at the world we live in today, there is no shock that mental illness is all around pre-teens, teens and young adults. In middle school, I and many kids had not a clue what suicide, self-harm, depression or anxiety is. However, I learned very quickly when I went through what most adults would disregard as "a phase."

I saw myself and my friends get bullied by students *and* their families in ways I had only ever seen on television. This unfortunately pushes most teens to question their very existence and develop self-harm tendencies, depression and anxiety.

Whether it's middle school, high school or college, students face verbal harassment in person and cyberbullying online. Truly, most kids do not get an escape from this mistreatment. This is what pushes kids to the edge. Even when they talk to a trusted adult, the answers tend to be insanely ridiculous. Their "solutions" often involve "get over it," "it's just kids being kids" and "don't be so sensitive." I was told this many times and eventually, I never talked about my mental health or trusted anyone again. I know many other young people who have wound up feeling the same.

The way society has stigmatized mental health is a big issue. People are afraid to speak, being told not to say anything about it. When this occurs, the worst could happen — from suicide to self-harm and self-hate. For myself, I felt alone, that I deserved it, that I was the only one. I even saw my best friend become so distant and "alone" that he killed himself. As a community, the negative outlook on mental health has silenced many young lives.

The isolation of the COVID-19 pandemic has especially become a detriment to youth. Coming of age has come faster than ever before.

It is time to look at the warning signs. Many are good at hiding their issues, fearing what their parents will think or say. Even friends are kept in the dark. There is no better time than to act and push for mental health awareness and suicide prevention. To save the generation of tomorrow, we need to break the stigma of today. We owe this to ourselves to make it better and more acceptable to reach out for help.

—Taylor Henry

"... Students face verbal harassment in person and cyberbullying online. Truly, most kids do not get an escape from this mistreatment. This is what pushes kids to the edge."

—Taylor Henry

Taylor Henry is a senior at Atherton High School and is Miss Bardstown 2021.

Crisis hotlines

National Suicide Prevention Lifeline: **(800) 273-8255**

Crisis Text Line: **Text "HOME" TO 741741**

Teen Talk: Mental Health Virtual Class May 13 • 6 to 7:30 p.m.

This free online discussion is led by a child psychologist for parents and teens to learn about teen mental health, get tools to relieve stress and hear about available resources. Recommended for ages 11 to 17 and their parents.

To register for this Zoom class, go to [NortonChildrens.com/Classes&Events](https://www.nortonchildrens.com/classesandevents).

Warning signs a teen needs help

- Stating that they want to die or don't want to live anymore
- Spending more time alone
- Feelings of hopelessness
- Change in sleeping patterns
- Prior psychiatric condition
- Family history of suicide
- Exposure to suicide

Hearing loss and ear infections

What you need to know

An ear infection can cause hearing loss in a child, but it usually is temporary and can last a few weeks or more even after the infection clears.

The infection causes fluid to build up in the middle ear — between the eardrum and the hearing nerve that carries electrical impulses to the brain. The fluid can limit the movement of the three bones in the middle ear that amplify sound waves as they are converted to electrical pulses in the hearing nerve.

If the fluid and any hearing loss are still present after more than three months, placement of ear tubes may be recommended.

"Children are more vulnerable to ear infections as the eustachian tube that drains fluid from the ear and equalizes air pressure is shorter and more horizontal than in adults. The adenoids in children also can interfere with the eustachian tubes," said Swapna K. Chandran, M.D., pediatric otolaryngologist with Norton Children's ENT & Audiology, affiliated with the UofL School of Medicine.

Three-quarters of children have at least one ear infection by age 3, and about half of them will have three or more ear infections.

Too much fluid in the ear eventually can tear the eardrum. A ruptured eardrum usually will heal within a few weeks to a couple months with no lasting hearing loss. More severe ruptures, typically due to injury, may require surgery.

When do ear infections cause permanent hearing loss?

Permanent hearing loss can result from a chronic infection in the middle ear. Recurring infections over time can cause permanent damage to the eardrum, the bones of the middle ear or the hearing nerve.

"Call your pediatrician if your child has an earache or sense of fullness in the ear, especially when combined with a fever. Even if you can work through ear infections at home, keep your pediatrician informed of how frequently they happen in case treatment is needed to prevent permanent damage," Dr. Chandran said.

Introducing Norton Children's ENT & Audiology

The ear, nose, throat and audiology providers of UofL Physicians – Pediatrics are now a part of Norton Children's. If you think your child needs ENT or audiology care, speak with your child's pediatrician about a referral. Learn more about available services at [NortonChildrens.com/Ear-Nose-Throat-Audiology](https://www.nortonchildrens.com/Ear-Nose-Throat-Audiology).



Swapna K. Chandran, M.D., checks the ears of young patient, Lilliah Burdoine-Lewis.

Signs of hearing loss in a child

- The child doesn't respond to soft sounds.
- You need to turn up the TV or radio for them.
- They talk louder.
- They seem inattentive at school.

A child whose eardrum has ruptured might have ringing or buzzing in the ear and not hear as well as usual.

Signs of ear infection in an infant or toddler

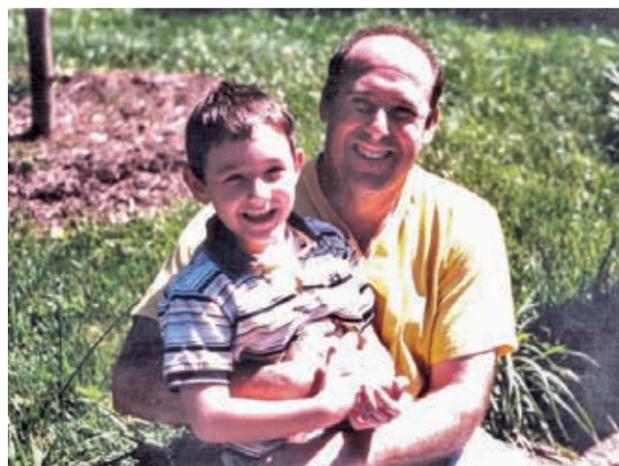
- Fever
- Trouble eating, drinking or sleeping
- Discomfort when chewing, sucking and lying down, which can cause painful pressure changes in the middle ear

Older kids may be able to say they have ear pain, but a younger child might just tug at the ear or be fussy and cry more than usual.

—Dan Blake

Donation benefits research of innovative cancer treatments for kids

Tom Dunbar honors son by furthering CAR-T immunotherapy and precision medicine



Tom and Evan Dunbar

Specialists at Norton Children's and the University of Louisville have long participated in research that has brought the latest cancer therapies to children. I see an opportunity to further that work, specifically around CAR-T, so that patients locally have access to this potentially life-changing treatment."

—Tom Dunbar

A Louisville philanthropist's \$288,000 commitment to the Norton Children's Hospital Foundation will help further research into CAR-T cell immunotherapy and other potentially life-changing new treatments for kids with cancer.

Tom Dunbar, who has now given more than \$500,000 to the foundation, said his newest gift will support clinical research into some of the latest treatment options at Norton Children's Cancer Institute, affiliated with the UofL School of Medicine.

"Specialists at Norton Children's and the University of Louisville have long participated in research that has brought the latest cancer therapies to children," Tom said. "I see an opportunity to further that work, specifically around CAR-T, so that patients locally have access to this potentially life-changing treatment."

Tom's gift will provide funding for additional research personnel to help with clinical trials, including upcoming CAR-T and precision medicine studies. Additional research includes new drug therapies and advancements in stem cell transplantation.

Clinical trials at Norton Children's Cancer Institute bring leading-edge treatments that, while still being tested, can help kids with cancer in the Louisville region. Norton Children's Cancer Institute is a long-standing member of the Children's Oncology Group, which is devoted exclusively to childhood and adolescent cancer research. More recently, Norton Children's Cancer Institute has joined the Beat Childhood Cancer Research Consortium of 47 children's hospitals and academic institutions nationwide.

With more than 60 years of pediatric cancer care expertise, Norton Children's is home to one of the oldest oncology programs in the U.S. and has been continuously accredited by the American College of Surgeons' Commission on Cancer.

Once considered virtually incurable, some pediatric cancers now have a survival rate of about 85%, thanks to research to develop new treatments.

"We are so grateful to Tom for his generosity that will truly serve as a catalyst in our continued efforts to increase research trials for our patients both now and in the future," said Ashok B. Raj, M.D., pediatric hematologist/oncologist, and medical director, Norton Children's Cancer Institute. "The community's support is vital in helping cure pediatric cancer and move our program forward."



The pediatric cancer research team, from left, Michael A. Huang, M.D.; Ashok B. Raj, M.D.; and William T. Tse, M.D., Ph.D.

CAR-T, or chimeric antigen receptor T cells, is a revolutionary immunotherapy in which a leukemia patient's own immune cells are collected and genetically reprogrammed before the cells are reinfused into the patient. The patient's reprogrammed immune system then will recognize and kill leukemia cells that have resisted conventional chemotherapy.

Tom's son, Evan, died from neuroblastoma in 2001 at age 6, and Tom's father died from melanoma in 2009, both of whom have served as catalysts for Tom's donations. Tom's wife, internist Stephanie Altobellis, M.D., diagnosed Tom's own cancer in 2019.

This clinical research builds on Tom's foundational gift to establish a research-based CAR-T Lab at the University of Louisville's Brown Cancer Center in Evan's and Tom's wife's names. Having the actual T-cell collection and infusion process occur in Louisville, when the research goals match up, allows local patients and their T-cells to stay in Louisville. When bench-level research is translated to the bedside, it offers the best opportunity to treat and cure children.

CAR-T immunotherapy first received U.S. Food and Drug Administration approval in 2017 for patients under age 25 who have hard-to-treat forms of B-cell acute lymphoblastic leukemia (ALL). Within two years, it rapidly became an essential part of treatment for these forms of leukemia, according to William T. Tse, M.D., Ph.D., pediatric hematologist/oncologist and medical director, Norton Children's Cancer Institute Pediatric Blood and Marrow Transplant Program.

"CAR-T is like a homing device to allow the T cells to find and kill the leukemia cells," Dr. Tse said.

Tom's gift will support Dr. Tse's research, which aims to bring innovative and effective CAR-T cell therapies to children with hard-

to-treat blood cancers and solid tumors such as neuroblastoma, osteosarcoma and brain tumors.

It will also support research initiatives by Michael A. Huang, M.D., pediatric hematologist/oncologist and co-director, Norton Children's Cancer Institute Neuro-oncology Program. This includes implementation of a pilot personalized medicine program that uses targeted cancer agents for high-risk pediatric solid tumors, including brain tumors. In collaboration with the Beat Childhood Cancer Consortium, Dr. Huang is spearheading an early phase clinical trial studying a drug called DFMO to prevent relapse in molecular high-risk medulloblastoma, which is the most common childhood brain malignancy.

Tom's generosity also has been used to establish the annual Evan Dunbar Lectureship series, bringing a high-profile speaker to present to pediatric oncology medical professionals at Norton Children's Cancer Institute, University of Louisville and others who have an interest in current pediatric oncology research.

—Maggie Roetker

UofL students support kids with cancer

For one week in February, University of Louisville students virtually danced and participated in other online activities to help kids with cancer during raiseRED, a student-led dance marathon supporting Norton Children's Cancer Institute.

It's not too late to support raiseRED or Norton Children's Cancer Institute. Go to <https://p2p.onecause.com/raisered/donate>.

Living like it's a pandemic — *forever*

For families living with cystic fibrosis, infection prevention never goes away



Albert and Hazel Leggett

Bourbon & Bowties chefs feed health care workers during COVID-19

Throughout the pandemic, Norton Healthcare has provided more than 65,000 meals for our health care heroes. This was made possible with support from the community totaling more than \$279,000 through the Norton Healthcare Foundation and Norton Children's Hospital Foundation.

Many Bourbon & Bowties restaurants and chefs partnered with the foundations to prepare meals, including Bar Vetti, Biscuit Belly, Bourbons Bistro, Drake's, The Fat Lamb Kitchen & Bar, Portage House, Fork & Barrel, Gustavo's Mexican Grill, Martin's Bar-B-Que Joint, Martini Italian Bistro, Masterson's, Mercato Italiano, Mesh, Morrison Healthcare, Napa River Grill, River House, Sevice, Taco Luchador, Tea Station Asian Bistro, Vincenzo's and Volare Italian Ristorante.

Having a child with cystic fibrosis (CF) can be an isolating experience. Strangely, a global pandemic has made it feel less so as the rest of the world has grown accustomed to infection prevention strategies that have been part of everyday life for Julia and Albert Leggett since their 2-year-old daughter, Hazel, was born.

"This past year has felt like the world around us is saturated with the parts of CF that overwhelm us the most," Julia said. "Sanitizing, social distancing, uncertainty, weighing risk and isolation — in a strange way, it feels like everyone has CF and is talking about it!"

Like many others, the Leggetts decided to forgo Hazel's second birthday party this year — as they did for her first birthday — because the risk of exposure to infection is just too great.

Julia and Albert received Hazel's diagnosis before she was born, and they've been fighting for her health — and the health of others with CF — ever since. Hazel and her parents will be honored at this year's Norton Children's Hospital Foundation Bourbon & Bowties™ event.

What is cystic fibrosis?

People with CF have a defective gene that causes a thick, sticky buildup of mucus in the lungs, pancreas and other organs. The mucus in the lungs clogs the airways and traps bacteria, leading to infections, extensive lung damage and, eventually, respiratory failure. In the pancreas, mucus prevents the release of digestive enzymes that allow the body to break down food and absorb vital nutrients.

—Julie Kruer

Bourbon & Bowties™

Mark your calendar!

Tickets for this sellout event go on sale Thursday, May 6. This year's Bourbon & Bowties will be held on Thursday, Aug. 26, and will help fund a social worker to support families of kids with CF through the Norton Children's Hospital Cystic Fibrosis Program.

Visit NortonChildrens.com/BourbonAndBowties for details on how to get event tickets and to purchase \$25 raffle tickets for a chance to win \$2,600 in restaurant gift cards.



Dean Lavenson Photo

On a mission to reach more kids Shelbyville family's story illustrates why

Over the past decade, Norton Children's has set out to make it easier for families to receive care. That's meant expanding offices throughout the region. Having locations closer to families' homes can make a huge difference when it comes to keeping kids healthy and especially when specialized care is needed.

For Elizabeth and Kyle Nichols, having Norton Children's Medical Group — Shelbyville to turn to for their oldest daughter, Reese, has been a blessing. Reese was born with MECP2 duplication syndrome, a rare condition that is part of the Rhett family of syndromes. While thousands of boys throughout the world have this condition, Reese is one of only a few hundred girls to be diagnosed.

Symptoms and severity can vary with each child. Reese is unable to talk, uses a wheelchair and has low muscle tone. This makes her prone to frequent lung infections and gastrointestinal issues. It also means she has spent a lot of time at Norton Children's Hospital and Norton Women's & Children's Hospital.

"We average around 20 to 30 overnight visits and countless visits to the emergency room," Kyle said.

Every time Reese comes home from a hospital stay, she has follow-up visits with Lisa B. Lyon, M.D., her Norton Children's pediatrician in Shelbyville, Kentucky.

"Dr. Lyon is amazing. When we get out of the hospital, she takes over," Kyle said.

Being able to receive care close to home and from a physician connected to the Norton Children's network makes the transition seamless. Dr. Lyon coordinates care with Reese's specialists and communicates on Reese's care plan.

"The Shelbyville office has been a godsend for us," Elizabeth said.

This sentiment is echoed by the many families who receive care at more than 170 Norton Children's locations. Thanks to support from the Norton Children's Hospital Foundation, Norton Children's is able to continue to expand the reach to families as far away from Louisville as Ashland and Paducah.

"We know it's important for children to receive care that is specialized to meet their needs throughout childhood — from infants to teens. Investing in the continued growth of Norton Children's throughout the state through clinical centers and expanded services is an important goal of the Norton Children's Hospital Foundation," said Lynn Meyer, Ed.D., R.N., CFRE, senior vice president and chief development officer, Norton Healthcare.

—Anne Cannon

Norton Children's — for all your children's needs

From acupuncture to urology and 27 specialties in between, Norton Children's is here when you need us. Whether you're looking for a pediatrician or a specialist, find one near you at NortonChildrens.com.

Learn how you can support the continued growth of Norton Children's through the Norton Children's Hospital Foundation at HelpNortonChildrens.com.

Photo: Reese Nichols visits Lisa Lyon, M.D., at her Shelbyville, Kentucky, office.

Much-needed **AUTISM CENTER** coming to St. Matthews

Alysia Wade's goal for her son Joey, who has autism spectrum disorder, always has been independence.

"If you don't have independence, what do you have?" she said. "Nothing, you're just stuck at home."

Joey, who is 18 and nonverbal, is quite capable, according to Alysia, but needs help learning life skills such as how to fold laundry and live with adults other than his parents.

Alysia and her husband, Tim, who live in Floyds Knobs, Indiana, have been fighting for services for Joey since he was diagnosed at age 3, but availability of quality caregivers and affordable services — much less any services at all — have been what she describes as a nightmare, especially as Joey has gotten older.

To better serve patients like Joey, Norton Children's is in the process of building Norton Children's Autism Center, affiliated with the UofL School of Medicine. It will be located in Hikes Point with three other unique Norton Children's practices. The 13,000-square-foot center will be a one-stop resource for families across the region to access evaluation, treatment, research and training for ages 3 to 21. The facility is scheduled to open in 2022.

It's the type of facility that Alysia has been dreaming of for her son, and she's not alone. According to the Centers for Disease Control and Prevention's most recent data from 2016, 1 in 54 U.S. children ages 8 to 11 has received an autism diagnosis. In 2000, that number was 1 in 150.

"With this new facility, we will have the capacity to serve many more patients than we have served before," said Gregory Barnes, M.D., Ph.D., executive director, Norton Children's Autism Center.

The vision for the autism center incorporates therapy rooms for psychologists, speech therapists, occupational therapists and behavioral analysts, along with medical exam rooms, small and large group therapy rooms, an occupational therapy gym, indoor play space, a feeding therapy kitchen, a simulation apartment for individual and group skills classes, a family resource library and conference space.

One of focuses will be a robust transition to adulthood program in partnership with various community organizations and schools to help ease young adults from pediatric care into a successful adult care experience. The vision is to garner community support to fund resources for housing, job readiness and vocational training. This vision also has a \$500,000 research component with the University of Louisville.

"Combining the resources of Norton Children's and the UofL School of Medicine — along with this new facility — are a huge step in providing the care that families in our region so desperately need,"

said Linnie Meyer, Ed.D., R.N., CFRE, senior vice president and chief development officer, Norton Healthcare. "But we still have a lot of work to do, and it's exciting to see the community rally behind this project to make this vision a reality."

The center will be staffed by pediatric neurologists, pediatricians, sleep medicine specialists, gastroenterologists and more. There also will be a robust feeding therapy program.

"Children with autism have sensory issues, and one of those issues is that the taste and texture of food can be problematic," Dr. Barnes said. "It can get so bad that a child can need a feeding tube if it is not addressed."

The center also will offer an augmentative-assisted communication program that helps children use devices to communicate in a number of ways.

"Being able to communicate is key to developing," Dr. Barnes said. "Without a way to communicate their wants and needs, children with autism can get frustrated and aggressive."

As the teaching program for the UofL School of Medicine, the center will train future autism providers. Fellowships and endowed chairs will be created to continue to attract a skilled workforce to our community.

Alysia describes what the center will offer as life-changing for families like hers.

"Often, especially with individuals who are nonverbal, there is a tendency to lower expectations for them," she said. "An inability to speak does not mean an inability to think. We should always assume an autistic person has the capacity to think, learn and understand."

—Julie Kruer



Alysia, Joey and Tim Wade

You can help make the autism center a reality

To support this project through the Norton Children's Hospital Foundation, visit **NortonChildrens.com/Donate** and designate Norton Children's Autism Center as the gift recipient. Or call **(502) 629-8060** to find out more.



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- In recognition of someone's anniversary or marriage
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To make a tribute gift, return the envelope enclosed in this issue of Cart Wheels or visit HelpNortonChildrens.com. You also may contact the Norton Children's Hospital Foundation at (502) 629-8060.

Efforts have been made to include all tribute gifts. If a name was overlooked or printed incorrectly, please accept our apologies. You are invited to contact us to correct the error: Norton Children's Hospital Foundation, 234 E. Gray St., Suite 450, Louisville, KY 40202, (502) 629-8060 or foundations@nortonhealthcare.org.



Congrats, Home and BMW raffle winners!

The Norton Children's Hospital Home & BMW Raffle, a part of the annual Festival of Trees & Lights, winners were announced on Nov. 21, 2020, at the virtual Snow Ball gala. Congratulations to the following winners:

John Barron of Prospect, Kentucky, won the new home in Norton Commons built by the Ramage Company.

Sari Norris of Louisville, Kentucky, won a 2021 BMW X3 from BMW of Louisville and \$10,000.

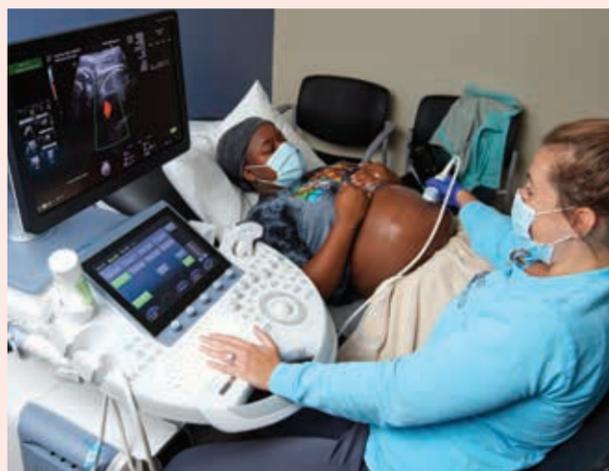
Other winners included Anne Mosely of Owensboro, Kentucky, who won groceries for a year; Christopher Aponte of Floyds Knobs, Indiana, who won a technology package; and Ferenc Nagy of Crestwood, Kentucky, who won gas for a year.



Virtual dancing saves lives

The pandemic didn't stop the Western Kentucky University Hilltoppers from holding its seventh annual Dance Big Red fundraising event via Zoom and Facebook Live on Feb. 26. This year's event raised nearly \$50,000 and benefited pediatric heart care at Norton Children's Heart Institute, affiliated with the UofL School of Medicine.

Since it began, Dance Big Red has raised over \$330,000 for pediatric cardiovascular services and adolescent cancer care at Norton Children's Hospital.



Western Kentucky babies get new heart technology

Norton Children's Maternal-Fetal Medicine in Norton Children's Hospital Outpatient Center – Bowling Green, Kentucky, received state-of-the-art diagnostic and ultrasound equipment designed to identify complex heart anomalies in unborn babies. This technology allows for the earliest identification of conditions that may require immediate treatment after birth, allowing physicians and families to make a plan of care before delivery.

Community support for the Norton Children's Hospital Foundation helped make purchasing the equipment possible. The Harold, Juanita, David, Dennis & Gary Koon Charitable Foundation provided a \$100,000 gift, and Dance Big Red's 2020 virtual fundraising event provided additional support.

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

	<p>APRIL</p> <p>26</p>	<p>Norton Children's Hospital Foundation Golf Outing, Lake Forest Country Club, Hurstbourne Country Club and Valhalla Golf Club. Gather your team for a scramble-style golf tournament benefiting Norton Children's Hospital. Various tee times available.</p>
	<p>MAY</p> <p>6</p>	<p>Tickets on sale for Bourbon & Bowties, Aug. 26, 2021. Louisville's top chefs serve up gourmet hors d'oeuvres accompanied by silent and live auctions, to help raise more than \$300,000 for Norton Children's. Visit NortonChildrens.com/BourbonAndBowties for details, where you also can purchase a \$25 raffle ticket for a chance to win \$2,600 in restaurant gift cards.</p>
	<p>10-16</p>	<p>Nurses Week at Norton Healthcare. Help us celebrate nurses by showing special appreciation to your nurse friends and family.</p>
	<p>SPRING</p> <p>ONGOING</p>	<p>Healthy Living Wellness Virtual Group for parents of children ages 8 to 17. This three-week class led by certified health coaches will help families reach their wellness goals in an engaging and supportive setting. A variety of start dates are available. Go to NortonChildrens.com/Classes&Events.</p>

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Providing care that's "Just for Kids"

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 Group pediatric practices throughout Kentucky and Southern Indiana. To learn more about our programs and services, visit NortonChildrens.com.

The Norton 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.

Spring 2021

Cart Wheels

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