

# hope

CHILDRENSHOSPITALVANDERBILT.ORG

WINTER 2019



## On Their Way

Young adults forge  
new paths after  
cancer diagnoses





## cover story

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**A**S WE BEGIN A NEW YEAR, we reflect upon what grounds us in our work, as well as what excites us about our future. Our mission at Monroe Carell Jr. Children's Hospital at Vanderbilt is to serve children of all ages and their families with programs tailored to meet their needs and designed to support their health and well-being. We start this year eagerly anticipating our move into our first two new expansion floors — supported by the Growing to New Heights Campaign — and planning for other internal program transitions that the additional space allows.

Every year, we treat over 250 patients with a new or relapsed diagnosis of cancer. This number grows a little every year. These patients come to us because of the multidisciplinary treatment options we offer — both as standards of care, but also as research protocols. To better accommodate the needs of these patients and our distinctive programs, we plan to reconfigure some of our clinical areas. Through the generosity of donors, we will develop space to better support the unique needs of adolescents and young adults with cancer. Through the tireless energy of our Children's Hospital Advisory Board leaders Allison DeMarcus and Kailey Hand, we are launching a new childhood cancer campaign that will result in redesigned clinical space to serve both outpatients and inpatients. And through the eyes of a remarkable young lady, Lily Hensiek, and her family, we share how the passion to find a cure for cancer has led them to support both research and training of future pediatric oncologists.

In addition to our growing cancer service, we celebrate our evolving liver transplant program. Liver disease in children most often arises from other conditions — genetic or anatomic problems present from birth or because of treatments or the duration of other chronic diseases. We share how liver transplantation became life changing for young Wyatt Nickle.

As a regional comprehensive center for children's health care, it is equally important to our mission to extend our efforts into the community through advocacy and programming to improve the health and well-being of our pediatric citizens. We celebrate 10 years of the Nashville Collaborative, a joint effort between our Children's Hospital teams and Metro Nashville Parks and Recreation. The Collaborative is a wonderful example of taking research questions into the field, resulting in the design of successful programs that help children live healthier lifestyles in the fight against childhood obesity.

What links these stories of innovation is the generous support and true partnerships that we have within our community. Through our unique clinical programs, our innovative inquiry and discovery and our commitment to education — all supported by our community — we are truly a place of healing and hope for our patients and families. What a great way to start another exciting year of growing to new heights and embracing novel opportunities.

Sincerely,

Luke Gregory, FACHE  
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Meg Rush, MD, MMHC  
*Chief of Staff and Executive Medical Director*

John W. Brock III, MD  
*Senior Vice President of Pediatric Surgical Services, Monroe Carell Jr. Professor and Surgeon-in-Chief*

Steven Webber, MBChB, MRCP  
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**and do outreach to secure resources to support**  
**the mission of Children's Hospital. Learn more at**  
**ChildrensHospitalVanderbilt.org/advisoryboard.**

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Brittany Burns, 25, recently graduated from Belmont University with a Bachelor of Science in Nursing.



# ON THEIR WAY

**Young adults forge  
new paths after cancer diagnoses**

Christmas break during her second year of college should have been a happy and relaxing time for Brittany Burns of Brentwood, Tennessee. She was looking forward to a month off with her close-knit family and hometown friends before returning to the University of Tennessee at Chattanooga.

The 20-year-old hadn't felt well for weeks, fighting extreme fatigue and a nagging cough. Between Thanksgiving and Christmas breaks, she visited an urgent care clinic and left with a prescription for cough medicine, but no diagnosis. The cough and fatigue lingered.

Shortly before Christmas in 2013, after a battery of doctors' visits and tests to rule out what was suspected to be cat-scratch disease, a biopsy of her lymph nodes revealed that she had Hodgkin lymphoma, a cancer of the white blood cells called lymphocytes, part of the body's immune system.

"It was a definite curveball," Brittany recalls. "I did not see it coming. I was excited about being home and seeing my cousin's twin girls have their first Christmas. Then, suddenly, I didn't know if it would be my last Christmas."

written by Nancy Humphrey  
photograph by John Russell

A diagnosis of cancer at any age is tragic, but during the adolescent and young adult (AYA) years (ages 15-39), it's especially complicated, said Scott Borinstein, MD, PhD, associate professor of Pediatrics at Vanderbilt University Medical Center and director of the Adolescent and Young Adult Oncology Program at Monroe Carell Jr. Children's Hospital at Vanderbilt.

"They're working hard in high school and trying to get into college, or they're right out of college trying to enter the workforce and becoming financially independent. It's a challenging time in their life without a diagnosis of cancer to complicate things."

Children's Hospital has providers attuned to the needs of teenagers and young adults who can offer coordinated and comprehensive cancer care, delivered in a nurturing and supportive way for the patients who aren't children, but in so many ways aren't adults either.

"This group of patients faces a fairly unique set of challenges," said Borinstein, the Scott and Tracie Hamilton Professor of Cancer Survivorship. "This is a developmentally critical moment in which you are learning to live on your own, making friends, developing your identity and often engaging in romantic relationships for the first time. A cancer diagnosis often puts a halt on all of this. It is very hard."

When an AYA cancer patient comes in for treatment, there is first a discussion about whether he or she should be treated by an adult or pediatric oncologist and whether that care should occur at Children's Hospital or Vanderbilt-Ingram Cancer Center, Borinstein said. The decision comes down to the type of cancer and the location of the expertise.

AYA patients receive their treatment from pediatric specialists at Children's Hospital if their cancers are of a pediatric type — leukemias, bone and soft tissue cancers — and they are treated by adult oncology physicians if they have a cancer normally found in adults — like breast, cervical and melanoma.

*Scott Borinstein, MD, PhD, is passionate about helping teens and young adults battle cancer during what he calls a "vulnerable time."*

SUSAN URMY



Borinstein said the program attracts patients from Tennessee, Kentucky, Alabama and other states.

"We have the benefit of being in a medical center with experts in pediatric and adult cancers who have the temperament and passion to take care of this unique population of patients," said Borinstein, who specializes in sarcomas, highly malignant cancers of the bone and soft tissue, and directs the pediatric sarcoma program at Children's Hospital.

"We try to identify for our teens and young adults the best oncologist, surgeon and radiation oncology team that not only provides the expertise needed to develop and implement the optimal treatment plan, but also will provide and coordinate supportive care services AYA patients need to assist them throughout cancer treatment. We try to merge aspects of adult oncology care with the support and nurturing we give patients in the pediatric world.

"I'm thankful our leadership and administration really understand the importance of letting our young adults get treatment in our Children's Hospital when it's in their best interest. We're the only place in Tennessee that has that breadth of cancer services in one place."

### A delayed diagnosis

About 70,000 young people (ages 15-39) are diagnosed with cancer each year in the United States, accounting for about 5 percent of all the nation's cancer diagnoses. This is about six times the number of cancers diagnosed in children from birth to 14, according to the National Cancer Institute (NCI). Leukemia, lymphoma, testicular cancer and thyroid cancer are the most common cancers among 15- to 24-year-olds. Among 25- to 39-year-olds, breast cancer and melanoma are most common.

Cancer is the leading cause of disease-related death in the AYA population — only accidents, suicide and homicide claimed more lives than cancer in 2011, according to the NCI.

Unfortunately, the treatment outcomes for AYA cancer patients have not improved over the past few decades compared to those for pediatric patients or older patients. The reasons for this "AYA gap" are complicated, Borinstein said, but lack of health insurance or a parent living with them to encourage medical attention often leads to a delay in seeing a doctor.

"Many put off the symptoms for a long time before they seek medical care. They're young. They also think they're invincible. They think nothing can happen to them, so they often blow off the symptoms. A delay in diagnosis can make the cancer more difficult to treat."

When they finally get to a physician, Borinstein added, the cancers that can affect AYA patients are often rare, not the type of cancers that community oncologists have much experience managing. Coming to a place like Vanderbilt, with experts who treat rare cancers in children, teenagers and young adults, is crucial.

It's also vital that this group receive psychosocial support before, during and after therapy since the incidence of depression and anxiety is very high in this patient population, Borinstein said.

"Patients diagnosed with cancer early in college, for example, might have to leave college and move back home with their parents. Instead of being on their own, learning to be independent and autonomous, they become dependent again.

"This can make them angry and sad and frustrated. They might lose friends. They lose their hair, which can affect their body image. They feel tired and weak. Significant surgeries and treatments can result in mobility limitations. It can hinder normal development of independence and their ability to have relationships of a romantic nature; it can affect their sexuality. It affects everything during such a vulnerable time."

Borinstein is passionate about treating AYA patients. "If you treat them respectfully, like an adult, you can often earn their trust, which is essential in the development of a strong therapeutic relationship. I find it inspiring to take care of these very special patients. I enjoy their humor, joking around with them, and helping them through their journey. But it's taken a lot of practice to find how to connect with them. It's a challenge, but an incredibly rewarding one."

The Children's Hospital team can also help the young adult who might be off his or her parents' insurance plan find financial support if needed.

### A new Brittany

Brittany, now 25, said that she relied heavily on her faith and her family during her cancer treatment. Two days before Christmas in 2013, she had a port put in for chemotherapy and had a bone marrow biopsy. On New Year's Eve, she had her first of five rounds of chemotherapy. "I got the kitchen sink — every concoction possible," she said. The cycle repeated for a year — three days inpatient, home one week, one day outpatient and 21 days to recover, for five rounds of chemotherapy.

The cancer responded, but she had many complications, including hospitalizations because of nausea and vomiting, weakness, weight loss and resulting muscle wasting.

"I weighed 150 pounds when I started chemo and was down to 88 by the end of my treatments," Brittany recalls. "Because of the muscle loss, I had to have physical therapy to learn how to walk again and occupational therapy because of neuropathy (nerve damage) in my fingers and toes."

In addition to the physical complications of chemotherapy, it was also an emotional time for Brittany. She had many friends at UTC and had planned to start nursing school in the fall of 2014. "Everybody says that your college years are the greatest years of your life. School had always been a large priority in my life, and I felt like that time was taken from me, and my social life was taken from me too," she said.

Her bond with her family became stronger, and she met



## Soaring Higher, Dreaming Bigger

A Campaign Against Childhood Cancer

As part of A Campaign Against Childhood Cancer, donors are helping address AYA cancer patients' needs.

To find out how to contribute, please visit:

[ChildrensHospitalVanderbilt.org/soaringhigher](http://ChildrensHospitalVanderbilt.org/soaringhigher)

friends she never would have met (without having cancer), but a few of her existing friendships suffered.

"They were in school and we'd talk on the phone, but they'd be getting ready to go to a party and it was hard," she said. Because of her compromised immune system during chemotherapy, she also had to use an abundance of caution as to whom she could be around and when. "I could be around my nurses, doctors and my parents, and I could go to church with my mom and dad, but I had to come right home after because I needed to sleep. I was susceptible to everything. I lost out on so many memories, and I lost some friends," Brittany said. "That was the scariest time. I wondered if I'd ever get well."

But she also feels like she gained a new outlook on life.

"The diagnosis happened so fast that I don't think I processed it until after I was in remission," she said. "I wasn't able to be the Brittany that everybody loved. But I'd never change what I've been through," she added. "I wouldn't be who I am or where I am without it. I'm a better person, a new Brittany."

She has been in remission since April 2014. She continues to be monitored periodically at Children's Hospital and will remain with Vanderbilt-Ingram Cancer Center's REACH survivor program, a comprehensive clinic for survivors of all ages who have faced any type of cancer.

"The (periodic) scans are scary," she said. "Now that we know that cancer can be the option, it's very scary. It's a trying time. You have the scans then you wait a few days to get the results. You sit by the phone. You pray."

In 2014, Brittany took two classes at Columbia State College. She kept that schedule for two years, then began nursing school at Belmont University where she received her nursing degree in December 2018 — one day short of the day five years prior when she was diagnosed with cancer.

She hopes to pursue a career in pediatric oncology. "It's my passion. There is so much I could do to help patients going through what I went through," she said, adding that she still keeps in touch with the nurses who helped her during such a difficult time in her life.

When she was still in treatment, she met a medical resident



*Dillon Porter, 18, who was diagnosed with non-Hodgkin lymphoma at age 14, is now a freshman at Brescia University.*

who had also battled Hodgkin lymphoma. “It meant a lot to me. It showed me that you can still become everything you want to be. If I could do that for someone else, to show them there’s a light at the end of the tunnel...”

### Pausing high school

Dillon Porter, 18, of Russellville, Kentucky, was 14 and a freshman in high school when he learned he had non-Hodgkin lymphoma, another type of white blood cell cancer.

He played saxophone in the band, was on the varsity soccer team, and was also set to play baseball and swim for his high school swim team. He had to take a year off from high school, but was able to pass his freshman year with the help of a teacher for homebound students. By about three months into his junior year, he finished treatment.

“It was pretty rough,” said Dillon, now a freshman at Brescia University in Owensboro, Kentucky. None of the nausea

medications helped with the side effects of chemotherapy, so he had to return to the hospital often to get it under control. His hair came out in patches, and he buzzed it, although his doctor at the time suggested that he “do something crazy with it,” like dyeing it a bright color or shaving it into a Mohawk. “Thank goodness my mom didn’t let me do that,” he laughed.

Polly Porter, Dillon’s mom, said when Dillon was first diagnosed, he worried that the diagnosis would keep him from being a normal teen. Would he be able to get his driver’s license? Could the family still go on vacation the following summer? But the family soon went into “autopilot mode,” trying to take one day at a time and focusing on the positives: his hair should grow back in time for prom and senior pictures, and he should be able to go off to college at the same time his friends were going.

Overwhelmed with the diagnosis and all it entailed, Dillon asked his mom to just let him know what he needed to think

about that day. But they had good and meaningful conversations as well. “We talked a lot about living each day as if it’s your last, being kind to everyone you meet, even if you feel like crap, and how we planned to use all of the things we were learning to help others,” Polly said. “We became so much more aware of others, the struggles people are going through that you have no clue about when your life is running smoothly.”

Dillon said although he missed out on several school activities, he didn’t lose friends. “I went to basketball games and hung out with my friends when my counts were high enough, but when my friends talk about stuff they did during our freshman year, I have no idea what they are talking about.”

Dillon said he is thankful he was treated at Children’s Hospital. “They didn’t treat me like a child. They kept me informed and let me have options the whole time. I had things to do there (for his age group). There were Xboxes (gaming consoles) for the older kids and things like Predators tickets.”

Now in remission, Dillon, a patient of Borinstein’s, returns to Children’s Hospital every six months for careful monitoring.

Borinstein said the good news with AYA cancers is that once you reach the five-year mark, it’s unlikely your cancer is going to come back. However, long-term side effects, such as infertility or the development of secondary cancers, are possible.

“A lot of the treatments we give can impact their ability to have children. We provide fertility counseling to every AYA cancer patient we treat and discuss fertility preservation resources like sperm banking and egg harvesting before starting therapy,” Borinstein said.

“Anytime we give chemotherapy or radiation therapy, you increase the risk of a secondary cancer. We have to use these tools judiciously, but at the same time we have to cure their primary cancer. I hope that I practice in a day that I don’t have to give these therapies, but we’re not anywhere near that yet.”

### Coming out on the other side

Holly Tyler, RN, BSN, has worked with adolescent and young adult cancer patients since completing a nurse residency program in 2005 at Vanderbilt. She worked on the inpatient floor taking care of AYA patients for a decade, and now works with them during their chemotherapy infusions. Dillon Porter is one of her patients.

“It’s an honor to be part of their care for as long as they’re seen at Children’s Hospital,” Tyler said.

She said it’s common to see patients’ anxiety manifest into physical symptoms. “They get nauseated in the waiting room just waiting for their infusion. Unlike younger patients, who might be oblivious until it’s right in front of them, they’re very aware of what’s coming. And younger patients don’t understand the ramifications of losing their hair, of their social life being put on pause, of losing weight or gaining weight. The AYA population does.”

AYA patients are often “mad at the world. But I love helping them deal with that, talking through difficult times,” Tyler said.

“I enjoy the awkward conversations. I worry they’re not having them otherwise. They’re going through so many things at this age, and then to throw cancer on top of that. Some kids don’t want to talk to their parents, they might be afraid of losing friends, and I try to help them get those thoughts out,” Tyler said.

“I like seeing them transformed — going from the first day when they’re scared and angry to being the person coming out on the other side, being able to advocate for others.” 

## Children’s Hospital’s “Last Chemo” celebrates patients

Holly Tyler, RN, BSN, has a knack for writing jingles.

What started off as a kind gesture — writing a little ditty to say goodbye to one of her longtime patients — has turned into a standard send-off for oncology patients at Monroe Carell Jr. Children’s Hospital at Vanderbilt.

Sung for the first time on June 15, 2011, to Marshall Billingsley, then 17 (now 24), the “Last Chemo” song has been used to serenade hundreds of patients since.

“The day Marshall completed his last chemo also happened to be the day he was being discharged,” recalled Tyler, who was one of his primary nurses. “I just kept thinking, I want to do something special for him.

“I ran to the fishbowl [the area where the nursing staff congregates] to think about a tune that everyone would be familiar with. The first thing that popped in my head was ‘The Macarena.’”

“The Macarena” was a worldwide hit for the group Los del Rio in 1993, and the earworm-ready tune and its accompanying dance have been recognizable and popular since.

After Tyler had a tune in mind, she started Googling words that ended in “-tion.”

“It took me about 10 minutes,” she said.

And the rest is history.

For 10 years, Tyler, who came to Vanderbilt in 2005, worked as a nurse on the Pediatric Hematology/Oncology inpatient service. She joined the clinic staff in the Doctors’ Office Tower in 2015.

And when she did, she heard the staff singing a song with the same lyrics, but the tune was off.

“When I first heard it over here, I was like, ‘that’s really not how it goes.’ Of course, people asked how I knew. I told them, ‘Because I wrote it,’” laughed Tyler.

Now, everyone sings the song to the tune of “The Macarena,” much to the delight of patients and families.

— by Jessica Pasley

*Lily Hensiek, 17, has twice battled pre-B cell leukemia since age 7.*



# Cancer Care Reimagined

*Families, community partners and businesses team up in the fight against childhood cancer*

written by Christina Echegaray  
photograph by John Russell

**L**ily Hensiek has battled through 1,344 active treatment days for pre-B cell leukemia — first for an original diagnosis at age 7, and then for a relapse at age 15.

During the initial diagnosis, her doctor likened the cancer to weeds that had taken over her garden of cells. Chemotherapy would remove the weeds — the bad cancer cells — to allow her garden to grow and flourish. Hearing this, Lily unselfishly thought about other children who had been diagnosed with cancer, who needed their weeds plucked and their garden nurtured. She would raise \$1 million, she declared.

And she did.

Then came the relapse, 24 hours after a fatigued and pale Lily, then 15, played her last volleyball game of the season.

For the second time, she and her family would unselfishly ponder how they could keep this from happening to other children, teens and young adults; how researchers could find ways to lessen the toll chemotherapy and radiation take on their young bodies, now and in the future; and how she could support and encourage the next generation of doctors to care for pediatric cancer patients.

Three generations — Lily, her mother and stepfather, Larisa and Phillip Featherstone, and her grandparents, Carol and Ronald Johnston — have come together to devote time and financial support to this cause. Lily, now 17 and a senior in high school, surpassed her original \$1 million fundraising goal, through her family's support, community fundraisers and individual donors, to create two funds to support pediatric cancer research and training at Monroe Carell Jr. Children's Hospital at Vanderbilt. The funds, Lily's Garden Endowed Lecture in Childhood Cancer and the Lily's Garden Research Fund, support guest lectures and research opportunities for junior faculty members and fellows in pediatric hematology/oncology. Most recently, her family established a separate endowment to fully fund a named fellowship.

"It felt great to reach the goal, but I knew that I wanted to keep moving forward until there was a cure for childhood cancer," Lily said. "I knew it wasn't just about a dollar amount; it was about finding a cure."

## A call to action

Lily and her family are now joining with other families, the community and businesses to step up the fight against cancer. Children's Hospital has launched A Campaign Against Childhood Cancer: Soaring Higher, Dreaming Bigger.

The goal is to raise \$15 million, with \$10 million to expand and upgrade space for cancer treatment and another \$5 million for research, training and program support.

"About 84 percent of the children diagnosed are cured of their cancer. Ten years ago, that rate was about 78 percent, so we're making strides. But 84 percent is not 100 percent, and if your child is in that 16 percent, it matters," said Debra Friedman, MD, director of the Division of Pediatric Hematology/Oncology, and who holds the E. Bronson Ingram Chair of Pediatric Oncology.

"Childhood cancer is a terrible thing for parents and children to go through, and treatment is hard. We want to provide them with the least toxic therapies in the best environment possible. We can always do better; we can always improve. When we conduct research, we can make a difference. Additional resources and philanthropy will allow us to get there."

Leading the effort are campaign chair Allison DeMarcus and co-chair Kailey Hand, both of whom are Children's Hospital Advisory Board members and longtime supporters of the hospital and its programs. DeMarcus serves as chair of the advisory board.

"There is nothing more important than a child's health. These donations can change the lives of many children and their families. By contributing, the community is helping build a treatment center that will allow a child to fight with all the tools that are available and needed," said Hand.

"Cancer does not discriminate. On any given day, any family could face this disease. If those horrible cards are thrown your way, you

want to be somewhere where the fight is strong and the outcomes are good. This place is Vanderbilt. My message is, 'Put yourself in the shoes of the parents who walk the halls of the hospital every day searching for an answer and for hope.' To me, the question is, 'how could anyone not help?'"

### Improving cancer care

When Friedman arrived at Vanderbilt in 2008, the Division of Pediatric Hematology/Oncology treated 94 cancer patients that year. As more families and children from Tennessee and across the region seek the expertise of Children's Hospital oncologists, the number of new cancer patients treated has grown to more than 250 in 2017, with no signs of slowing. That figure doesn't include hematology patients, who have noncancerous blood disorders such as sickle cell disease or other conditions that might require infusions. While the program has grown significantly, the treatment space has not.

The addition of four floors to Children's Hospital, made possible through community partners and friends who supported the Growing to New Heights Campaign, is making room for an expanded childhood cancer center.

The first two new floors are scheduled to open by fall 2019, which will allow renovations to begin on the oncology inpatient and outpatient units.

Child, adolescent and young adult cancer patients will see expanded spaces, including for those patients receiving inpatient cancer therapy — an average daily need of 26 rooms — who also require oncology nurses with specialized training.

Currently, outpatient infusion happens in one large room, where patients are seated side by side in recliners.

A renovation of hospital and clinic space will provide private infusion rooms and dedicated, tailored space for the youngest children and for the teenagers and young adults who have very different needs. It will allow infusion therapies that take longer than normal clinic hours to be conducted in the outpatient setting, without requiring an overnight admission.



## Soaring Higher, Dreaming Bigger

A Campaign Against Childhood Cancer

A Campaign Against Childhood Cancer builds on the strengths of Monroe Carell Jr. Children's Hospital at Vanderbilt by creating space dedicated to clinical care for pediatric and adolescent cancer and addressing the needs of families in our region.

Find out how you can help more of our community's young people find expert specialty cancer care by visiting:

[ChildrensHospitalVanderbilt.org/soaringhigher](http://ChildrensHospitalVanderbilt.org/soaringhigher)



JOHN RUSSELL

*Three generations of one family have come together to devote time and financial support to curing childhood cancer. Two generations pose here (from left): Phillip and Larisa Featherstone, and sisters, Lily and Sophie Hensiek.*

Families and patients also will be involved in the redesign to give their input on how to best utilize space and accommodate their needs.

"Through these changes, we can help bring additional comfort and reassurance to patients and their families during such a difficult time," said DeMarcus. "Not only will we have space for more children and teens who need our care, but we can provide families more scheduling flexibility and privacy during treatment."

In addition to the capital investments, pediatric oncology will continue its emphasis on recruiting and researching, with plans to put even more resources toward that effort with support from the childhood cancer campaign, Friedman said.

"We have a phenomenal group of physicians and researchers, and people want to come here to do tremendous work. The funds for research will allow us to continue to recruit the best and brightest," Friedman said. "When we conduct research, we can make a difference. History has shown us that with cure rates. Additional resources will help us get there."

Drawing on the strengths of Vanderbilt University Medical Center and through collaboration with Vanderbilt-Ingram Cancer Center, pediatric oncology will continue to improve personalized cancer care, with targeted life-saving therapies and improved outcomes based on the biology of each individual patient.

"We have the benefit of the collaborative environment on campus and the leverage of resources at Vanderbilt-Ingram Cancer Center," Friedman said. "We can do even more if we have more funding, and we can move the needle on cancer research and move it faster." 

# Comfort Companions

*My Special Aflac Duck engages and comforts children battling cancer*

**P**atients at Monroe Carell Jr. Children's Hospital at Vanderbilt are being paired with a special support friend on their cancer journey — the *My Special Aflac Duck*, a high-tech robot that uses medical play, lifelike movement and emotions to engage and help comfort children during their cancer care.

“When we care for children with cancer, we focus on the whole child and family and not just the disease,” said Debra Friedman, MD, director of the Division of Pediatric Hematology/Oncology, and who holds the E. Bronson Ingram Chair of Pediatric Oncology. “*My Special Aflac Duck* will be an important part of the comprehensive care benefiting children with cancer and their families. Our pediatric cancer program is extremely grateful to Aflac for their generosity in partnering with us in the care of our patients.”

The therapeutic duck, designed by Sproutel, is a social robot to help patients cope with their treatment. The delivery included a demonstration of the supportive components of the robotic duck and how it can serve as a tool for health care professionals to use with their patients.

Following a demonstration of the duck at a surprise event for patients, children and their parents were sent on a fun scavenger hunt, finding clues and visiting various locations at the hospital, eventually leading them to the discovery of their very own *My Special Aflac Duck*.

“The duck delivery in Nashville marks an important milestone in our mission to get *My Special Aflac Duck* into the arms of every



*Five-year-old Caroline Lantz finds her very own My Special Aflac Duck, a support friend for children with cancer, as her prize at the end of a scavenger hunt held at Monroe Carell Jr. Children's Hospital at Vanderbilt.*

child newly diagnosed with cancer in America and help them during their often challenging cancer journey,” said Aflac Chairman and CEO Dan Amos. “It has been a joy to witness the smiles on kids’ faces when they receive their own comforting companion. We at Aflac, our employees and independent agents, are honored to provide those memorable moments to the brave patients being treated at Monroe Carell Jr. Children’s Hospital at Vanderbilt.”

Children’s Hospital is the fourth health care facility where Aflac has hosted a special event to distribute the free ducks for children (ages 3-13) diagnosed with cancer.

In addition to *My Special Aflac Duck*, Sproutel has created a companion app available on the Apple App Store and Google Play. The app can be downloaded on smartphones and tablets free of charge. Additional features of *My Special Aflac Duck* include:

- Emotional expression: Seven radio-frequency identification-enabled feeling cards help children communicate; the duck

acts out a given feeling when that feeling card is tapped to its chest.

- Medical and nurturing play: A chemotherapy port allows children to mirror their care experiences via play, giving them a sense of control during the process. The duck’s no-cost companion app allows users to “bathe, feed and give it medicine” via augmented reality.

- Music, dancing and nuzzling: The duck dances when music is played. Customizable sounds include gentle waves, wind and a farm.

- Breathing and heartbeat: The duck produces a naturalistic heartbeat and deep breathing, which caregivers can incorporate into calming routines and exercises.

- Batteries and accessories: Provided so it is ready to use out of the box.

- Convenience: A removable exterior skin, which can be washed to adhere to hospital hygiene standards.

– by Jessica Pasley



*Wyatt Nickle, 5, had a life-changing liver transplant to treat a genetic condition called Alagille syndrome.*

# Field of Dreams



**“Before, we always stopped ourselves from dreaming. Now, we are finding happiness in the simple things.”**

Amber Nickle watches in awe as her 5-year-old son runs the bases at his first tee-ball practice. She also sneaks peeks of him playing with groups of other children on the playground.

A year ago, Wyatt was barely walking. He was plagued by incessant itching. Shoes didn't fit his feet due to growths caused by a liver condition.

But with the help of a multitude of medical specialists at Monroe Carell Jr. Children's Hospital at Vanderbilt, Wyatt has made a remarkable health transformation that has allowed the Nickle family to experience basic milestones. Initially afraid for Wyatt's future, they finally dared to dream.

“These are things we prayed about and dreamed about,” Nickle said. “It's nice to be able to just breathe and be in cruise control. For the first four and a half years, we never experienced that.”

## **From the beginning**

Before having children of her own, Nickle had been a nanny for 10 years. She was accustomed to the cries of a fussy baby.

For the first two months of her son's life, she thought she was dealing with a colicky newborn.

But what she learned during Wyatt's 2-month-old checkup was life changing. The date, July 8, 2013, is still seared in her mind.

“That is when everything changed. Everything shifted for us,” said Nickle, remembering the phone call that urged her to bring Wyatt to the Children's Hospital Emergency Department. “Early that day during our visit, the pediatrician said Wyatt was looking a bit jaundiced (a yellow tint to the skin) and wanted to do some labs. We were told that if there was anything concerning, we would get a call from Vanderbilt. That call came around 5 p.m., and we were urged to get to the emergency room immediately.”

Nickle and her husband, John Louis, who was a nurse at Vanderbilt University Adult Hospital, were shocked by what they learned after a gamut of tests and a four-day hospitalization. Their son was diagnosed with Alagille syndrome, a rare genetic disorder that can affect the liver, heart and other parts of the body.

About 1 in 70,000 newborns is diagnosed with the disease, though it is not always detected in infancy. The condition manifests differently in every patient — some with an array of symptoms and effects, while other people never know they have the condition.

written by *Jessica Pasley*  
photograph by *Susan Urmey*



s Wyatt grew, the symptoms of the disorder began to severely impact him.

Developmental delays with muscle tone and learning became apparent. He required supplemental formula to ensure his nutritional needs were being met. And the telltale signs of the disorder became unbearable — itching and

the development of xanthomas, or deposits of cholesterol in the skin.

“We felt so out of control,” said Nickle. “Our only job as parents was to provide and protect, and we couldn’t do either of those things for him. The wait-and-see period was tough. We didn’t want his condition to define him or us. We didn’t want it to be a crutch or to control him.

“Within the walls of our home, we felt stuck. We didn’t let others know that.”

### **Tough decisions**

Wyatt’s unrelenting cries and begging for the itching (caused by the condition) to cease became a regular occurrence in the Nickle household.

“He was waking up every two to three hours,” said Nickle. “He would scratch himself and cry out in the middle of the night. We would hear him over the baby monitor crying, ‘Mommy, help. Mommy, help.’

“And there was nothing we found to keep him from scratching his skin raw. We tried to keep him in footy pajamas, but he would scratch and rub his feet together and create holes and scratch through those. His feet, ears, nose and face were the worst. They were hot spots.”

Drug trials and myriad medications to manage the symptoms were not successful. The pair had exhausted all available treatments, and they wanted to pursue curative options.

In 2017, the decision was made to seek liver transplantation for Wyatt. The choice was not an easy one. To be placed on the liver transplant waitlist, Wyatt would require open-heart surgery to repair narrowing of both pulmonary arteries, which compromised blood flow to the lungs, as well as to repair narrowing in the aorta that limited blood flow to the rest of the body. The repairs were particularly important in order to take the additional burden off the donor liver.

David Bichell, MD, William S. Stoney, Jr. Professor of Cardiac and Thoracic Surgery at Children’s Hospital, performed the surgery.

“This case was an interplay of all of our specialists,” said Bichell. “We wanted to do the fewest invasive procedures as possible with the largest impact. We had to have a plan that included doing what was best for the liver. To ensure an optimal situation for the transplanted liver to do well, we needed to fix the heart first.

“When you talk about our Children’s Hospital, you point to fully integrated teams. We pride ourselves in having strengths in all our pediatric specialties. We work really hard to ensure that everyone is thinking about the entire patient and not just their area of expertise.”

Wyatt’s heart surgery was in January 2017. Nine months later, he was placed on the liver transplant list.

In the meantime, not only was Wyatt tormented by intolerable itching, but the xanthomas were developing under his skin. Although not painful, the sensitive, fatty growths covered his body and limited his mobility as well as his ability to accomplish tasks using fine motor skills.

The xanthomas were the result of extremely high cholesterol due to the liver damage caused by Alagille syndrome. According to his medical team, his cholesterol levels “were among the highest” recorded at Children’s Hospital. These growths can appear anywhere on the body, including the eyelids and face, but are most often found in the joints (knees and elbows), feet and hands. They can vary in size from as small as a pinhead to as large as a grape.

The clustered growths caused rising alarm for Wyatt’s parents and physicians.

“Being a normal little boy sounds so simple,” said Nickle. “Kids were calling him ‘monster’ because he looked different. Even though you know your child’s value, it hurt to think, ‘Will he be 6 or 8 years old and still hearing this?’

“He didn’t really know what he was hearing, and he didn’t understand it, but that would last only so long.”

According to Sophoclis Alexopoulos, MD, chief of Vanderbilt’s Division of Hepatobiliary Surgery and Liver Transplantation, many children with Alagille become progressively disfigured with xanthomas.

“I think that the quality of a person’s life is just as important as the quantity of someone’s life,” said Alexopoulos. “One of the drivers in moving forward with transplantation was the xanthomas, and then add on the fragile bones and the incessant itching.

“This was a really tough decision for his parents because it is not a scenario where the child is going to die without a transplant. It is a case where you are desperate to improve the quality of your child’s life. When you are making that kind of risk-benefit decision, it’s very difficult.”

**“When you talk about our Children’s Hospital, you point to fully integrated teams. We pride ourselves in having strengths in all our pediatric specialties. We work really hard to ensure that everyone is thinking about the entire patient and not just their area of expertise.”**

Alagille is a rare disease, reiterated Alexopoulos. Patients with this disease do not typically receive transplants at Vanderbilt — until Wyatt.

“We are growing our pediatric liver program. We have a multidisciplinary approach with very good outcomes. We are proud of all the expertise the entire team brings, and because of that skill level, we are able to treat so many more children with liver disease.”

In 2018, the pediatric liver transplant team performed seven transplantations. Alexopoulos hopes to grow the program to 15 transplants in 2019.

### Road to transplantation

Wyatt was placed on the liver transplant list in October 2017. The Nickles were told it could take a few months before the right organ was located for their son.

In early October, Wyatt was placed in a body cast after he fractured his leg while playing. Two weeks later, Nickle received the call from the hospital that a potential liver was available.

She panicked.

“I remember calling my husband and asking to be put on a three-way call,” she said. “My husband asked if we could have 20 minutes to talk. He had just pulled into our neighborhood. He came into the house, looked at me and said, ‘We can’t fix Wyatt ourselves, but they can. They feel very good about this. This is what Wyatt needs.’”

Shortly after midnight on Oct. 26, Wyatt was rolled into his room in the pediatric intensive care unit, where his parents waited during the nearly eight-hour surgery. When it was over, they immediately recognized an improvement in their son’s skin color.

It was four days later that Nickle recognized the biggest change.

“With past procedures and anesthesia, he would stay a bit sedated,” she said. “But after this one, he was lying still. I kept asking myself, ‘Is it the anesthesia or is he just not itching?’ On that same day, he was extubated, and we knew. He wasn’t squirming or wiggling.

“I was like, ‘Are we really seeing this?’ Then every day after that, it was like, ‘oh my gosh.’ Each day, he was only getting better.”

It was a life-changing decision for the family — one that also brought a lot of satisfaction to his medical team.

“It’s difficult to express the joy after seeing that his life completely changed,” said Lynette Gillis, MD, assistant professor of Pediatrics and medical director of Pediatric Hepatology and Liver Transplantation at Children’s Hospital. “He was so miserable from the itching. And now, he is such a happy kid. The xanthomas are basically melting away. We have been able to see the profound changes in his life.”

Today, Wyatt is a healthy 43 pounds — a stark improve-

ment from 27 pounds prior to transplant. He is enrolled in preschool with his younger sister, Evy Grace, 4. They are navigating developmental milestones together.

“Since the liver transplant, Wyatt has become a new kid,” his father, John Louis, said. “He is more happy and full of energy. We hope that Wyatt can live a long and full life. We want him to grow and achieve whatever he wants. We want him to feel like he is loved and supported and that he can be a normal child who is not defined by a syndrome.”

### Next steps

Going forward, Wyatt’s diagnosis will be one less thing that separates him from his peers.

The liver transplant allowed his parents to experience hope for their son.

“Before, we always stopped ourselves from dreaming,” said Nickle. “While it (the diagnosis) wasn’t a loss of a person, it was the loss of a dream and of hope. It was heartbreaking and very heavy.”

Nickle struggles to find words to describe her son’s transformation and how the life-changing liver transplant gave their family a different outlook. Although Wyatt’s health is much improved, the journey is not over. He will continue to be monitored for his cardiac issues caused by the original diagnosis.

“It has been hard at times just to navigate life,” Nickle admitted of the time before the transplant. “Now, we are finding happiness in the simple things, like having his shoes fit, and looking forward to enjoying sweet moments like watching him run the bases.

“This is a new Wyatt, full of giggles and smiles and energy. Our hearts are full.”  hope

*The Nickle family (from left): Evy Grace, 4, Amber, John Louis and Wyatt, 5.*



SUSAN URMY



*The Jimenez family has benefited from the Growing Right Onto Wellness (GROW) program.*

# Growing Healthy Families

*Community collaboration strives for  
generational lifestyle changes*

## W

hile many working moms might be accustomed to receiving afternoon text messages from their children about homework or a planned sleepover, when Gloria Jimenez hears her cell-phone ping, it's more often a reminder from her 10-year-old son, Eduardo, to pick up some avocados or tomatoes at the grocery on her way home.

"My son always checks now to see how much sugar is in something, especially in drinks," Jimenez laughed. "If it's too much, he won't drink it. He'll drink water instead. And he'll tell me, 'Mommy, please don't buy this one. It has a lot of sugar.' For me, that's amazing."

While Eduardo is hypervigilant about the family's diet, his younger sisters, Sophia, 8, and Andrea, 6, are just as likely to pipe up with advice about making smarter food choices.

"My little one, Andrea, remembers even more than her brother," Jimenez said. "She talks about healthy foods a lot, and she keeps me straight. She says, 'Mommy, I like broccoli,' or 'Don't put in too much salt!'"

Jimenez said she and her children have benefited tremendously from programming offered through the Nashville Collaborative, a unique academic-community partnership between Monroe Carell Jr. Children's Hospital at Vanderbilt, the Division of Academic General Pediatrics, and the Nashville Metropolitan Board of Parks and Recreation. The Nashville Collaborative's mission is to develop and test innovative, potentially sustainable, evidence-based, family-centered, community-based programs that measurably improve child and family health, prevent chronic disease and reduce health disparities.

written by Jill Clendening  
photograph by John Russell

Since its launch in 2008, the Nashville Collaborative has conducted landmark research, influenced health policy and offered public programs to encourage lifestyle changes for families, including skills-building classes and after-school programming designed to increase physical activity and improve dietary habits.

There have been more than 40 journal articles based on the Collaborative's work, including in the *Journal of the American Medical Association (JAMA)*, *Pediatrics*, and the *Journal of Obesity*, and team members have presented at international and national meetings, earning awards from the International Child Health Congress and the Tennessee Chapter of the American Academy of Pediatrics.

Jimenez and her children have been participants in the Nashville Collaborative through its largest project to date — GROW (Growing Right Onto Wellness). GROW began as an eight-year trial, which included more than 600 families with preschool-age children and received funding from the National Institutes of Health's National Heart, Blood and Lung Institute and the Eunice Kennedy Shriver National Institute of Child Health and Human Development.

GROW was designed as a "pragmatic randomized controlled trial that tests the efficacy of a family-centered and community-based behavioral intervention to prevent childhood obesity among preschool-age children."

For the participating families, GROW meant building skills to better use local community recreation centers and public libraries, learning about better nutrition and increasing their physical activity, and connecting with other families with young children in their neighborhoods to support behaviors that strengthen family health. The underlying goal was better overall health for both parents and children.

"I'm new in this country — I came here just five years ago from Mexico," Jimenez said. "We didn't know how to use the library, and we didn't know if we could use the community center, so we learned a lot. There are many opportunities through the public library to learn the English language. It's my second language, and I'm trying to speak it fluently. So, this program has helped me, too — not just my children."

By focusing on family-centered projects that actively involve both parents and children, the Nashville Collaborative hopes to encourage different generations to learn from each other and to drive positive change that will have a ripple effect through the family and the community, especially when it comes to fighting obesity and chronic disease. Their family's behavior now at the dinner table is proof that just that type of transformation can happen, Jimenez said.

"Growing up, my mom would tell me, 'You need to eat all your food on your plate,'" she said. "I started doing the same

thing with my children. Now, because of this program, I learned that when they stop eating, it's OK. They're full, and their bodies told them they're full. This is a big change for us."

The results of the GROW study were published in *JAMA* in August 2018. While the three-year intervention improved nutrition behavior (so that intervention families were consuming about 100 calories fewer than the control families and sustaining that improvement over three years) and increased the use of the community recreation center for family physical activity, it did not result in a difference in child body mass index. The Collaborative continues to build programs and projects, drawing from the successes of GROW.

"We gave out 550 new library cards to families that had never had a library card," said Shari Barkin, MD, MSHS, executive director of the Nashville Collaborative, chief of the Division of Academic General Pediatrics at Children's Hospital, William K. Warren Foundation Professor and primary investigator of the GROW trial. "And we built sustained use of existing community resources such as community centers and libraries. That means that both the child and the parent are still accessing those resources. These are now default behaviors that can support both learning and health throughout childhood."

The Nashville Collaborative is Barkin's brainchild. When she was recruited to join Children's Hospital 12 years ago, she planned to replicate a community-based partnership she'd been successful with while a faculty member at Wake Forest University School of Medicine. There, she partnered with the YWCA and secured funding from the Doris Duke Charitable Foundation to support the development of communities centered around family-based recreation and health programs that brought measurable change. Before relocating to Nashville, Barkin witnessed the opening of a new 90,000-square-foot YWCA sports and wellness center in the heart of Winston-Salem, North Carolina, an improvement that was a direct result of that partnership.

While seeking a partner with a similar objective, Barkin heard about then Nashville Mayor Bill Purcell's goal of doubling the number of community centers in the Metro area, with a focus on offering family-based health and recreation programs that were easily accessible to the metropolitan area's growing population.

"It was perfect timing for me," said Barkin. "One of my goals as a primary care provider is to measurably improve the

public's health. I recognized that what we do in the hospital and in the clinic is important, but health typically happens in families and health happens in communities. I met with the Nashville Metropolitan Board of Parks and Recreation, and they told me, 'We don't know how to do this, but we know it's the right thing to do.' That's what partnerships are all about. You're not supposed to know everything; you partner with people because you make each other stronger."

And the Nashville Collaborative was born.

"The core foundation of the Nashville Collaborative is to measurably improve family health in the communities in which we live," Barkin said. "We don't look at this as one child at a time. We look at it as families living in communities. That means we strive for two-generation solutions. We want to improve both the health of the parent and the child. If you do that right, you can amplify health throughout the family.

"We operate on four key principles. We are a learning lab, so we develop and test programs that are measurable. We address sustainability on the front end, and our programs have to be family-based and community-centered."

More than a dozen organizations are now part of the Collaborative's programs, including Nashville Public Library Foundation, the Governor's Foundation for Health and Wellness (Healthier Tennessee) and Second Harvest Food Bank. Organizations represented on the Community Advisory Board include Metro Nashville Public Schools, Head Start, Conexión Américas, YMCA, United Way, the office of Mayor David Briley and the Tennessee Department of Health, among others.

The group's first project was a study named Salud con la Familia, or Health with the Family, that was supported with funding from the State of Tennessee's Project Diabetes and the Vanderbilt Institute for Clinical and Translational Research.

*Children and families learn how to make baked apples during a Teaching Kitchen session, which has since evolved into the Teaching Kitchen Outreach (TKO) project.*



SUBMITTED PHOTO

"We wanted to show that we could develop and test family-based interventions for parent-preschool child pairs," Barkin said. "We focused on Latino families because also at that time, we saw that there were disproportionate poor outcomes in this population. That study, Salud con la Familia, taught us how to be partners. It taught us what we were each good at and what we weren't good at so that we could really understand how to function in effective ways together."

Based at Coleman Community Center on Nolensville Road, the study showed that overweight/obese Latino preschoolers who participated in a 12-week skills-building program were twice as likely to achieve a normal body mass index compared to a control group over a three-month period.

"This is one of the only studies that has demonstrated a reversal of early childhood obesity in preschool children, and because of that, the project was selected for an international award," Barkin said. "We were also given a special achievement award from the Tennessee Chapter of the American Academy of Pediatrics. That was our very first Nashville Collaborative project."

In 2018, the Nashville Collaborative launched its 11th project, Teaching Kitchen Outreach (TKO), an expansion of an educational program piloted in four Metro Parks and Recreation community centers. Centered around 20-minute, hands-on healthy cooking skills building for children participating in after-school programs, TKO will now be offered in more than 20 of Metro Parks' community centers based in urban population centers throughout Davidson County.

During the short cooking lesson, school-aged children are guided by Metro Parks staff through the preparation of a dietitian-tested and approved snack or a meal that can be easily completed in less than 30 minutes, that has less than 10

*Nashville Collaborative team members celebrate the group's 10th anniversary.*



KRISTI IRVING

*“We don’t look at this as one child at a time. We look at it as families living in communities. That means we strive for two-generation solutions. We want to improve both the health of the parent and the child. If you do that right, you can amplify health throughout the family.”*

grams of sugar, more than five grams of fiber per serving and costs between \$1 and \$3 per serving. The staff instruct the students on how to complete every step, from safely chopping up ingredients to properly using a stovetop or oven.

TKO is the direct result of the generosity of an anonymous donor who wanted to support a Children’s Hospital program that had the potential to directly impact childhood obesity, particularly among children in minority populations.

“This is the first philanthropic gift that we’ve received, and it has really jump-started our ability to spread and scale up our programs,” Barkin said. “We are so grateful. My wish list is for sustainable infrastructure funding for the Nashville Collaborative, because when you’re an innovation lab, you need to maintain momentum and have the ability to try new things. You want to be able to connect with new partnerships, build policy and practice and ensure financial sustainability. To date, the way I’ve kept the Nashville Collaborative going is by writing as many grants as I can.”

What keeps those grants flowing and what Barkin hopes will drive further philanthropic support is the long list of evidence-based practice and policy recommendations that have already resulted from the Nashville’s Collaborative’s first decade of work. Among the group’s many findings:

*The Nashville Collaborative is the brainchild of Shari Barkin, MD, MSHS. For her work and contributions to pediatrics, Barkin was named the 2018 Pediatrician of the Year by the Tennessee Chapter of the American Academy of Pediatrics.*



LAUREN HOLLAND

- A 12-week skills-building program aimed at improving both parent and preschool child health reduces short-term pediatric obesity;

- Preschool-age children from low-income families are more likely to be physically active if parents increase activity and reduce their sedentary behavior; and

- Most preschool-age children manage to get enough recommended daily physical activity, but how they move varies with noticeable differences between boys and girls. The Nashville Collaborative has recommended that this should direct practice and policy for preschool-age children.

Recently, Metro Parks employees who lead TKO during the after-school programs met for booster training as the program was being rolled out to all the community centers, and Program Manager Juan Escarfuller, MDiv, MA, one of Barkin’s first hires to implement Nashville Collaborative initiatives, spelled out the need for the program’s expansion.

“Why TKO?” asked Escarfuller. “Tennessee is now the worst — at No. 1 — when it comes to obesity among children. Thirty-eight percent of our children are either overweight or obese. In the Latino community, it is closer to one in every two children is overweight or obese. What’s happening? It’s getting worse, not better. With TKO, we’re trying to make a difference in the family and in the community.”

Jai McCrary, a Metro Parks staff member at the Southeast Regional Community Center in Antioch, Tennessee, started teaching the TKO program to her after-school crowd in April, and the biggest hit has been assembling healthy zucchini pizza boats with marinara sauce.

“We had a lot of children who said they had never had zucchini, but we also had children who said they’d tried zucchini before but never in that way,” she said. “They, of course, love pizza, so to be able to do something similar with healthier ingredients was great.”

Leslie Martinez-Garcia, an employee at Coleman Community Center where the teaching kitchen concept was piloted, said the children in her program are always excited for kitchen time.

“It is so important to introduce healthy food to children early on,” she said. “Even for myself, I’ll admit, I tried eggplant for the first time today. When I’m introducing these foods to them, I always make sure I share important facts about the ingredients and why they’re so healthy. These children are our future, and we want to see them thrive.”

Barkin said she’s thrilled to watch TKO take off in the Metro Parks community centers, but she’s also eager to scale the Nashville Collaborative’s work throughout the state and even throughout the nation so the benefit can reach more families.

“We strive to create programs that can be exportable,” she said. “We are very practical people, and we are about practical science. Since Parks and Recreation is an existing infrastructure, we hope to export tested programs that are poised to scale up across our state and the country to improve the public’s health.” 

*The Jimenez family hikes on a public trail close to their home. From left: Sophia, 8, Eduardo, 10, mom, Gloria, and Andrea, 6.*



# pioneers of hope

*At Monroe Carell Jr. Children's Hospital at Vanderbilt, our work extends beyond patient exam rooms. We are also searching for discoveries to offer better treatments, provide quality care and train the next generation of clinicians. The profiles here represent only a sampling of the tireless work performed daily to make Children's Hospital a place of unwavering hope. In each issue, we also include a profile to highlight our longstanding partnership with our community pediatricians who help ensure all children receive the best care each and every day.*

Few things have given **John Pietsch, MD**, greater satisfaction than watching the critically ill infants and children he has treated grow up to lead happy, healthy and productive lives.

Pietsch has contributed to hundreds of these success stories since 1989, when he established the extracorporeal membrane oxygenation (ECMO) program at then Vanderbilt Children's Hospital, now known as Monroe Carell Jr. Children's Hospital at Vanderbilt.

His first ECMO patient at Vanderbilt, Chelsea Brown, graduated from Northeastern University in Boston in 2013 with a degree in architecture. Currently, she is a project manager for a Boston-based architectural firm.

Brown's mother, Norma Dam, of Hendersonville, remembers receiving a Polaroid photo of her baby daughter on the ECMO machine and being told she was Vanderbilt's first ECMO patient. "I asked, 'First this month?'"

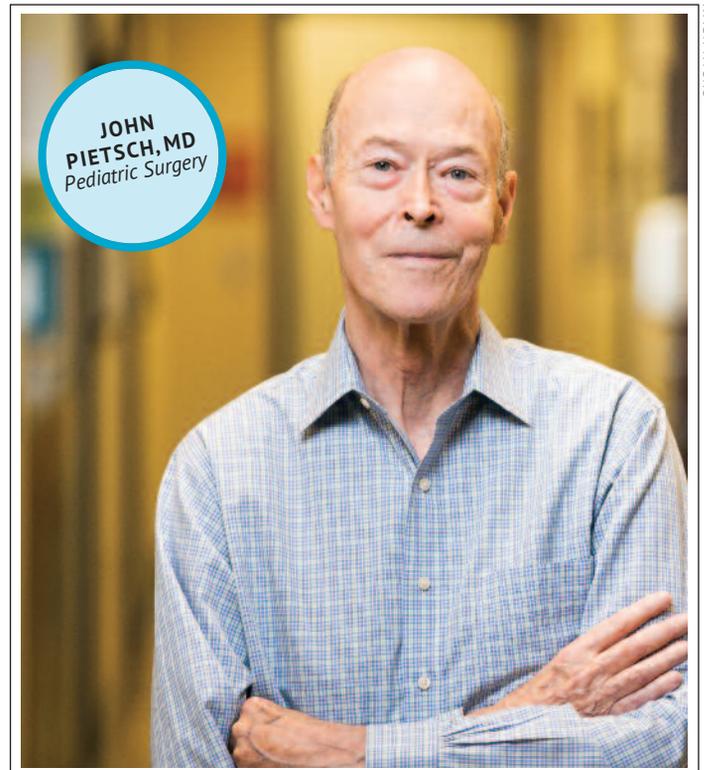
"'No,' they said, 'First ever.' I was nervous," Dam said, "but the procedure worked, and I was able to take my baby home a month later."

ECMO delivers oxygen and removes carbon dioxide from the blood as it passes through a machine outside the body. This allows the lungs and hearts of critically ill patients the time to rest and heal. First shown to be effective in newborn babies, ECMO is now used in older children and adults.

Pietsch joined the Vanderbilt faculty in 1986. Three years later, he brought the ECMO program from the University of Louisville in Kentucky to Vanderbilt.

Since then, more than 1,100 ECMO procedures have been performed at Children's Hospital, and now there is a separate program for adults at Vanderbilt University Adult Hospital. As one of the nation's top ECMO centers, the program at Vanderbilt has received the Extracorporeal Life Support Organization's Award for Excellence in Life Support.

Pietsch was able to reconnect with Brown in October when she attended an ECMO reunion for patients and families. "When these patients go home, they're still recovering and not fully



back to normal," he said. "It is nice to see them living their lives after ECMO."

On July 1, 2018, after 29 years, Pietsch stepped down from his role as director of the ECMO program at Children's Hospital. But that doesn't mean the 72-year-old professor of Pediatric Surgery and Pediatrics is retiring — far from it.

The move gives him more time to devote to the Junior League Center for Advanced Maternal Fetal Care, which he co-directs, as well as teaching and research.

A fellow of the American Academy of Pediatrics, the American College of Surgeons and the Royal College of Surgeons of

Canada, Pietsch grew up in Michigan and attended medical school at the University of Michigan.

During his junior year, he thought that he might want to become a pediatric surgeon. After spending a month with the group at Boston Children's Hospital, he was convinced. He trained in general surgery and pediatric surgery at McGill University in Montreal, Canada.

He began his pediatric surgery career at Louisiana State University in Shreveport, and then at the University of Louisville before joining the faculty at Vanderbilt. Thirty-two years later, he's still excited to come to work. One of his research interests is finding ways to prevent malnutrition in pregnant women.

Lack of adequate nutrition during pregnancy can increase the risk of premature delivery, gestational diabetes and preeclampsia, high blood pressure during pregnancy that can lead to serious complications for both mother and baby.

At the Fetal Center, Pietsch and his colleagues are treating lung problems in the fetus before birth, and improving the treatment of diaphragmatic hernia, an opening in the diaphragm that allows the stomach and other abdominal organs to squeeze the developing heart and lungs.

In addition to his professional pursuits, Pietsch said he's looking forward to spending more time with his family, including five grandchildren.

— by Bill Snyder



**Candy Stefansic, RN, MSN, CPON**, a former Neonatal Intensive Care Unit (NICU) nurse at Monroe Carell Jr. Children's Hospital at Vanderbilt, had just given birth to her triplets — Thomas, Althea and Eva — and found herself needing help from the place she'd worked for years.

Two of her babies were admitted to the NICU for feeding issues. They spent 13 days there and received amazing care.

"My NICU training assisted when the triplets were babies," said Stefansic, now a nurse manager for the Pediatric Hematology/Oncology Clinic and Infusion at Children's Hospital. "I had lots of friends to help, many of whom I used to work with in the NICU. They all helped me learn how to put my life together with triplets."

Wonderful co-workers is one of the reasons Stefansic has been devoted to her health care career at Children's Hospital for 23 years.

"This is my extended family," she said about her co-workers. "I've been here long enough that I have friends who are a big part of my life. It's a special place to work. I've learned so much from all the nurses, doctors and patients I've taken care of. I think it's made me the person I am today."

Stefansic began her journey at Vanderbilt University Medical Center (VUMC) the day she was born in its labor and delivery ward.

Medicine had always been a part of her life. Her mother, Carolyn Fruin, was a nurse at Vanderbilt, and her father, Alan Fruin, MD, now a retired neurosurgeon, was doing his residency at Vanderbilt when she was born. Following his residency, her father moved the family to Nebraska, where Stefansic was raised.

She completed her undergraduate degree at Peabody College of Education and Human Development at Vanderbilt University, and then went through the Bridge Program to earn her Master of Science in Nursing with a concentration in pediatrics.

"From what I can remember, I always knew I wanted to be a nurse. I was always good at working with children. I babysat for everyone in the neighborhood through college. It was a natural fit to work with children," Stefansic said. "Here at Children's Hospital, I love the patients we serve. I truly love the people I work with. I've created a lot of great relationships with my co-workers, and that's the reason you come to work. You know they stand by your side, put the patients first and do what we are here to do, and that's to take care of children."

She began working at VUMC in 1995, and over the years, she held many roles in the hospital, including a NICU staff nurse, charge nurse, transport nurse and night shift assignment manager. In 2002, she transferred to the Pediatric Oncology unit as a staff and charge nurse and later served as a neuro-oncology case manager and manager for Pediatric Hematology/Oncology.



SUSAN URMY

Helping children who have cancer has been life changing for her.

“Children are so resilient; they want to play at the end of the day. Even when they are the sickest of the sick, they still want to have fun,” she said. “I think all my experiences here have helped me put my life into perspective. You see so many things that are tragic and sad. It’s hard to go home at the end of the day and think that things are bad. You pray that you don’t ever have to be in these situations, but at the same time, I know I can come here and get great care for my children.”

Stefansic has been married for 17 years to her husband, Jim, a biomedical engineer. They have four children: Clara, 10, and the triplets, now 8. When she’s not spending time with her family, she enjoys early morning exercise.

– by Tavia Smith



When expectant parents interview **Deepak Mehrotra, MD**, as a potential pediatrician for their unborn child, they often ask questions about how long he has been practicing and how long he plans to stay in his current position.

“They seem to be reassured that I’ve been practicing at the same clinic for 20 years, and that I don’t plan to leave,” Mehrotra says.

Mehrotra joined Children’s Clinic East in 1998 after completing his residency in Pediatrics and serving for an additional

year as chief resident at the University of Mississippi. At that time, Children’s Clinic East, which was founded in 1951, had one location in Hermitage, Tennessee. Mehrotra was the fifth physician in the practice. The clinic has since expanded to include two more Tennessee locations in Mt. Juliet and Lebanon and now has 15 pediatricians and two pediatric nurse practitioners.

“I found my niche, and I’m very happy that I did that with my first attempt,” Mehrotra says. “I’ve been fortunate to work with a wonderful team of physicians, nurses and clinic staff.”

Mehrotra values the long-term relationships he has been able to build with patients and their families.

“I really enjoy the fact that a good number of my patients are now bringing their own young children to see me,” he says. “It has been so rewarding and such a pleasure to play a small part in the lives of my patients ... to watch them grow into young adults and then parents themselves.”

Mehrotra grew up in Jackson, Mississippi, the son of two college professors. Having “inherited a love of teaching” from his parents, he volunteered to mentor Vanderbilt University School of Medicine students and residents as soon as he started practicing at Children’s Clinic East. Trainees rotate through the clinic to gain experience in a community pediatric practice.

Mehrotra is also the current president of the Cumberland Pediatric Foundation (CPF) board. CPF is a nonprofit company that promotes the health care and wellness of children and their pediatricians by providing primary care physicians — members of CPF — with education, research and networking resources. CPF is affiliated with Monroe Carell Jr. Children’s Hospital at Vanderbilt and offers opportunities for community physicians and their patients to participate in clinical research.

Mehrotra has been a member of the CPF board since 2014.

“I enjoy helping guide the organization and its mission of providing education and research connections between the Department of Pediatrics at Vanderbilt and community physicians,” he says.

In his free time, Mehrotra enjoys hiking, biking, playing tennis and spending time with his family. He and his wife, Seema, are proud parents of two young adults — a daughter who is a second-year graduate student and a son who is a junior in college.

Mehrotra calls himself an “ardent fan” of the NHL Nashville Predators and says his family has enjoyed the lively atmosphere and fast pace of hockey games. The team’s first season was in 1998, the same year the Mehrotra family arrived in the Nashville area.

“It was inevitable for us to be Predators fans,” Mehrotra says with a chuckle.

– by Leigh MacMillan



**Kris Rehm, MD**, loves running for the same reason she is passionate about pediatric medicine — even when something seems too difficult to overcome, you must at least try. That same mantra also helped her through a battle with breast cancer in 2013.

“What I love about running, and that I think is most applicable to medicine, is that you learn with hard work, dedication and persistence that you can continue to improve,” said Rehm, vice chair of Outreach Medicine and medical director of Hospital Operations for Monroe Carell Jr. Children’s Hospital at Vanderbilt. She has run 12 marathons and is training to run her third Boston Marathon.

Running, after all, is what led her on a path toward medicine.

Growing up in the small, rural community of Macomb, Illinois — where most worked in either farming or education — Rehm fell in love with athletics, participating in basketball, softball, track and field as well as cross country running. She knew she wanted to be a collegiate athlete and decided to focus on running, believing that was her best shot.

Recruited on athletic and academic scholarships, she chose to attend Ohio University in Athens, Ohio. She intended to pursue physical therapy with a focus in musculoskeletal rehab but switched her trajectory toward medicine the summer before her junior year. After graduation, she attended Northwestern University Feinberg School of Medicine, in Evanston, Illinois.

As a medical student at Northwestern, she participated in the Cabrini Green Youth Program in Chicago, working through Children’s Memorial Hospital in a health care clinic to address the needs of socioeconomically disadvantaged children. She also started a running club for middle school-age girls and participated in reading, tutoring and mentoring programs.

“I loved Children’s Memorial Hospital, loved working with children and working with children from urban and underserved backgrounds. The experience completely sealed the deal for me to do pediatrics,” Rehm said.

While in medical school, Rehm met her husband, Christopher, whose focus is in physical and medical rehabilitation. They matched as a couple for residency in Boston, Massachusetts, where Rehm went through Boston Children’s Hospital’s Combined Residency Program and also served as chief resident.

In 2002, they decided to move to Nashville, where Christopher had attended Vanderbilt University for his undergraduate education. Rehm joined Old Harding Pediatrics and its teaching team that worked with students at Vanderbilt University’s School of Medicine.

Shortly after her first set of twin sons, Jackson and Lucas, were born in 2004, she decided to change tracks and joined Children’s Hospital, signing on to help launch the first hospital medicine program. Three years later, in 2007, Rehm gave birth to another set of twin boys, Grant and Logan.

“I love the academic environment. I love teaching. I love

JOHN RUSSELL



collaborating with subspecialty colleagues and the diversity of the patient demographics,” she said.

Children’s Hospital had three hospitalists when she began. In 2009, the hospital formed the Division of Hospital Medicine, with Rehm serving as the inaugural director. Currently, there are 22 hospitalists. Hospitalist medicine provides general clinical pediatric care to hospitalized patients. The concept arose in the mid-1990s, when across the nation, busy private practices, combined with increased traffic congestion and higher patient acuity made it difficult for community pediatricians to always round on their patients who had been hospitalized.

In January 2018, Rehm took on the role of vice chair of Outreach for the Vanderbilt Department of Pediatrics. She is currently working toward her Master of Management in Health Care at Vanderbilt University.

When she’s not at work, Rehm loves to travel with her family, which has included a trip to Abu Dhabi and Dubai in the United Arab Emirates. While there, she was able to share the latest trends in U.S.-based hospital medicine with the Cleveland Clinic, Abu Dhabi. Her four sons, now 11 and 14, keep her busy with their many athletics — soccer, lacrosse, baseball, cross country and tennis.

She’ll always find time for running. “I feel a million times better if I can be outside, be with friends and be on the move,” Rehm said.

— by Christina Echegaray



STEVE GREEN

In 2017-18, Dance Marathon students from six schools raised more than \$340,000 for Monroe Carell Jr. Children's Hospital at Vanderbilt, a Children's Miracle Network Hospital®.

## Giving Back Starts Early

Students in the community are taking part in activities to support Monroe Carell Jr. Children's Hospital at Vanderbilt. With programs for all school sizes, elementary through college-age students are organizing toy drives for the Red Wagon Project, organizing fundraising events, taking part in Extra Life gaming marathons and more. Student leaders also host schoolwide Miracle Network Dance Marathon events each year to raise money for Children's Hospital. This year's list of participating schools is growing to include Ensworth

School, Franklin Road Academy, Kenwood High School, Ravenwood High School, Webb School, Vanderbilt University, Middle Tennessee State University, Tennessee Technical University, Lipscomb University and Sewanee: The University of the South. As more schools join the nationwide, student-driven movement, these students give back while gaining leadership skills through service learning and peer-to-peer mentoring. For more information, contact Casey Stein at [casey.stein@vumc.org](mailto:casey.stein@vumc.org) or 615-322-0226.



JOHN RUSSELL

(From left): Krystal Clark, the Junior League of Nashville's past president, and Jennifer Osland Hillen, current president, received thank-you cards from patient ambassadors on their tour of the construction at Children's Hospital.

## Nearing a Century of Support

The Junior League of Nashville and Monroe Carell Jr. Children's Hospital at Vanderbilt have partnered for nearly a century to advance care for children in our community. Since 1970, the Junior League of Nashville has provided more than \$17 million to support Children's Hospital. The League most recently committed \$1.5 million, with \$500,000 for the Growing to New Heights Campaign that supports the hospital's current four-floor expansion. The remaining \$1 million was committed to continued support for the Child Life Program, which promotes a positive medical experience for patients and their families. The group also volunteers and hosts special events for patients and their families. On May 30, 2018, Junior League members were given a construction update as the growth continues at Children's Hospital.

## Celebrating Children's Smallest Patients in a Big Way

Nationally broadcast to millions of viewers, the Nashville Christmas Parade takes over Broadway each year with stars and singers performing and floats filling the streets with giant balloons towering above. The 2018 parade, held Dec. 1, once again benefited Monroe Carell Jr. Children's Hospital at Vanderbilt. The Give to the Next Breath initiative, a philanthropic marketing effort to support the hospital's Neonatal Intensive Care Unit, debuted during the parade's live broadcast. As a pioneer and worldwide leader in newborn intensive care, Children's Hospital has been a place of hope for families with premature babies or high-risk pregnancies for decades. Learn more at [GiveToTheNextBreath.org](https://GiveToTheNextBreath.org).



The Nashville Christmas Parade brings national awareness to Children's Hospital and was nominated for two Midsouth Regional Emmy® Awards for the 2017 production.

## Community Partner Twice Daily Chips In

Tri Star Energy LLC was the first corporate partner of the Growing to New Heights Campaign with a \$1 million commitment to support the expansion of Monroe Carell Jr. Children's Hospital at Vanderbilt. To help fulfill this commitment, the parent company's local store brand Twice Daily hosts an in-store campaign each April and May. In addition, Twice Daily has had a golf tournament each year since 2002 to benefit Children's Hospital. Over the years, Tri Star Energy and Twice Daily have raised more than \$3 million to support care for patients and families in the community.



Twice Daily employees volunteer at their annual golf tournament benefiting Children's Hospital.

### Study finds sharp rise in suicide risk for children

The number of school-aged children and adolescents hospitalized for suicidal thoughts or attempts has more than doubled since 2008, according to a Vanderbilt-led study published in *Pediatrics*.

The study, "Hospitalization for Suicide Ideation or Attempt," looked at trends in emergency room and inpatient encounters for suicide ideation and attempts in children ages 5-17 years at U.S. children's hospitals from 2008 to 2015. The study was led by Greg Plemmons, MD, associate professor of Clinical Pediatrics at Monroe Carell Jr. Children's Hospital at Vanderbilt.



Greg Plemmons, MD

During the study period, researchers identified 115,856 encounters for suicide ideation and attempts in emergency departments at 31 children's hospitals. Nearly two-thirds of those encounters were girls. While increases were seen across all age groups, they were highest among teens ages 15-17, followed by ages 12-14.

Just over half of the encounters were children ages 15-17; another 37 percent were children ages 12-14; and 12.8 percent were children ages 5-11. Seasonal variation was also seen consistently across the period, with October accounting for nearly twice as many encounters as reported in July. Suicide is the third leading cause of death among adolescents in the United States, surpassed only by accidents and homicides, according to the U.S. Centers for Disease Control and Prevention.

Other researchers involved in the study were: Matthew Hall, PhD; Stephanie Doupnik, MD; James Gay, MD; Charlotte Brown, MD; Whitney Browning, MD; Katherine Freundlich, MD; David Johnson, MD; Carrie Lind, MD; Kris Rehm, MD; Susan Thomas, MD; and Derek Williams, MD, MPH.

— by Christina Echegaray

### Children's Hospital joins Food Allergy Research and Education Clinical Network

Monroe Carell Jr. Children's Hospital at Vanderbilt's new pediatric food allergy clinic has been named a Center of Excellence by Food Allergy Research and Education (FARE).

Children's Hospital also joined the FARE Clinical Network — a food allergy research collaborative comprised of 31 leading research and clinical care facilities across the country, and will participate in cutting-edge research and clinical trials for patients in Tennessee and surrounding states.

Led by Jonathan Hemler, MD, assistant professor of Pediatrics within the Division of Pediatric Allergy, Immunology and Pulmonology, the clinic is a collaboration between Hemler,

dietitian Nancy Cranford, MS, RD, LDN, and a research nurse, who will handle patient recruitment for basic science research projects and work on clinical trials.

An estimated 1 in 13 children is affected by food allergies — about two children in every classroom. A food allergy is a medical condition in which exposure to certain foods triggers a harmful immune response, which can range from mild (itchiness, hives) to severe or life-threatening (difficulty breathing, throat tightening).

The FARE Clinical Network seeks to accelerate the development of effective approaches to food allergy treatment while improving the quality of patient care for this potentially life-threatening disease that affects 15 million Americans.

While more than 170 foods are known to cause allergic reactions, the most common are known as the Top 8 — milk, eggs, peanuts, tree nuts, shellfish, fish, soy and wheat. The number of children with peanut and tree nut allergies tripled between 1997 and 2008.

— by Christina Echegaray

### Vanderbilt physician helps CDC craft new mild TBI guidelines

The Centers for Disease Control and Prevention (CDC) released new clinical recommendations for health care providers treating children with mild traumatic brain injury (mTBI), often referred to as concussion. The CDC Guideline on the Diagnosis and Management of Pediatric Mild Traumatic Brain Injury, published in *JAMA Pediatrics*, is based on the most comprehensive review of the science on pediatric mTBI to date — covering 25 years of research.

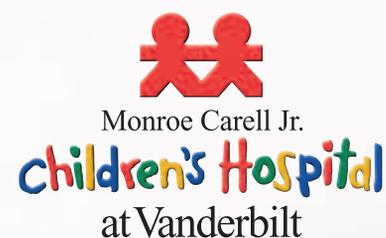
Andrew Gregory, MD, with the Vanderbilt Sports Concussion Center, was one of the authors of the guideline.

The guideline also has a summary page for busy clinicians who need quick reference points. All materials and tools are available at [www.cdc.gov/HEADSUP](http://www.cdc.gov/HEADSUP).

Offering 19 sets of clinical recommendations that cover diagnosis, prognosis, and management and treatment, the CDC Pediatric mTBI Guideline is applicable to health care providers in all practice settings.

— by Tom Wilemon





## Soaring Higher, Dreaming Bigger

A Campaign Against Childhood Cancer

### Small but Mighty

Days after his third birthday, John Martin was diagnosed with leukemia. A year later as he continues treatment, the now 4-year-old superhero fan is ready to take on adventures with his family and school with his friends. Help us care for more children with cancer by supporting Monroe Carell Jr. Children's Hospital at Vanderbilt.

Help now: [ChildrensHospitalVanderbilt.org/soaringhigher](https://ChildrensHospitalVanderbilt.org/soaringhigher)

# hope

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## U.S. News ranks Children's Hospital among the nation's best

Monroe Carell Jr. Children's Hospital at Vanderbilt is once again named among the nation's Best Children's Hospitals in *U.S. News & World Report's* annual rankings. Children's Hospital, a regional comprehensive pediatric care center providing an array of specialty and subspecialty services, achieved national rankings for 10 out of 10 pediatric specialty programs.