

hope

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SUMMER 2018



Survive and Thrive

Advances in childhood cancer
treatment give children a
chance to grow up



cover story

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MOVING INTO SUMMER MONTHS TYPICALLY BRINGS anticipation of slowing down and relaxing. However, we find our summer routine more like that of the children we serve — constant activity from sunup to sundown. Our expansion floors in the hospital look a little different every day — also like children who grow quickly. Even as we witness daily structural change, we are busy planning and preparing for the internal program transitions that will occur as we open our new floors beginning summer 2019. We are excited about the opportunity the new space affords to co-locate existing services as well as introduce new programs that meet the needs of our patients and families. Yet, we realize daily that Monroe Carell Jr. Children's Hospital at Vanderbilt is more than our bricks and beds — it is our culture of people committed to providing healing and hope.

The foundation of our daily work is built upon excellence in clinical care, discovery, innovation and education, all of which are integrated to deliver specialized and personalized care plans for patients and families. Nearly 50 years ago, three of our early pioneers in subspecialty pediatrics launched their work and our subsequent services by bringing research to the bedside: John Lukens, MD, in cancer, Thomas Graham, MD, in cardiology, and Mildred Stahlman, MD, in neonatology. Today, through our stories, we are pleased to share the legacy of these pioneers and more. We highlight our pediatric cancer program and some of the unique treatments and services we offer that set us apart as the region's leading center for children and adolescents with cancer. Through the eyes of three boys who became friends while awaiting new hearts, we share the story of what it is like to be a patient in our hospital supported by the many services that truly make it a place of healing. We also introduce two new innovative lung programs that illustrate the longstanding tradition of integrating patient care with clinical research. And finally, we celebrate the careers of some of our faculty members — the people who deliver the care, mentor the next generation, lead programs and make discoveries.

The core of our mission and daily work is to serve all children, and their families, through the delivery of specialized medical and surgical programs. Our early pioneers set this vision many decades ago. It is a true privilege to participate in improving the health and well-being of children and adolescents. We are grateful to our partners in the community who make it possible for us to continue to build a place, create the programs and recruit the people to deliver healing and hope for decades to come.

Sincerely,

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Chief of Staff and Executive Medical Director

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Senior Vice President of Pediatric Surgical Services, Monroe Carell Jr. Professor and Surgeon-in-Chief

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SURVIVE AND THRIVE

*Advances in childhood cancer treatment
give children a chance to grow up*

Jurnee Scantling cartwheels across her living room floor, arches into a backbend and then drops into the splits. Her lavender shirt says “Love to Smile” in colorful letters, and she sports a broad grin that affirms the statement.

As soon as she could walk, Jurnee, now 5 years old, loved to “jump and flip and spin around,” remembers her mother, Erika Scivally. When Jurnee had what seemed like a few too many bruises on her legs, her mother attributed them to her exuberant activity.

She also had the occasional high fever, without any other symptoms, her mother says.

Scivally, who was a care partner for children with cancer at Monroe Carell Jr. Children’s Hospital at Vanderbilt for several years, had some nagging concerns.

written by Leigh MacMillan
photograph by John Russell





remember telling the pediatrician, her dad and my mom that something's not right, because she has these bruises and keeps getting these fevers," Scivally said. Jurnee's blood work was normal though, and the fevers always went away.

Until one didn't.

On Father's Day in 2015, when she was two-and-a-half, Jurnee was diagnosed with acute lymphoblastic leukemia (ALL), the most common childhood cancer.

"Of course I screamed and I cried," Scivally said. "Even though I saw the signs and had a feeling something was wrong, hearing that diagnosis and getting moved to the cancer floor in the hospital and seeing all the nurses I used to work with...it was horrible."

Jurnee's treatment started the next day.

Clinical trials increase survival

Leukemias are cancers of blood-forming cells. They begin in the bone marrow and result in high numbers of abnormal white blood cells, called blasts. Multiple types of leukemia affect both children and adults, and they may be acute or chronic. Acute leukemias progress quickly, and without treatment, can be fatal in months.

Progress in treating childhood ALL is "one of the most incredible stories in all of oncology," says John Greer, MD, professor of Medicine and Pediatrics.

A Place for Survivors

The end of cancer treatment is reason to celebrate and a relief for patients and their families, but it can also be a time of new concerns.

Vanderbilt-Ingram Cancer Center offers the REACH for Survivorship Program, a comprehensive clinic for survivors of all ages who have faced any type of cancer and who have received cancer treatment from any health care provider.

It doesn't matter if the treatment was recent or received long ago — the program can help those who have concerns about physical, emotional or practical issues related to their cancer and its treatment. The clinic is not restricted to those who have issues that need resolving. Even for those doing well who simply want to remain healthy, the clinic has services that can help achieve that goal.

Those seen in the clinic complete a comprehensive health history and receive a personalized Cancer Survivorship Care Plan that will serve as a roadmap for their future health and well-being. Patients are often referred by their oncologists, but may initiate the visit on their own.

Learn more by calling (615) 343-7400 or visit VanderbiltHealth.org/cancersurvivor.

Greer completed a fellowship in hematology/oncology at Vanderbilt in 1984, and then he joined the faculty and worked closely with John Lukens, MD, the founding director of the Vanderbilt Division of Pediatric Hematology/Oncology.

"John Lukens was a phenomenal person," Greer says. "He was kind and smart, and he had the foresight to get involved early in testing new treatments for childhood cancer."

When Lukens started Vanderbilt's childhood cancer program in 1975, the survival rate for ALL was less than 30 percent, Greer says. Today, it's close to 90 percent, "because of well-designed clinical trials."

Advances in therapy, made possible by large clinical trials, have improved survival "exponentially over the years" in all childhood cancers, says Debra Friedman, MD, E. Bronson Ingram Professor of Pediatric Oncology and director of the Division of Pediatric Hematology/Oncology.

About 16,000 children are diagnosed with cancer each year in the United States. Most of these children are cared for at academic medical centers like Vanderbilt, which work together to develop improved therapies.

"Nationally, we've conducted clinical trials in childhood cancer since the mid-1970s, and when a trial is available, about 70 percent of eligible children enroll," Friedman says.

"Because we can treat children in a uniform way and test new therapies on larger numbers of children, we are able to learn quickly and improve outcomes," Friedman says.

Vanderbilt is an active member of the Children's Oncology Group (COG), a National Cancer Institute-supported cooperative group that oversees clinical trials. Lukens was a founding member of the Children's Cancer Study Group, which merged with another oncology group to become the COG.

"John Lukens had the vision to say we can cure children with cancer," Friedman says. "He was truly one of the pioneers of pediatric oncology."

Today, the COG unites more than 9,000 experts in childhood cancer at more than 200 leading children's hospitals, universities and cancer centers.

Vanderbilt's program enrolls more patients in clinical trials than 90 percent of the COG programs, Friedman notes.

"Our physicians are national leaders who are actively involved in the design and execution of clinical trials being conducted by the COG as well as by the pharmaceutical industry," she says. "We have more trials open, and we enroll more patients on trials than most other centers our size. We have a commitment to offer our patients the very best therapies."

Expertise under one roof

Jurnee, who is Friedman's patient, was eligible for a trial testing a new therapy for ALL. Scivally didn't hesitate to enroll her.

Desmond Scantling, Jurnee's father, "was a little concerned about it," Scivally says, "but I told him to think about

the things we take for the little illnesses we have...they had to try it on somebody. People have to be willing to say OK, and if it works for Jurnee, then maybe it will help other kids too."

The trial, like many others offered by Vanderbilt's childhood cancer program, compared a new treatment to the standard of care.

"We're asking if we can improve the survival rate," Friedman says. "Every trial we've conducted has given us valuable information."

Jurnee's treatment started with "induction" chemotherapy, a high-dose treatment administered in the hospital and aimed at putting the disease into remission. After 37 days in the hospital, Jurnee went home in remission. For the next two-plus years, she and her family followed the schedule of visits to the clinic, outpatient and inpatient chemotherapy infusions, intrathecal (spinal cord) treatments and oral chemotherapy. She completed treatment in September 2017.

"It was exhausting, but we got into the routine and just did it," Scivally says.

Jurnee tolerated the treatment well. She experienced a serious side effect just once, requiring a two-week hospitalization for neutropenia — an abnormally low number of neutrophils, white blood cells that act as "first responders" to fight infections.

"I knew from my experience working on the floor that some patients with neutropenia don't do well, so that was scary," Scivally says.

"Cancer therapy is not kind and gentle, and we can cause damage to virtually any organ in the body," Friedman says. Pediatric oncologists "need to have subspecialists — for example, cardiologists, pulmonologists, infectious disease doctors — by our side to make a coordinated plan for care. That makes a huge difference in survival."

Vanderbilt's program is the only childhood cancer program in the state "that has all the subspecialties needed to support children who are receiving cancer therapy under one roof," Friedman says.

Active collaboration with the Vanderbilt-Ingram Cancer Center also brings special expertise to the care of children with cancer, Friedman says, noting that the pediatric oncology program is also the only program in the state that is part of a National Cancer Institute-designated Comprehensive Cancer Center that treats children and adults.

"We have all the pieces in place that we know are responsible for increased survival," Friedman says. "We're doing everything we can to provide state-of-the-art care and the best clinical options for our patients."

A sense of family

When Katharine Wiggins and her family walked into the pediatric hematology/oncology clinic for the first time with their 14-month-old son Jonathan, the space was new to them, but the experience wasn't.

Expanding childhood cancer care

In the last decade, the number of children with cancer treated at Monroe Carell Jr. Children's Hospital at Vanderbilt has more than doubled, with families from Tennessee and throughout the region coming here for expert specialty cancer care.

This growing number of clinic visits and increased need for chemotherapy infusion treatments places heavy demands on spaces that were designed for an earlier era in treatment. The addition of floors to Children's Hospital, made possible through community partners and friends who donated to the Growing to New Heights Campaign, is making room for an expanded childhood cancer center, says Debra Friedman, MD, E. Bronson Ingram Professor of Pediatric Oncology and director of the Division of Pediatric Hematology/Oncology.

The expansion will help create more space for childhood cancer patients, including children receiving inpatient cancer therapy — an average daily need of 26 rooms — who also require oncology nurses with specialized training.

"The drugs we give these children are serious, and oncology nurses have the training and experience to know what to look for when a child isn't doing well," says Kelly Newman, RN, who works in the outpatient infusion clinic.

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

"It's a crowded space," says Katharine Wiggins, a parent of two children who have been treated in the clinic. "And it's difficult when a child has a reaction to treatment. Infusion rooms with privacy would be a great improvement."

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

"We're excited about the future of our childhood cancer program and the improvements in care it will bring to our patients," Friedman says.

— by Leigh MacMillan

The family's oldest child, Hogan, had been treated in the same division 10 years earlier for a different disease, and the nurse who came out to greet them happened to be the nurse who had cared for Hogan.

Kelly Newman, RN, BSN, clinic infusion nurse, says it was "a punch in the gut to see them come in for another child."

"It was rather shocking and very emotional, but at the same time so comforting," Wiggins says. "Without Kelly, I don't think I could have survived; she's amazing, and there's truly a sense of family in that clinic."



Kelly Newman, RN, BSN, clinic infusion nurse, cared for brothers Jonathan, 7, (left) and Hogan Wiggins, 17, for different diseases 10 years apart.

Hogan and Jonathan Wiggins have rare, unrelated disorders, one with no known cause and the other usually resulting from a random genetic mutation.

Jonathan, 7, was diagnosed with Beckwith-Wiedemann syndrome in utero. The syndrome is marked by overgrowth of organs and an increased risk for childhood kidney and liver cancer.

"At birth, he was healthy and just a really big baby, about 12 pounds even though he was two weeks early," Katharine Wiggins says. When he was a toddler, routine X-rays and ultrasounds revealed a cancerous tumor on his left kidney, which required surgical removal followed by eight months of chemotherapy.

Jonathan, who plays sports of all kinds, including soccer, golf and baseball, will be followed twice a year until he is 12 years old, when there is no longer a known risk of cancer from the syndrome.

Hogan, 17, was treated with chemotherapy for two years for Kasabach-Merritt syndrome, which caused a vascular tumor on his face when he was just 3 months old.

Today, only the scars from the port-a-caths placed under

their skin to draw blood and give treatments hint at what the brothers went through as babies.

"We called the port-a-caths their 'special spots,' and they have a little bit of a special bond because of those scars and that shared experience," Katharine Wiggins says.

Caring for children like Hogan and Jonathan over time, and building relationships with them and their families, is what Newman enjoys most about her work. Newman has treated children with cancer for 30 years and has been part of the Vanderbilt program for 27 years. She has worked in the clinic, mostly in the infusion room, for 22 years.

"When I first started this work in 1988, there weren't any survivorship clinics and we didn't monitor for late-term effects," Newman says. "Now, we have children with very good prognoses who survive, and we continue to monitor them into adulthood. That has been really rewarding, that there is a need for that now."

Vanderbilt offers the only survivorship program in the country that sees patients regardless of where they've been treated, how they've been treated or their age at treatment, says Friedman, who established and leads the survivorship program.

Program growth and innovative treatments

With strong leadership since its founding in 1975, the Division of Pediatric Hematology/Oncology has seen steady growth and rising national prominence.

"John Lukens really set the foundation by making sure the program had wonderful nurses and support staff, and a sense of mission that you were doing something that's unique and vital," Greer says. "It's been remarkable to witness it and be a part of it."

Lukens led the division until 1998. The second director, James Whitlock, MD, was a trainee of Lukens.

"Jim Whitlock continued to build the division and to bring an increased number of clinical trials to Vanderbilt," Friedman says. "He's an internationally recognized leader in leukemia and a rare disease called Langerhans cell histiocytosis, and a leader in the Children's Oncology Group."

Whitlock now directs the Division of Hematology/Oncology at The Hospital for Sick Children in Toronto, Canada.

Friedman has directed the division since 2010. During her tenure, the program has more than doubled the number of new patients it treats each year.

"When I came to Vanderbilt in 2008, we had 94 new oncology patients, and last year we had 248 new patients," she says.

The growth can't be explained by a spike in the incidence of childhood cancer. Rather, more families are choosing to come to Vanderbilt "because we can offer so much in terms of specialized therapies, clinical trials and access to subspecialists," Friedman says.


Novel and innovative treatments offered at Vanderbilt include:

- CAR T-cell therapy: Only program in the state approved to provide personalized medicine immunotherapy for ALL that doesn't respond to, or recurs after treatment
- Targeted cancer therapies: Tumor genes are analyzed to determine signaling pathways that drive tumor growth and to provide targeted therapies that block those signaling pathways
- Pharmacogenetics: Patient's genes that are involved in chemotherapy metabolism are evaluated to tailor chemotherapy dosage
- Intra-arterial therapy for retinoblastoma: Only program in the state providing all treatment options for eye tumors in young children
- Specialized radiation therapy for neuroblastoma and other childhood cancers

Friedman also notes the expertise of a variety of general and specialized surgeons who work closely with medical oncologists

Vanderbilt's program is the only childhood cancer program in the state "that has all the subspecialties needed to support children who are receiving cancer therapy under one roof."

in the division to provide the best options to patients. In addition, two psychologists in the division provide a behavioral oncology program.

"We are taking care of the whole patient and their family," Friedman says. "Our team has the expertise to look at the big picture and design the very best treatment plans for our patients."  hope

Cancer immunotherapy gets personal

A novel immunotherapy that uses a patient's own cells to fight cancer is now available at only a select group of health care institutions. Monroe Carell Jr. Children's Hospital at Vanderbilt is the only center in Tennessee approved to provide the new treatment, a CAR T-cell therapy called Kymriah.

Kymriah was approved by the FDA to treat a subset of acute lymphoblastic leukemia (ALL) — pre-B cell ALL that was unresponsive to treatment (refractory) or that has come back after treatment (relapsed).

ALL, which develops from blood-forming cells in the bone marrow, is the most common childhood cancer. Typically, 90 percent of patients with ALL achieve remission with intensive chemotherapy treatment. The remaining 10 percent

don't respond to chemotherapy or relapse and have a poor prognosis.

"We are thrilled to be able to offer this cutting-edge therapy to our patients, particularly when these families may be starting to feel like they have run out of treatment options for ALL," says Carrie Kitko, MD, associate professor of Pediatrics and director of the Pediatric Stem Cell Transplant Program in the Division of Hematology/Oncology.

CAR T-cell therapy works like this: a patient's T cells — white blood cells that normally help fight infection — are collected and shipped to the pharmaceutical company Novartis. At Novartis, the cells are engineered to express a chimeric antigen receptor (CAR) designed to recognize the patient's leukemia cells. Large num-

bers of engineered CAR T cells are grown in the laboratory and then shipped back to the hospital, where they are infused into the patient.

The CAR T cells recognize and kill the leukemia cells, and send a signal instructing CAR T cells to divide, which produces even more of the cancer-fighting cells.

Because the therapy can have serious and life-threatening complications, the FDA requires that treatment sites have special certification.

"Vanderbilt is ideally suited to care for these patients," Kitko says. "Our team has been providing cellular therapy to the Middle Tennessee community in the form of stem cell transplantation for many years, and CAR T-cell therapy is the latest and most personalized cellular therapy ever designed."

In addition to offering

Kymriah, Children's Hospital is an active site for a clinical trial of another CAR T-cell therapy for leukemia.

Marriott International, the longest standing corporate partner of Children's Miracle Network Hospitals®, has committed \$300,000 to pediatric cancer initiatives at Vanderbilt. In doing so, Marriott joins other community partners who are supporting CAR T-cell therapy.

"Marriott International is delighted to support this unique and innovative therapy at Children's Hospital," says Nicole Randazzo-Cipriani, president of Marriott's Nashville Business Council. "We look forward to the advances that Vanderbilt physicians will continue making to improve the treatment and survival of children with cancer."

— by Leigh MacMillan

Sarah Pryor, 13, was diagnosed at age 7 with pulmonary arterial hypertension, a rare and life-threatening lung disorder.



The Art of Caring

*Enhancing care and treatments
for common and complex lung disorders*

A large, stylized, pink letter 'S' with a textured, watercolor-like appearance, serving as a decorative element for the start of the paragraph.

even-year-old Sarah Pryor couldn't walk up a flight of stairs in December 2012 without gasping for air. Her father, Ben, had to carry her upstairs to bed where she slept propped up against her mother, Jody. If she lay down, she couldn't breathe.

Her heart was failing, but more than two years of doctors' visits at two children's hospitals in Missouri — pediatricians, neurologists, cardiologists and pulmonologists — hadn't answered the one question Jody and Ben needed answered: what was wrong with their daughter?

written by [Nancy Humphrey](#)
photograph by [John Russell](#)



fter a series of frustrating misdiagnoses, a move to Middle Tennessee and the good fortune of ending up with the pediatric pulmonary hypertension team at Monroe Carell Jr. Children's Hospital at Vanderbilt provided the Pryor family with a diagnosis — Sarah, now 13, had pulmonary arterial hypertension (PAH), a subtype of pulmonary hypertension (PH). It's a chronic and life-threatening disease that can lead to right heart failure if untreated.

PH is a condition of high blood pressure in the blood vessel system that delivers de-oxygenated blood from the right side of the heart to the lungs, and returns oxygenated-rich blood back to the left side of the heart for subsequent delivery to the body. The elevated blood pressure strains the right ventricle of the heart over time. This can cause heart failure, which is the most common cause of death in people who have PH.

After the diagnosis, Jody said, "I realized how horrible it was."

Most children with PAH progressively worsen over time. There is no cure, although many children respond to treatment that can lessen symptoms and improve their quality of life. Median survival for children with PH is seven years after diagnosis. Before current medications were available, it was two to three years.

The symptoms of pulmonary hypertension in its early stages might not be noticeable for months or even years. They include shortness of breath during normal activities, fatigue, dizziness, fainting spells, chest pain and a racing heartbeat. At its worst, the condition may limit all physical activity.

About 200 children with PH are currently treated by the pediatric pulmonary hypertension team at Children's Hospital, a component of pediatric pulmonary medicine which is ranked 13th in the nation by *U.S. News and World Report*. Children treated in the pulmonary medicine program have access to nationally recognized experts in common and complex breathing problems including PH, primary ciliary dyskinesia (PCD), cystic fibrosis, bronchopulmonary dysplasia, asthma and other conditions.

Children's Hospital is one of eight accredited pediatric comprehensive care centers in the country caring for children with PH and the only accredited program in the Southeast, said Sarah's physician, Eric Austin, MD, MSCI, associate professor of Pediatrics.

"We offer a comprehensive, multidisciplinary approach for children with PH with a physician and nurse practitioner, along with dietary, palliative care and pharmacy support," Austin said. "Our pulmonary hypertension care is centered around a collaborative network of physician/scientists."

PH, which is caused by a gene mutation in about 20 percent of the cases, can be idiopathic, with no known cause. Other conditions can also result in PH, including congenital

heart disease, chronic lung disorders, blood clots in the lungs, etc. Sarah's form of PH is idiopathic.

Sarah's one and one-half year "crazy journey" to diagnosis was harrowing for Sarah, Jody and Ben. In perfect health until age 6, at the end of her kindergarten year in Missouri, Sarah fainted in the hallway at school. A witness saw her grab her chest and fall face first to the ground. Her parents took her to two children's hospitals in Missouri, where they were told her episode had been a seizure.

Episodes of fainting, shortness of breath and what were believed to be seizures persisted. At first, the episodes occurred when she was doing some sort of basic physical activity, like climbing stairs, and later, when she was at rest. She saw neurologists, cardiologists and pulmonologists. The physicians didn't think the seizures and shortness of breath were related. Her parents insisted they were.

When the family moved to Franklin, Tennessee, in 2012, Sarah's condition, still undiagnosed, was progressing rapidly. Their pediatrician sent them to a Nashville cardiologist who was concerned about a possible rhythm problem with her heart. He referred them to Vanderbilt pediatric cardiologist Frank Fish, MD, who recognized the possibility of PH. Fish referred her for further testing by Dana Janssen, MD, an interventional cardiologist and member of the Pediatric PH Program, who performed a heart catheterization which formally diagnosed Sarah with PH.

She was then immediately referred to Austin and the pediatric PH team at Children's, including Anna Brown, DNP, CPNP. "Dr. Austin and his team have been by our side ever since the day Sarah was officially diagnosed," Jody said.

By the time most patients are referred, they've had symptoms for two or three years, Brown said. "PH is a challenging condition to diagnose early, because even if you have sustained high pressures for a while, you may not see signs or symptoms."

Finding the right treatment

Current available therapies slow down the progression of the disease but won't cure it. The therapies work in different ways to relax the pulmonary arteries to relieve stress on the right side of the heart. They include oral therapies to target different biologic pathways relevant to PH, inhaled versions of these medications, and continuously infused versions of these medications. For the continual infusions, children are connected to small pumps for delivery of the medication to the skin or blood vessel, similar to insulin pumps for diabetes. While only one therapy is approved for use in pediatric patients by the Food and Drug Administration, all the therapies are used by specialists in the pediatric PH field.

Sarah is currently on three oral medications and one-half liter of oxygen at night and her pressures have decreased, Jody said. She has a difficult time during cold and flu season and her

parents have to be extra cautious to keep her away from anyone who is sick. Like other children, Sarah gets respiratory infections and other illnesses, although these may be harder for a PH patient to recover from.

Still, Sarah is one of the “rare of the rare,” Jody said. “PH is a rare disease and Sarah is even more rare because she responds so well to treatment. We are grateful that she is doing well, but we never forget her prognosis. We know that things could change at any time...I don’t know how long Sarah would have been with us if we hadn’t been referred to Vanderbilt.

“I know they care for Sarah deeply and want what is best for her. They encourage us and help us make tough decisions. I would travel across the country if we ever moved so Sarah could continue treatment with them.”

The quality of life for PH patients varies depending on the subtype, Austin said. “At the highest challenge of illness there’s a massive impact on quality of life. For example, several of our patients are able to get to and from their car and around their house, but get winded beyond that. Many can’t play outside for any length of time or participate in physical education. Our patients who have a continuous pump requirement can’t swim and they have to be careful not to dislodge their pump with typical daily activities. Children with PH have to think carefully about their activity and endurance; for example, for some children with a school on multiple levels, they need to wait on elevators all day long. So, many children with PH deal with a level of challenge and impact that’s quite burdensome.”

Brown said the only “cure” for PH is a lung transplant,

“which in pediatrics is trading one set of problems for another, so we try to manage our patients with available therapies for as long as we can.” Average survival for pediatric lung transplant patients is five years. Many of Vanderbilt’s PH patients are referred for transplant evaluation and discussions early, but the transplant typically will not occur until the end of the disease, if at all.

“The quality of life post-transplant is often quite difficult and the timing of transplant is a multifactorial decision. In fact, not all children and families elect to pursue transplant. We aim to support our families with their decision-making regardless of their ultimate preferences,” she said.

Sarah’s parents have hopes for her future. Currently, she is homeschooled in Hendersonville, Tennessee. Her mom, Jody, wishes for Sarah to be able to attend high school, “so she can be a typical kid.” That will depend on her condition at the time. She loves arts and crafts, especially sewing, and enjoys acting and baking.

“We have hope for a cure in Sarah’s lifetime. Sarah is our comeback kid. She is tougher than she looks and is a fighter,” Jody said.

Delivering specialized care

Zion Horton, a kindergartener who lives in Laverne, Tennessee, is another patient seen by the pediatric pulmonary team at Children’s Hospital. Zion, a bubbly, vibrant and active 5-year-old, has a “smile as big as her hair,” says her mom, Valency. “She lights up a room,” she adds.

Improving screening and treatments for cystic fibrosis

In 2015, for the first time, adults with cystic fibrosis (CF) outnumbered children with the disease. The lifespan for those diagnosed with the inherited disorder that causes severe damage to the lungs, digestive system and other organs in the body, is also increasing.

Improvements in screening and treatments mean people with cystic fibrosis are living longer — some into their 40s and 50s or even later, said Rebekah Brown, MD, a pediatric pulmonologist at Monroe Carell Jr. Children’s Hospital at Vanderbilt and director of the Cystic Fibrosis Center at Vanderbilt. Patients are also being diagnosed earlier.

“A lot of our patients are diagnosed as newborns during the newborn blood screening (required in Tennessee since 2008) before they ever have any symptoms of CF,” said Brown, assistant professor of Pediatrics. “It

allows us to intervene and be proactive to decrease the rate of progression of the disease and maybe prevent some of the complications like malnutrition which used to make children with CF very sick in their first year of life.” The screening also detects those who are carriers, but who might not develop the disease themselves.

Cystic fibrosis affects a salt channel which lines tubes in the body such as the airways, digestive tract and sweat glands. In people with the disease, a defective gene causes the secretions to become sticky and thick, plugging up tubes, ducts and passageways, especially in the lungs and pancreas.

People with CF can manage their disease by following a regular treatment routine that includes airway clearance, medication, a fitness plan and nutritional therapies. Presently, there is no cure.

About 220 CF patients are treated at Children’s Hospital, coming from Middle Tennessee, southern Kentucky, northern Alabama, Louisiana and Arkansas. Another 270 are treated at Vanderbilt University Adult Hospital, where pediatric patients transition at age 18.

The Vanderbilt CF team, accredited by the Cystic Fibrosis Foundation, takes an interdisciplinary, collective approach to the disease process. The team includes a pediatric pulmonary medical provider (physician or nurse practitioner), dietitian, social worker, respiratory therapist, pharmacist, physical therapist and Child Life specialist, who provides psychosocial support to children with CF and their families.

— by Nancy Humphrey



Zion Horton, 5, regularly partakes in physical activities that clear her airways to help with her lung disorder called primary ciliary dyskinesia, or PCD.

Zion was diagnosed with primary ciliary dyskinesia (PCD) in her mother's womb. PCD is an inherited rare disease that affects tiny, hair-like structures that line the airways, including nasal passages, sinuses, lungs, Eustachian tubes of the ear, the reproductive organs and ventricles of the brain.

Cilia move together in wave-like motions and carry mucus toward the mouth to be coughed or sneezed out of the body. The mucus contains inhaled dust, bacteria and other small particles. If the cilia don't work well, bacteria stay in your airways and can cause breathing problems such as frequent cough and recurrent pneumonia. Cilia dysfunction can also lead to ear and sinus infections, along with hearing and speech development issues. In addition, about 75 percent of individuals with PCD have a history of breathing difficulty at birth. PCD can also cause fertility issues because sperm cells have structures that are like cilia and there can be faulty cilia in the fallopian tubes.

"PCD affects the lung's ability to get rid of the normal things we breathe in every day and creates extra mucus in the

lungs, putting these kids at risk for respiratory infections and pneumonia over and over again," said Michael O'Connor, MD, assistant professor of Pediatrics.

PCD affects between one in 10,000 and 30,000 births, but most children born with PCD have a normal lifespan ahead of them. The Children's Hospital pulmonary team follows about 50 children with PCD.

Ciliary activity is also responsible for organ placement in the developing embryo. A condition called Situs inversus totalis occurs in about 50 percent of all PCD patients, including Zion whose heart, stomach, liver and spleen are on the opposite side of the body from where they should be.

"While PCD is a rare disease, there is a significant need for increased awareness of the disease, both in the community and among health care providers," said Lisa Young, MD, associate professor of Pediatrics, who co-directs the PCD Center with O'Connor. Vanderbilt's is one of 40 centers accredited by the PCD Foundation throughout the United States and Canada.

"It can take a long time to get to this diagnosis. PCD is not just misdiagnosed. What's more common is it's missed altogether," Young said.

Children's Hospital is also one of a limited number of centers and one of only two centers in Tennessee that offers specialized nasal nitric oxide testing to diagnose PCD. It's a simple test in which a tiny foam piece with suction (about the size of a miniature marshmallow) connected to an analyzer is inserted into your nose to measure the level of nitric oxide in the nasal cavity. People with PCD have very low levels of this gas in their sinus cavity. "It's a very reliable test, and we are quickly learning how helpful this testing can be in making a diagnosis of PCD," O'Connor said.

Valency, who said Zion has good and bad days, said that she tries to instill in her daughter that PCD is what she has, not who she is. "It doesn't define her, but we've taught her to be her own advocate as well, to speak up for herself (if there are respiratory irritants around her). We don't want PCD to hinder her in her day-to-day activities."

But the family, which includes Zion's 8-year-old sister, Nia, 21-year-old brother, Edward, and father, Emmanuel, does have to build in time each day for Zion's airway clearance. Although it sounds simple, it's crucial that she blow her nose thoroughly throughout the day — to help clear mucus. She wears a heavy airway clearance vest twice a day (before school and before dinner) and takes medication to keep her airway clear. Nia attends the same school and can check on Zion throughout the day.

Children with PCD are seen by a multidisciplinary team at Children's Hospital, including pediatric otolaryngology and respiratory therapists. They are monitored closely for respiratory infections and treated aggressively with antibiotics if they develop one.

"We're partnering with other centers around the country to implement new therapies to improve care for our patients," Young said. "PCD has been a very lonely diagnosis and we're working to change that by setting up accredited centers providing education to families and their providers about the diagnosis, and by conducting research to improve our understanding of PCD and develop new therapies."

Zion has come a long way in understanding PCD, Valency said. "When she was around 3 or 4, she couldn't understand why she was the way she was. She cried a lot because she didn't understand. We did a lot of explaining and told her she was uniquely created and that God has a purpose for her."

"Now she'll tell people 'I have PCD. My heart is here (points to the right side of her chest) and yours is there (points to the left)'. We've also helped explain her condition at school so she doesn't feel different. The pledge of allegiance seems like a minor thing to teach your child, but she came home and said 'I'm supposed to put my hand over my heart. Is it OK to put it where my heart is, or where everybody else's is,'" Valency said. "We told her either side is just fine." 🐦 hope

Long-running clinic helps premature babies with lung disease

Premature babies born with underdeveloped lungs often receive pressurized oxygen from machines to help them breathe. But sometimes the machines can damage the babies' delicate airways and cause respiratory distress syndrome. If symptoms continue for more than a month after birth, the babies develop bronchopulmonary dysplasia (BPD) from inflammation, swelling and scarring in their lungs.

For 34 years, Monroe Carell Jr. Children's Hospital at Vanderbilt has offered a BPD clinic for these infants, many of whom leave the hospital requiring temporary supplemental oxygen. It's one of the longest running clinics of its type in the country.

"(The infants) are left in various stages of healing after they're discharged from the hospital," said Odessa Settles, RN, MSN, BPD Follow-up Clinic Coordinator. "They come to our clinic until they no longer need supplemental oxygen."

In addition to checking the child's pulmonary status at each visit, Settles does some patient education about BPD, expectations and planning. Babies with increased oxygen need also have increased caloric need, so maintaining proper growth is one of the most important and challenging issues. "I view the family as my patient," Settles said.

About one-third of newborns in the United States each year develop BPD, Settles said. Children's Hospital sees about 50 infants totaling 90 to 110 visits each quarter in the BPD Clinic.

Most infants outgrow the disease and lead healthy, productive lives, though some may continue to have lingering lung problems similar to asthma.

"Even though it's a chronic lung disease, with proper growth and oxygenation, their lungs heal and continue to develop healthy air sacs throughout the first 36 months of life, and their pulmonary reserve improves over time," Settles said.

"Other than having a great team, one of the best things about our clinic is being able to give adequate time to these families. It takes a lot of education following their discharge from the Neonatal Intensive Care Unit. It takes empowering the families in order for them to take care of these babies who have such an increased need," she said.

Settles, who has been at Vanderbilt since 1969, said some of the parents she cared for as infants are now coming to the clinic with their own babies who have BPD. "When I started here the survival rate of pre-term babies was about 20 percent. Now, thanks in part to improved treatment modalities, it's about 80 percent," she said, adding that the youngest baby she has cared for was born at 23 weeks gestation.

— by Nancy Humphrey



Heart Warriors, Best Friends

*Waiting for heart transplants, three young boys
built a lasting friendship*

Caleb Daniel, 5, Jayden Bradley, 6, and Caleb Aslinger, 5, have celebrated birthdays and holidays together, gone on scavenger hunts, held dance parties, played baseball and have met celebrity musicians and athletes like the Nashville Predators hockey players. They've seen animals from the Nashville Zoo, watched dog shows and puppet shows, and they even created a music band named the "Vandy Rockers."

The events are memorable childhood milestones — with one difference. The boys' experiences all happened within the walls of Monroe Carell Jr. Children's Hospital as each waited for a lifesaving heart transplant.

written by Christina Echegaray
photograph by John Russell



From left: Best friends Caleb Aslinger, Jayden Bradley and Caleb Daniel reunite after spending months in the hospital together.

For approximately five months, each boy lived on the seventh floor of Children's Hospital in the pediatric cardiology unit. With failing hearts, their names were put on the transplant waiting list. First admitted was Caleb Daniel, then Jayden Bradley, and third was Caleb Aslinger — all within a few months of one another.

Not long after their admissions, the Vandy Rockers became well known around Children's Hospital, often seen pulling their IV poles in tow, wearing portable oxygen nasal cannulas and, sometimes, facemasks to protect them from germs. Where one went, people were sure to see the other two not far behind. Their bright faces, when unmasked, always displayed smiles.

"It's rare for kids to be in the hospital and to be that happy for that long of a period," said Ashley Daniel, Caleb's mom. "They are the three most awesome kids that God blessed with the best personalities. They trusted and had each other, instead of feeling so isolated."

The boys also shared the same heart condition, hypoplastic left heart syndrome, or HLHS, a congenital heart disorder (CHD) affecting the left side of a newborn's heart during fetal development. The cause is unknown. With this syndrome, the lower left chamber of the heart is too small and unable to adequately pump blood through the aorta, also smaller than normal, to the rest of the body. In addition, the mitral valves don't work properly.

Treatment for HLHS usually involves a series of complex heart procedures — the Norwood, the Glenn and the Fontan — and if those don't work, a heart transplant is required.

Then the waiting game for a new heart begins, which, for their age group, can average two to four months.

"Families draw strength from each other during their time in the hospital. They become communities of support for one another as they are facing the same challenges," said Ann Kavanaugh-McHugh, MD, who specializes in congenital heart disease at Children's Hospital and was part of the care teams for the boys. "In this case, there were three families waiting in the hospital with similar challenges and in the same age group. These are amazing loving families who you would love to have as your neighbors or friends."

As Caleb Daniel, Jayden Bradley and Caleb Aslinger waited for their new hearts at Children's Hospital, their friendship and personalities during those months inspired the many people they came in contact with — doctors, surgeons, nurses, Child Life specialists, music and art therapists, the Seacrest Studios manager and beyond.

"Our hospital has a tremendous sense of community — community in the way the staff interacts, the way we partner with outside organizations, and in the way we operate on a day-to-day basis with patients and families to give them the support and bonding experiences they need while waiting for

a transplant. We believe 'it takes a village' and Children's Hospital knows exactly how to pull that village together for the benefit of each individual child," said Meredith "Mamie" Shepherd, Seacrest Studios manager at Children's Hospital.

"The Calebs and Jayden were a special group...They really were a band of brothers. They developed a community of friendship."

Caleb Daniel

Caleb is the fifth child of Ashley and Zack Daniel, of Franklin, Tennessee. Because their older son, Jake, now 11, had a congenital heart disorder, the Daniels had their three younger boys screened for CHD during prenatal ultrasounds as well as after birth. It was at Ashley's ultrasound during her 20th week of pregnancy that doctors raised concerns about Caleb's heart, and she was referred to Vanderbilt.

Born April 10, 2013, Caleb was whisked away to begin a medication to help his heart work. At 1 week old, he underwent the Norwood procedure, the first in a series of reconstructive surgeries of the heart.

"We had quite a few issues develop after the first surgery," Ashley said. "He had a stroke, he had seizures and we struggled to keep his oxygen saturation levels where he needed them to be."

When Caleb had the Fontan surgery, he never seemed to fully recover. He had plural effusions, meaning fluid from the heart develops around the lung.

"He had a heart catheterization in May 2017, and it showed he was in heart failure. He was listed for transplant and remained in the hospital as an inpatient to wait for his heart," Ashley said.

Jayden Bradley

By the time Jayden Bradley arrived at age 2 to live with the family who would eventually adopt him, he had already been through six heart surgeries. Annie and Jonathan Bradley were determined to provide Jayden, who was unable to walk or talk, with love, make him feel at home and care for his hypoplastic left heart syndrome. Only married two years, the Bradleys suddenly became guardians of two children, Jayden and his sister, Alli, then 7. The brother and sister were also family — Annie's second cousins.

Annie knew that Jayden was diagnosed in utero with hypoplastic left heart syndrome. He had not done well with his past surgeries before coming to live with the Bradleys. Soon after his arrival in their home, Jayden began walking and talking. Once more steady on his feet, he would run, but would get short of breath and his face had a bluish tint due to lack of oxygen.

"We knew eventually he would have to have a heart transplant. We didn't think it would be as soon as it was, but his

oxygen was getting down to 50 percent. When he was running, doing anything with physical activity, his oxygen was dropping, but you would have never known that with how he always ran. He was a superhero,” said Annie, who is also a home health nurse.

When Jayden’s shortness of breath worsened, his cardiologist English Flack, MD, admitted him to the hospital July 7, 2017, to wait for his new heart.

“I don’t think we fully knew what we were getting into, having to stay so long, but I know other kids have to stay longer. He knew his heart was sick. We told him he we had to get a special new heart put into his body so he could be better. He was OK with that,” Annie said.

Caleb Aslinger

Stephanie and Rodney Aslinger learned that Caleb’s heart was not developing correctly at 19 weeks gestation. They would wait another four weeks to learn from a specialist that he had HLHS. At the time they lived in Chattanooga, Tennessee, and the plan was to deliver their son at Children’s Hospital at Vanderbilt under the care of the fetal specialty team.

“Our two older sons both had healthy hearts. All this was completely eye opening and a learning experience,” said Stephanie Aslinger. “When we found out something was wrong, all I cared about was getting the baby healthy. The only name we really talked about was Caleb. Some friends at church told us that Caleb means ‘whole hearted.’ We knew that was his name, end of story.”

Caleb was born April 9, 2013, weighing 10 pounds, 1 ounce, an unusually large baby given his heart condition. His size, however, made it easier for surgeons when they performed his first heart surgery at 2 days old.

Like the other two boys, Caleb would have several heart surgeries in attempt to repair his heart — the Norwood, the Glenn and the Fontan — with each stage carrying its own challenges and sometimes isolation to avoid illness.

Caleb was admitted Aug. 28, 2017, when he developed plastic bronchitis, a serious respiratory illness where fluid from the lymphatic system creates rubbery plugs that block the airways in the lungs. He had to wear a special vest around his chest that would shake him for 20 minutes, four times a day, along with breathing treatments.

Every day was an adventure

The two Calebs, born only a day apart, and their parents were friends with each other before the long hospital stays to wait for a transplant. The parents first met in the family waiting room at Children’s Hospital. After the dads began talking about baseball, the rest of their stories unfolded, which had striking similarities. Ashley and Stephanie soon connected by phone.

“At first I didn’t want to talk to anyone; I didn’t want any advice. My husband pressed me to call Ashley,” Stephanie said. “To know someone else is going through the same thing, even though there may be differences, helps.”

When Caleb Aslinger was admitted, Stephanie says, he noticed

Jayden across the hall from him and was intrigued that “there was another little person besides him.”

“Once we got adjusted and his treatments in order, we went on walks and more adventures,” Stephanie said. “I’ll never forget the time the nurses took all the boys to the fish pond. Caleb (Aslinger) put his hand on Jayden’s shoulder. I think Caleb realized he wasn’t alone.”

The boys spent a lot of their early years of life more isolated than most toddlers or



From left: Caleb Aslinger, Caleb Daniel and Jayden Bradley dress up for the reverse trick-or-treat Halloween event at Children’s Hospital.

preschoolers, not able to play freely on potentially germ-y play-ground equipment or roam through large crowds of children, particularly during cold and flu season.

“Caleb hadn’t been around a lot of kids because of having to stay in a lot. So with the other Caleb and Jayden, he wanted to go on a lot of adventures and to Seacrest Studios. It helped him tremendously,” said Stephanie Aslinger. “I hate that all three of those little boys had to go through what they went through, but to put all of them together at that time, I think helped all three of them.”

The boys spent time at Seacrest Studios for special guest visits or events whenever they could, often made possible by their medical teams. The studio, opened in partnership with the Ryan Seacrest Foundation, allows patients to explore the creative realms of radio, television and new media that can aid in the healing process for children and families during a visit to or stay in the hospital.

“It was the perfect thing for the boys that they were able to develop lifelong friends,” said Ashley Daniel. “They played hockey and baseball out in the hallway. And I give full credit to the staff. They would create story time for them. The chaplain

Caleb Daniel, Jayden Bradley and Caleb Aslinger went on adventures together at Children’s Hospital, including this visit to the hospital’s Friends Garden.



came and did Bible stories. The nurses would sing songs at night to them. I can’t say enough about the wonderful team.”

The team also organized a scavenger hunt for the boys on Jayden’s 6th birthday.

“I thought we would be stuck in a room and Jayden would be miserable. We had never had that length of stay. But to see what Vanderbilt offers children is just very heartwarming. The hospital is amazing,” said Annie Bradley. “The boys all had the same idea of funny. They were family; they are family. It’s difficult being somewhere five-and-a-half months and not being around people that you know. So to be able to form those relationships, not only with the mothers and fathers, but with the nurses and everyone else, it makes everything seem better.”

Often alongside them, leading the adventure, was their Child Life specialist, Camille Fraser, who is dedicated to the pediatric cardiac ICU. Child Life specialists are trained members of the health care team who seek to provide patients with developmentally appropriate information to help them understand their need for prolonged hospitalization or to offer procedural support.

“I try to make the hospital feel more normal for my families through play, inviting them to participate in the hospital-wide special events, and continued therapeutic visits. In the case of Caleb, Caleb and Jayden, their story is unique because they found support not only from me and other staff members, but also from each other. The same can be said for their parents,” said Fraser.

“These boys got to know each other very well by going on ‘adventures’ to Seacrest Studios. Each morning, the boys would ask me, ‘What’s our adventure today?’ They would plan their days around getting to be a part of the fun (at hospital events).”

In Seacrest Studios when talking to celebrities, like the Nashville Predators hockey players, the boys used the code word ‘toilet paper’ because they thought it was funny. It also meant the celebrity could be a part of their “club.”

“Our hospital not only provided critically important health care, we also provided activities that enhanced their stay and got right to the heart of a child’s happiness, even if it included talk of toilet paper,” said Seacrest Studios manager Shepherd.

‘The call’ and going home

For each family, the news that a new heart was available came in different ways — and at different times. In the order they were admitted, so went the order of the heart transplants — Caleb Daniel, Jayden Bradley and Caleb Aslinger.

For the Daniel family, the call came on the evening of Friday, Sept. 29, 2017. Ashley had just arrived home from the hospital. When she looked at the caller ID, it said ‘Vanderbilt,’ and she knew. “I went numb,” Ashley said. The surgery began



What is Hypoplastic Left Heart Syndrome (HLHS)?

Congenital heart conditions are present when a child is born. Doctors and surgeons with the Pediatric Heart Institute at Monroe Carell Jr. Children's Hospital at Vanderbilt provide comprehensive, quality care to children with a variety of congenital heart conditions. Hypoplastic left heart syndrome (HLHS) is one of the many heart conditions they treat.

Congenital heart disease is sometimes diagnosed while the baby is in utero during a gestational ultrasound. Newborns not diagnosed in the womb who exhibit symptoms — such as shortness of breath, rapid breathing, pounding heart, bluish skin from lack of circulation, cold arms and legs, weak pulses, difficulty feeding and lethargy — may have an echocardiogram to explore for heart defects.

In patients with HLHS, the right side structures of the heart are normal, but the left side structures are hypoplastic, or small, though the extent of the defect can vary from patient to patient. The aortic and mitral valves can be small or absent. Also, the left ventricles vary in size, from quite small

to near normal size. The defects affect normal blood flow through the heart, resulting in a lack of oxygen-rich blood to the rest of the body.

HLHS accounts for 2 to 3 percent of all congenital heart disease and has a prevalence rate of about two to three cases per 10,000 live births, according to UptoDate, an evidence-based, physician-authored clinical decision support resource used by many doctors.

"This defect is universally fatal without surgery," said Ann Kavanaugh-McHugh, MD, associate professor of Pediatrics and director of Vanderbilt's Fetal Cardiology Program. "Patients require lifesaving surgery which will either consist of single ventricle palliation (called the Norwood) or initial transplantation."

"When a surgery doesn't 'fix' things it is a palliation (seeks to provide relief from symptoms). At the end of the three operations that make up single ventricle palliation, the heart is a single ventricle, not the two pump heart that the rest of us have. The initial surgery, the Norwood repair, is

done usually in the first week of life, the Glenn at four to six months and the Fontan generally at about 3 years of age."

Each procedure can require a lengthy stay in the hospital with Norwood being about 40 days; the Glenn and Fontan about nine days each, though recovery time can vary from patient to patient. Some patients have multiple readmissions in between surgeries because they are medically more fragile. If a heart transplant is needed, the wait in the hospital can average two to four months, sometimes longer.

Often during that time, the heart families will bond.

"Families draw strength from each other during their time in the hospital," said Kavanaugh-McHugh. "They become communities of support for one another as they are facing the same challenges. Families look to one another for information and are tremendous supports for each other." Doctors know data. It is not the same as speaking with someone who has 'walked the walk.' We encourage families to support each other."

— by Christina Echegaray

the next day, finishing Oct. 1. They left the hospital a month later.

The Bradley family got the call at 12:55 a.m., Dec. 8. Jayden was able to leave the hospital about two weeks later, just in time for Christmas.

Stephanie Aslinger learned on her wedding anniversary, Jan. 31, that Caleb, who was missing his buddies, was getting his heart the next day. "It was the best anniversary gift ever." By Feb. 17, Caleb Aslinger, the last of the Vandy Rockers left the hospital.

"When you leave the hospital it's with mixed emotions," said Ashley Daniel. "Obviously, you're very excited to be able to go home. But we miss our friends and the staff who are truly our family."

"Families draw strength from each other during their time in hospital. They become communities of support for one another as they are facing the same challenges."

The Vandy Rockers are all at home now doing well post-transplant. They don't live too far apart. Both Calebs live in Franklin, Tennessee, with Jayden living about an hour further south in Lawrenceburg. With their suppressed immune systems and need to avoid germs, they've only been able to get together a couple times since leaving the hospital, but sometimes see each other at their follow-up appointments at the hospital.

Caleb Daniel, an avid Nashville Predators hockey fan who carries around a Pekke Rinne doll, spends his time watching NHL hockey and playing with his golden retriever, Macie.

Jayden, who went home to a newly decorated room with décor from his favorite cartoon show "Paw Patrol," has begun playing T-ball and will soon begin going to school.

Caleb Aslinger loves going on walks and practices hitting the baseball with his dad. Now that the weather is nice, he sits on the backyard deck or likes to lie in the hammock.

"We've FaceTimed (the other boys), we've talked on the phone and we've run into Jayden on appointment days. It's like they're getting to know each other again after heart transplant," said Stephanie Aslinger. "I can't wait until they're all better and they can have play dates and interactions and just be kids." 🍀 hope

William Walsh, MD, served as chief of Nurseries for 25 years at Vanderbilt.



Passing the Baton

After four decades of caring for babies, William Walsh, MD, is retiring

written by Christina Echegaray
photograph by John Russell

William Walsh, MD, has always “put the baby in the middle” — sometimes literally, but most often figuratively.

“Put the baby in the middle” is one of many Walsh-created idioms, dubbed “Walshisms” by people who know him. That saying in particular, perhaps, best defines the beloved neonatologist’s career focus.

“He told me and preached to me ‘if you put the baby in the middle, you can take care of all the rest after,’ whether it’s an insurance issue, or a form. ‘Do what’s best and you’ll come out OK,’” said Marlee Crankshaw, RN, DNP, CNML, director of Neonatal Services and Walsh’s longtime friend and colleague. “He has always been so caring and patient with our families. He is not just a wonderful physician, but also a wonderful man.”

In a career spanning four decades, with 25 of those years as chief of Nurseries at Vanderbilt University Medical Center and Monroe Carell Jr. Children’s Hospital at Vanderbilt, Walsh has focused on caring for some of the hospital’s tiniest and sickest patients.

Along the way, he impacted policy, trained future providers and championed innovative treatments. He’s published more than five dozen articles, given more than 100 invited lectures, taken care of thousands of babies and mentored too many people to count.

“Witnessing the phenomenal growth of Monroe Carell Jr. Children’s Hospital at Vanderbilt has been one of the great pleasures of my career,” said Walsh. “The greatest strength of Children’s Hospital is a focus and dedication to the primary mission of providing unsurpassed health care to the children of Middle Tennessee and to training the next generation of providers.

“I have never encountered an objection to doing what is best for the babies despite costs and insurance obstacles. That dogged determination to do the right thing for our babies has been a true blessing. I am so proud of the hundreds of graduate residents and fellows who now provide excellent care throughout the region, and many even worldwide.”

Walsh’s retirement is effective June 30.

“While I will miss the daily interactions with

my colleagues and the critically ill infants, I look forward to a new chapter of dedicated family time,” Walsh said.

Walsh initially thought he would be a pilot, signing up for the U.S. Air Force, which offered a free college education. He attended the Air Force Academy, soon realizing that flying wasn’t for him, and changed his major to life sciences.

While at the Air Force Academy, he secretly eloped with his high school sweetheart, Karen Gannon, because the Academy didn’t allow students to marry.

Walsh went to medical school at the University of Texas in San Antonio, where Gannon earned a degree in nursing. During his service in the Air Force, he completed his residency and internship in pediatrics and a fellowship in neonatology at Wilford Hall Medical Center, an Air Force treatment facility.

In 1976, he and Gannon began their family, adopting the first two of their six children, premature twin girls Pauline and Virginia. From then until 1988, they adopted four more: Hope, Matthew, Andrew and Brian.

As their family grew, they moved to Maryland, where Walsh became chief of newborn medicine and assistant professor of Pediatrics at Malcolm Grow Medical Center at Andrews Air Force Base. A few years later, they moved to Mississippi, where he took over as head of NICU and Newborn Nursery at Kessler Air Force Base. Subsequently, he returned to Wilford.

Walsh arrived at Vanderbilt in 1992 from Wilford Hall Medical Center in San Antonio, Texas, where he was director of Clinical Neonatology. At the time, Vanderbilt’s NICU had 42 beds — a number that has more than doubled to the current 96 beds under his guidance.

At Vanderbilt, Walsh’s love for children and babies is evident to all who know him.

“Dr. Walsh is the epitome of a master clinician, a true ‘baby whisperer,’” said Susan Guttentag, MD, Julia Carell Stadler Professor and chief of the Mildred Stahlman Division of Neonatology.

“But even more so, he has been a kind, guiding hand across the many groups of providers, administrators, educators and learners that together make up the NICUs that we serve in Nashville, Clarksville, Columbia and Jackson. He has been a tireless advocate for mothers and their babies across the state of Tennessee through his work on Newborn Screening, Infant Mortality Review, and the Perinatal Advisory Committee. I think that it is safe to say that there is no one person able to replace everything that he does on a daily basis.”

His wife, Karen, a neonatal nurse practitioner, has worked alongside him all these years. They understand what families are going through. The couple lost their daughter, Hope, when she was 7 due to congenital medical complications.

Walsh’s experiences and mentoring helped shape the careers of the people he worked with, such as Meg Rush, MD, chief of staff at Children’s Hospital.

“I have had the honor and joy of knowing Bill Walsh since

“Witnessing the phenomenal growth of Monroe Carell Jr. Children’s Hospital at Vanderbilt has been one of the great pleasures of my career.”

the day he interviewed for his position here at Vanderbilt — he will recall the story that my office was so hot, he dozed off a couple of times. It has been a true privilege to learn from and partner with him in the care and advocacy for babies and moms, in the development of training and research programs, and in the growth of our neonatology services,” Rush said.

“Bill is one of the kindest, smartest and most intuitive and attentive physicians I know. He is truly the consummate academic neonatologist, having excelled in each of our missions over his career. Bill has touched the lives of so many — and those who have worked with him will carry on this legacy ‘What Would Walsh Do?’ His daily presence will be missed but his approach to clinical care and teaching live on in his families and those he has mentored,” she added.


Frank Boehm, MD, vice chair of Obstetrics and Gynecology, has witnessed Walsh’s expertise and impact over the years.

“In my capacity as Maternal Fetal Medicine director for 24 years and then as vice chair of the Department of OB/GYN for eight years, I can say that working with Dr. Bill Walsh has been a truly wonderful experience. His expertise in the field of neonatology is exceptional and his professional, calm, easygoing and friendly manner makes each encounter an exceptional as well as educational experience,” Boehm said.

“Vanderbilt has been fortunate to have Bill on its faculty, and the many children whose lives he has saved or improved can also be thankful. From the entire maternal fetal medicine faculty we thank him for his dedicated work and wish him well in the road ahead.”

Bekah Gannon, a Child Life specialist at Children’s Hospital, has witnessed Walsh’s work firsthand. She recalls meeting him when her twins, Eli and Isaac, were born weighing 1 pound and 2 pounds, respectively, and were in the NICU.

“One terrible night when one of our twins, Eli, coded, I remember Dr. Walsh standing over Eli’s bed, giving his tiny body chest compressions with just his pointer fingers, because Eli was still so little,” Gannon said. “He and his team saved Eli’s life that night, among many other times in those five months.”

“One day when we were nearing the end of our NICU stay he came by the room and delivered a keychain with the ‘Gannon’ family crest on it (also being his wife’s maiden name). A small gesture, but at the time brought me so much needed hope for the future. Eli and his twin brother, Isaac, are 7 now...and we still have that keychain taped to our refrigerator, waiting for when Eli gets his first set of keys. That keychain will rightfully be his.”  hope

pioneers 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.

When **Elizabeth Humphreys, PharmD, MMHC**, was a child she would often go to work with her father, a Memphis pharmacist. Sometimes he let her count pills.

"He told me, 'Elizabeth, do something meaningful with your life — something that means something to someone, including yourself.'"

He'd be proud of his daughter.

She took his advice, became a pharmacist herself, and since 2009 has directed the pharmacy at Monroe Carell Jr. Children's Hospital at Vanderbilt, responsible for all inpatient, clinic and retail pharmacy operations, direct supervision of the management team and indirect supervision of about 100 pharmacy employees who handle the medication needs for the thousands of children who pass through the hospital and clinics each year — about 220 prescriptions a day in the retail outpatient pharmacy and 120,000 doses a month for inpatients.

Being a pediatric pharmacist is challenging work, Humphreys said. "You have to manipulate more doses since most medication comes in adult-sized doses. We have tiny NICU babies and 4- and 5-year-olds who can't take a tablet. Many of our patients are so sick. We have to do workarounds to make treatments for our patients. They're not just little grownups."

Humphreys joined the Children's Hospital staff in 2007 as a staff pharmacist. Previously she had been a staff pharmacist at St. Jude Children's Research Hospital in Memphis, and before that a staff pharmacist, pharmacy systems manager and interim director of pharmacy at Le Bonheur Children's Medical Center in Memphis.

A graduate of University of Tennessee College of Pharmacy in Memphis, Humphreys also earned a Master of Management in Health Care degree from Vanderbilt University in 2015.

At work, Humphreys often jumps in to fill staffing spots when there is a need, serving as a staff pharmacist on evening shifts, one out of six weekends, and occasional holidays, to ensure she does her share and remains up-to-date on practices and



SUSAN URMAY

understands the roles of her staff. It's something she loves to do.

"At the end of the day, I love being a pharmacist," Humphreys said. "That's what I'm passionate about. If I had to pick one of my roles, I'd be a pharmacist. No doubt about it. But being a pharmacist also enables me to make good decisions for my team and it helps me build relationships. I like to work side by side with my staff, drawing up medication. I want people to know me as more than just the leader of the department."

Her life outside of the hospital is equally busy. She and her husband, Mark, who works at Vanderbilt University Medical

Center as a program manager in the specialty pharmacy, have seven children, ranging in age from 6 to 22 — “one at every stage of life,” Humphreys said. Her eldest child, Austin, is married and works at VUMC in Health Information Technology. The youngest is in kindergarten.

Humphreys, a former competitive figure skater, said that she works hard to balance a demanding job with spending quality time with her family. Mark and her mother, Jane, who lives with them, have provided “incredible support.”

“My family is my priority. They always are. But when my job is pressing I have to make a decision. Do I miss an event with my family or take care of the issue at work? I’ve had frank discussions with my children and they know my job affects a lot of sick children. They’ve always been very receptive. They understand and they get it,” she said.

— by Nancy Humphrey



Mentoring matters to **Jill Kilkelly, MD.**

It’s been a crucial building block of her own professional journey and is a cornerstone of her leadership philosophy as chief of the Division of Pediatric Anesthesiology and medical director of Perioperative Services at Monroe Carell Jr. Children’s Hospital at Vanderbilt.

Whether it’s with the other anesthesiologists in her division, residents, students, nurses or perioperative support personnel, Kilkelly strives to help people create roles they’re able to thrive in and enjoy.

“Relationships and mentoring are so crucial; nobody is an island, that’s for sure,” Kilkelly said. “The folks here are already amazing self-starters, so I see my chief role as being to help them grow the way they want to, whether that’s with resources or connecting them with other people.”

In addition to working with surgical teams and managing the Children’s Hospital operating rooms, helping educate fellows, residents and student nurse anesthetists, and performing administrative work for her division and Perioperative Services, Kilkelly serves on the Children’s Transformational Healthcare Committee, a diverse group of stakeholders who conduct strategic planning and brainstorm next phases of growth for Children’s Hospital.

She’s also clinical director of the Pediatric Complex Coordination of Care Program, an initiative she helped create in 2011 that combines multiple procedures or radiological studies a child may need with the goal of minimizing separate episodes of anesthetic care when possible.

“We all love the kids more than anything else. They haven’t done any of this to themselves, so anything we can do to make them less afraid, have less pain and have a more positive experience seems to me like a great reason to get up in the morning,” Kilkelly said.

Born and raised in Albany, New York, Kilkelly attended Cornell University, where she received both her undergraduate and medical degrees.

She always loved science growing up, but it was a summer job following her freshman year that convinced her to pursue medicine. That year, her parents moved to Marietta, Georgia, and Kilkelly worked as an orderly at Kennestone Hospital, cleaning the operating rooms.

“There was a surgeon there, Dr. John Kennedy, who learned I was interested in becoming a doctor. During evening hours, when my shift was done, he would invite me into his operating room to observe and would talk me through anatomy. He took me under his wing, took my enthusiasm seriously and showed me why he loved what he did,” Kilkelly said.

Kilkelly came to Vanderbilt in 1997 for General Surgery residency. She did three years of surgery training, then two years in the surgical oncology lab of R. Daniel Beauchamp, MD. Ultimately, she chose a career in anesthesiology. She pursued a year of adult critical care fellowship, then anesthesiology residency — during which she fell in love with the care of children — and then stayed on to complete a pediatric anesthesiology fellowship.

She was invited to remain as an attending physician in Pediatric Anesthesiology following her fellowship in 2007, and became clinical chief of the division as well as medical director of Perioperative Services in 2012. She was appointed division chief in 2017.



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The mentors she credits with influencing her career include her parents, who she says raised her to take great joy in every day, with teachings of, ‘in all things, PMA (positive mental attitude)’ and that, ‘you don’t have to be the smartest person in the room, just the most committed and perseverant;’ John W. Brock III, MD, Surgeon-in-Chief for Children’s Hospital and Senior Vice President of Pediatric Surgical Services; Jay Deshpande, MD, chief medical officer, professor of Pediatrics and Anesthesiology, Arkansas Children’s Hospital; and John Tarpley, MD, professor of Surgery, emeritus, Vanderbilt.

“When anybody asks, what I always say is that, without the support of fantastic mentors, you’re going nowhere,” Kilkelly said.

Kilkelly, along with her husband, fellow anesthesiologist Shannon Kilkelly, DO, enjoys traveling, trying new restaurants, exercise and spending time with her 16-year-old stepson, Lochlan.

— by Doug Campbell



Daphne Hardison, MSN, RN, grew up on her family’s ancestral farm in Scotts Hill, Tennessee (pop. 984), with cows, pigs, chickens, fields of soybeans and a horse named Demon.

“Have I driven a tractor? — yes; was I good at it? — probably not so much,” she says. Less of a farmhand than her sisters were, Hardison instead helped with the cooking. “I can remember

cutting up a chicken at the age of 12, with my grandmother talking me through it over the phone.”

Her father, a truck driver, didn’t finish high school. Her mother was the secretary at Scotts Hill High School, where Hardison’s graduating class numbered 41 students. “I couldn’t date anybody who was from the town because my mother knew them all,” she says. Hardison worked as a nurse’s assistant while in high school.

“I loved biology, adored it. I looked at medicine; I thought I might become a doctor, but once I got to college I decided I wanted to have kids, and for that reason I began to think medicine wasn’t for me.” Thinking it would give her more time to devote to raising a family, she studied nursing instead.

“I believe in having a job and I knew nursing would provide that. And I really, really like nursing,” she said.

A week after graduation from Tennessee Tech in Cookeville, she married Steve Hardison, who works as an information specialist. The newlyweds moved to Columbia, South Carolina, where Daphne Hardison’s successive jobs included staff nurse on an adult neurology unit, staff nurse on a cardiac intensive care unit and scrub nurse for an orthopaedic surgery practice.

“Then I went into my love of nursing, which is the neonatal ICU. I am an ICU nurse at heart. I like adrenaline; I like moving. I also wanted to be doing something that I thought was making a difference,” she said. “You get to know the families and the patients, then you get to see the infant grow up.”

In 1995, Hardison joined what was then known as Vanderbilt Children’s Hospital as a NICU nurse, and in 2003, she joined Vanderbilt University Medical Center’s Extracorporeal Membrane Oxygenation (ECMO) Unit, becoming manager of the unit in 2008. She earned her master’s degree in nursing from Loyola University in New Orleans in 2012.

The first use of ECMO in Tennessee was at VUMC in 1989. ECMO provides inpatients with ongoing cardiac and respiratory support; blood drained from a vein via tubing is oxygenated outside of the body, then pumped back through a tube placed in a vein or artery. For patients on ECMO at Monroe Carell Jr. Children’s Hospital at Vanderbilt, a specialist from the ECMO Unit is at the bedside 24 hours per day.

Hardison first encountered ECMO as a NICU nurse. “I just remember the adrenaline. It’s wonderful to watch a patient who has a 10 percent survival rate or less be put on this machine and given time to heal. They don’t all make it, but when they do, it’s like, ‘wow, we’ve really done something great here.’”

ECMO specialists at Children’s Hospital are required to have at least two years of ICU experience.

“I watch them and I’m amazed. They really know what to do with the patient. They have the experience of working in the critical care unit and they have all these ideas of ways to improve the patient that you wouldn’t have in someone without that background,” said Hardison.



This year, Vanderbilt ECMO split into adult and pediatric services, and Hardison remained with the pediatric team. With a staff of 25 nurses and respiratory therapists, the ECMO Unit at Children's Hospital also provides continuous renal replacement therapy (kidney support). This year Hardison took on an additional role as manager of the Vascular Access Team at Children's Hospital.

The Hardisons have three sons: Spencer, 21, Zach, 18, and Noah, 16.

— by Paul Govern



Scott Brooks, MD, grew up knowing the importance of higher education, helping patients heal and caring for family.

As a child, he often visited Vanderbilt University Medical Center, as his late father, Arthur L. Brooks, MD, a renowned Vanderbilt orthopaedic surgeon who developed several innovative orthopaedic surgical techniques, instilled in him these important qualities.

"I'd go with him when he would do rounds at the hospital. (Those moments) introduced me to the practice of medicine and helped guide me in my future choice to become a physician," Brooks said.

Brooks knew early in life he had a love for science and through his own educational journey decided to work in pediatrics. He's practiced at Pediatric Associates of Franklin since June 1984.

"Every age is a wonder," he said. "From early to late (development), it's a new adventure. It is great to see how they grow through their lives, follow them longitudinally and make sure they are happy, healthy citizens of this world."

Brooks, a Nashville native, received his medical degree from the University of Tennessee Center for the Health Sciences in Memphis in 1981 after completing his undergraduate degree in chemistry at Vanderbilt University.

He completed his residency in pediatrics at what was then known as Vanderbilt Children's Hospital in June 1984, and now provides care through roughly 3,800 patient visits annually at Pediatric Associates of Franklin.

"When I first started, we saw most of the patients in Williamson County on Medicaid," he said. "We've grown to seven doctors and two nurse practitioners. We have a big practice, and are now one of the many pediatric offices in Franklin."

Brooks, who is board-certified in pediatrics, a fellow of the American Academy of Pediatrics and an associate clinical professor at Vanderbilt University School of Medicine, has a passion for caring for children's health.

"I enjoy the interactions with the patients and the parents and being a good educator and resource of information to help parents as they raise their babies, toddlers, school-age children and then send their children off to college," Brooks said. "I really enjoy it."

SUSAN URMY



"What has been truly fulfilling is that now I am taking care of the children of some of my former patients. I call them my grandpatients."

He has received the Physicians Recognition Award from the American Medical Association and the James C. Overall Award for his contribution to the residency program at Monroe Carell Jr. Children's Hospital at Vanderbilt as an outstanding instructor.

Brooks is a member of the National and Tennessee chapters of the American Academy of Pediatrics, and the Cumberland Pediatric Foundation. He is actively involved with Children's Hospital and previously served as a member of the Emergency Department Committee and the Performance, Management and Improvement Council as well as numerous other committees at Williamson Medical Center and Vanderbilt University Medical Center.

Brooks and his wife, Cindy, have been married for 42 years and have two children. Their son, Westley Brooks, lives in Pittsburgh and has three sons, Owen, Miles and Quinn. His daughter, Emily Bray, is a third-grade teacher at Percy Priest Elementary, in Nashville, and is the mother to 2-year-old, Benjamin. Brooks and his wife find their greatest joy in being grandparents to their four grandsons.

Brooks, who grew up on a farm, tends to a basement garden with his wife using grow lights for various heirloom tomato varieties. On Thursdays — his day off — he and his grandson, Benjamin, pick tomatoes, cucumbers and other vegetables from the garden.

— by Tavia Smith

Topgolf and Country Stars Join to Support Children's



JOE HOWELL



Country music superstars Jake Owen and Lady Antebellum's Charles Kelley recently partnered with Topgolf Nashville for The Children's Cup, an evening of golf and music to benefit pediatric cancer research at Monroe Carell Jr. Children's Hospital at Vanderbilt. Competing teams were designated as either "Team Jake" or "Team Charles," with Team Charles ultimately winning The Children's Cup. The evening concluded with an exclusive concert by Owen and Kelley, and CMT's Cody Alan entertained the crowd as emcee.

Top (from left): Jake Owen, patient ambassadors Jessica Meyer and Dillon Porter and Charles Kelley with Champ. Bottom: Jake Owen and Lady Antebellum's Charles Kelley

30 Years of Miracles – Walmart and Children’s Miracle Network Hospitals

In 2017, Walmart celebrated its 30th year of partnering with Children’s Miracle Network Hospitals®, which includes Monroe Carell Jr. Children’s Hospital at Vanderbilt. During this time, Walmart has raised nearly \$1 billion for CMN Hospitals nationwide — more than any other corporation has given to pediatric hospitals. Locally, Walmart raises more than \$500,000 each year and has raised more than \$10 million so far for Children’s Hospital. This support includes a communitywide fundraising effort with customers asked for donations during a four-week period, which will happen Aug. 27 – Sept. 23. These proceeds have supported important programs and services for children and families at Children’s Hospital. Walmart’s support also funded two new nurses’ stations in the expanded space made possible by donors to the Growing to New Heights Campaign.



KAREN HUNTER-LOWERY

A Walmart associate thanks his customer for making a donation to Children’s Hospital through the retail chain’s Children’s Miracle Network Hospitals® campaign.

Celebrating Star Supporters

On March 15, longtime friend of Children’s Hospital Dierks Bentley received the first star on the newly created Walk of Champions, presented by Live Nation, for his continued dedication to the patients and families at Children’s Hospital. The Walk of Champions will be located on the main floor of the hospital and is designed to honor lifelong advocates within the entertainment industry. After the ceremony, Bentley and his daughter visited with patients in Seacrest Studios. The celebration continued into the evening with the Center Stage Gala, an event that took place on the stage of Ascend Amphitheatre to recognize Bentley for his partnership through the years.



Pictured (from left) are patient ambassadors Dalton Waggoner, Zamarian Gillespie and Lily Paris with Dierks Bentley and his daughter, Jordan.

Vanderbilt study affirms effectiveness, promise of telemedicine for autism evaluations

Researchers at Vanderbilt University Medical Center have found that autism spectrum disorder (ASD) can be accurately diagnosed in young children via remote, telemedicine assessments, a method that could significantly increase access and reduce wait times for autism services.

In a first-of-its-kind study, the researchers compared the accuracy of rapid telemedicine evaluations to in-person evaluations for ASD and found that in most cases, remote evaluators could accurately identify children with ASD with high levels of confidence.

The remote clinicians accurately identified 78.9 percent of all children who ultimately received ASD diagnoses based on a blinded comprehensive assessment with gold-standard identification tools. No children were inaccurately classified as having ASD based on the telemedicine consultation.

Zachary Warren, PhD, and colleagues had their findings published recently in the *Journal of Autism and Developmental Disorders*.

ASD is a neurodevelopmental disorder which, according to the U.S. Centers for Disease Control and Prevention (CDC), is identified in one in 59 children, with updated numbers to be released by the CDC this year.

Because an early autism diagnosis is critical, the American Academy of Pediatrics recommends screening for ASD starting at 18 months of age. However, in many parts of the country, the demand for services is so great that waits for an autism evaluation in a specialty clinic may exceed six to 12 months or more.

To address the need in Tennessee, the Treatment and Research Institute for Autism Spectrum Disorders has built its capacity to evaluate children for autism by expanding its telehealth initiatives, which use telecommunications technologies to support long-distance clinical health care.

To test the effectiveness of these telemedicine evaluations, children were evaluated using both in-person and remote diagnostic tools. The assessors, all licensed psychologists with expertise in ASD in young children, used audiovisual equipment that allowed them to observe and communicate with the child.

This study was completed with Vanderbilt Kennedy Center Hobbs Grant funding, support from the Eunice Kennedy Shriver National Institute of Child Health and Human Development (U54 HD08321), and support from the Department of Education Tennessee Early Intervention System.

Additional co-authors from Vanderbilt included Pablo Juarez, MEd; Amy Weitlauf, PhD; Amy Nicholson, MA.; Anna Pasternak, BASc; Neill Broderick, PhD; Jeffrey Hine, PhD, BCBA-D; and J. Alacia Stainbrook, PhD, BCBA-D.

— by Jennifer Wetzel

Hope for RSV vaccine

Respiratory syncytial virus (RSV) and its close relative, human metapneumovirus (hMPV), are leading causes of lower respiratory tract infections in infants and children, yet there are no licensed vaccines available to prevent these viral infections.

Attempts to develop an effective vaccine have been focused on a highly conserved viral protein called the fusion or F protein. When activated, the protein achieves infection by triggering fusion of viral and cell membranes in the lung.

Several antibodies that bind the F protein have been isolated previously. Using blood samples from healthy donors, Jarrod Mousa, PhD, James Crowe Jr., MD, and colleagues generated four new monoclonal antibodies that are specific to the site IV region of the RSV F protein.

One of the antibodies was highly potent in neutralizing RSV in laboratory studies, while another neutralized both RSV and hMPV. The findings, published in the journal *PLOS Pathogens*, reveal important structural features of the F protein that could be used in rational structure-based vaccine design.

This research was supported with funding from the Ann Scott Carell Chair held by Crowe.

— by Bill Snyder

A new target for neuroblastoma

Neuroblastoma — a cancer that starts in nerve tissue outside of the brain — is the third most common cancer in children and accounts for about 15 percent of pediatric cancer-related deaths.

Sirtuins (SIRT6), a family of proteins with roles in metabolism, aging and genomic stability, have been linked to various cancers, but their role in neuroblastoma has not been explored.

Dai Chung, MD, and colleagues found that a non-specific SIRT inhibitor reduced the growth rate of cultured neuroblastoma cells and induced the formation of neurite-like structures consistent with neuronal differentiation (maturation). Using a genetic strategy to knock down specific SIRT6, they discovered that SIRT6 promotes neuroblastoma cell growth and represses differentiation. SIRT6 expression was reduced in differentiated human neuroblastoma samples and in cultured neuroblastoma cells that were induced to differentiate using retinoic acid.

The findings, reported in the February issue of *Anticancer Research*, highlight the oncogenic properties of SIRT6 in neuroblastoma and suggest SIRT6 as a target for new therapeutics for neuroblastoma.

This research was supported by grants from the National Institutes of Health (DK061470) and Rally Foundation for Cancer Research.

— by Leigh MacMillan



Every Birthday is a Gift

At age 2 ½, Grace was diagnosed with leukemia and began a journey through nearly three years of cancer treatment. Thanks to the care of Monroe Carell Jr. Children's Hospital at Vanderbilt, now, at age 9, she's a fourth-grader who loves horses and reading. Each year, she celebrates her birthday by finding special ways to help comfort and encourage other patients. Help us care for more children like Grace by supporting Children's Hospital.

Help now: ChildrensHospital.Vanderbilt.org/giving



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Monroe Carell Jr. Children's Hospital at Vanderbilt is one of only 10 children's hospitals in the nation to be named a Leapfrog Top Hospital for 2017. Among all hospital categories rated — general, children's, rural and teaching — only about 6 percent of eligible hospitals from across the U.S. earned the Top Hospital award from The Leapfrog Group in 2017.