

DELIVERING ON A PROMISE

SUMMER 2016



# On the Mark

*Reshaping care for vascular anomalies*

- ▶ Threads of Care provides extra support for families
- ▶ Profile: Heart Surgeon Umar Boston, MD, leads growing transplant program



THE UNIVERSITY OF  
TENNESSEE  
HEALTH SCIENCE CENTER

LeBonheur  
Children's Hospital

# CLOSER TO HOME

## *Le Bonheur opens ED, inpatient unit in Memphis suburb*

**F**or the last four years, Whitney and Matt Marcuzzo have made the drive from their Germantown, Tenn., home to Le Bonheur Children's Hospital dozens of times.

Having a son with multiple, life-threatening health conditions, they're forced to make the nearly 30-minute trip from their suburban home to Le Bonheur, located in downtown Memphis, almost every month. After Le Bonheur opened its new pediatric units inside Methodist Le Bonheur Germantown Hospital in early 2016, the Marcuzzos rested easier knowing that Le Bonheur doctors are now only a few minutes away from their home.

"Being a mom of a medically fragile child, we're blessed to have Le Bonheur in our backyard," Marcuzzo said. "For parents, it's important to know that they have a team from Le Bonheur nearby that's highly trained and can take care of your sick child."

Having a pediatric emergency department and inpatient unit in Germantown, one of Memphis' largest suburbs, is important to the community, as it provides children and parents who live in the eastern portion of Memphis' Shelby County fast access to Le Bonheur doctors, said Barry Gilmore, MD, medical director of Emergency Services at Le Bonheur Children's. The time saved can be life changing.

"Emergencies involving children are time sensitive," Gilmore said. "Having immediate access to advanced pediatric emergency care is critical to ensure the best outcomes."

Methodist Le Bonheur Germantown Hospital pediatric units include an eight-bed Emergency Department and a 12-bed inpatient unit. Le Bonheur pediatric hospitalists, emergency medicine specialists, nurses, child life specialists, respiratory therapists and social workers serve the units. So far, patient numbers have been high. In its first five months, the emergency department has seen more than 5,300 children, and more than 330 have been admitted. On average, patients are seen by a provider in less than 30 minutes.

Whitney Marcuzzo credits the new Germantown location for saving her son, Louie, who came to the emergency department in March when he had difficulty breathing and was wheezing. As soon as Louie arrived, Le Bonheur staff began breathing treatments on the 4-year-old.

"There were so many in the room that was focused only on us, and we felt like royalty," Marcuzzo said. "When your child is sick, you want to go where everyone knows what they are doing, and that's what I felt when we went to Germantown."

Lelon Edwards, MD, a community pediatrician with Pediatrics East in Germantown said the opening of the pediatric units at Methodist Le Bonheur Germantown Hospital not only helps reduce travel time for patients, but it's also comforting for parents like the Marcuzzos to know Le Bonheur's expert care is always nearby.

"Most illnesses and injuries sustained do not require the expertise of a regional pediatric hospital," Edwards said. "But it is very important to have that option available if the severity of illness warrants stepping up to the next level."





Louie Marcuzzo, 4, with mom, Whitney



Le Bonheur Children's Hospital in Memphis, Tenn., treats more than 250,000 children each year in regional clinics and a 255-bed hospital that features state-of-the-art technology and family-friendly resources. Our medical staff of more than 240 physicians provide care in 40 specialties.



LE BONHEUR LEADERSHIP

Meri Armour – President and CEO  
Jon McCullers, MD – Pediatrician-in-Chief  
James "Trey" Eubanks, MD – Surgeon-in-Chief  
Harris Cohen, MD – Radiologist-in-Chief



The primary pediatric teaching affiliate of the University of Tennessee Health Science Center, College of Medicine

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Seven-month-old Sawyer Dembicky was born with a segmental facial hemangioma. By the time she was 6 weeks old, the lesion had drastically grown and was threatening her vision. Read her story on page 8.

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# ON THE MARK

*Reshaping care for vascular anomalies*





*Sawyer Dembicky's segmental hemangioma was barely noticeable at birth – just a reddish discoloration of the left side of her face.*

**Sawyer Dembicky had the lesion when she was born** – then just a small, reddish mark on the left side of her face. A birthmark, her parents thought, or maybe bruising from labor and delivery. Her pediatrician called it a hemangioma. The Covington, Tenn., parents were told to keep an eye on it. It would eventually go away with time.

By the time Sawyer was 5 weeks old, the lesion had swollen, and a hard lump had begun to develop under her skin. The tumor continued to grow.

“It was red and purple, and you could see all these blood vessels,” said Amanda McCorkle, Sawyer’s mom. “Her eye started swelling shut. We wondered what was going to happen to her eyesight.”



The family was referred to Le Bonheur Children’s Hospital, where a team of specialists were in place and ready to handle Sawyer’s complex segmental hemangioma

and save her eyesight.

In just eight weeks, the lesion had grown behind her eye, slowly pushing it out of orbit and threatening Sawyer’s vision.

The hospital formalized its Vascular Anomalies Center in July 2015 to provide more coordinated care for patients like Sawyer with vascular tumors or malformations –

*Neuroendovascular Surgeon Lucas Eljovich, MD, co-director of the Pediatric Vascular Anomalies Center, reviews images of each patient to be seen in the Vascular Anomalies Clinic, which began July 2015. Patients have a “broad spectrum” of lesions, he says.*



lesions that are often misunderstood and take a team of multidisciplinary specialists to properly diagnose and treat.

## MORE THAN A BIRTHMARK

Vascular anomalies are not uncommon. Many children are born with some sort of vascular birthmark. In the past few decades, though,



*Eisleigh Bennett, 6 weeks, was diagnosed with a vascular malformation in utero. Read her story on page 11.*

# Classification of Common Vascular Lesions

Grouped into one of two categories — vascular tumors or vascular malformations — these complex lesions can be present on any area of the body. A classification system was developed by the International Society for the Study of Vascular Anomalies to aid in proper diagnosis of these anomalies.

## VASCULAR ANOMALIES

### Vascular Tumors

Benign

Locally aggressive or borderline

Malignant

### Vascular Malformation

SIMPLE	COMBINED
Capillary malformations	CVM, CLM
Lymphatic malformations	LVM, CLVM
Venous malformations	CAVIM
Arteriovenous malformations	CLAVM
Arteriovenous fistula	others

*Source: International Society for the Study of Vascular Anomalies*



*Six-week-old patient Eisleigh Bennett undergoes an ultrasound before her first sclerotherapy procedure for a lymphangioma that was diagnosed in utero.*

doctors have learned that sometimes there is much more to these birthmarks than meets the eye.

“The catch-all term that encompasses what we see is vascular anomalies, but it’s a very mixed group of lesions. There’s a broad spectrum,” said Lucas Elijevich, MD, a neuroendovascular surgeon with Semmes-Murphey and

a co-director of Le Bonheur’s Vascular Anomalies Center.

Caused by abnormally developing blood vessels, vascular anomalies can present on any part of the body and may be composed of veins, arteries, capillaries, lymphatic vessels or a combination. Few lesions can be cured – only managed through various treatment options that range from medical therapy to interventional or

procedural treatment, including embolization and sclerotherapy. Because they are so complex and treatment is often multimodal, these lesions almost always require multidisciplinary collaboration and treatment for the best possible cosmetic or functional outcome.



*Sawyer Dembicky, with mom Amanda McCorkle, follow up regularly for her segmental hemangioma. Sawyer’s care team has included Pediatric Dermatologist Teresa Wright, MD, (right) and an ophthalmologist, among others.*

Such was the case for Sawyer.

She needed the expertise of both a pediatric dermatologist and a pediatric ophthalmologist, who worked together to determine the best option for Sawyer’s segmental facial hemangioma and rule out any underlying syndromes



*Teresa Wright, MD, examines 14-year-old Kyran McFarland.*

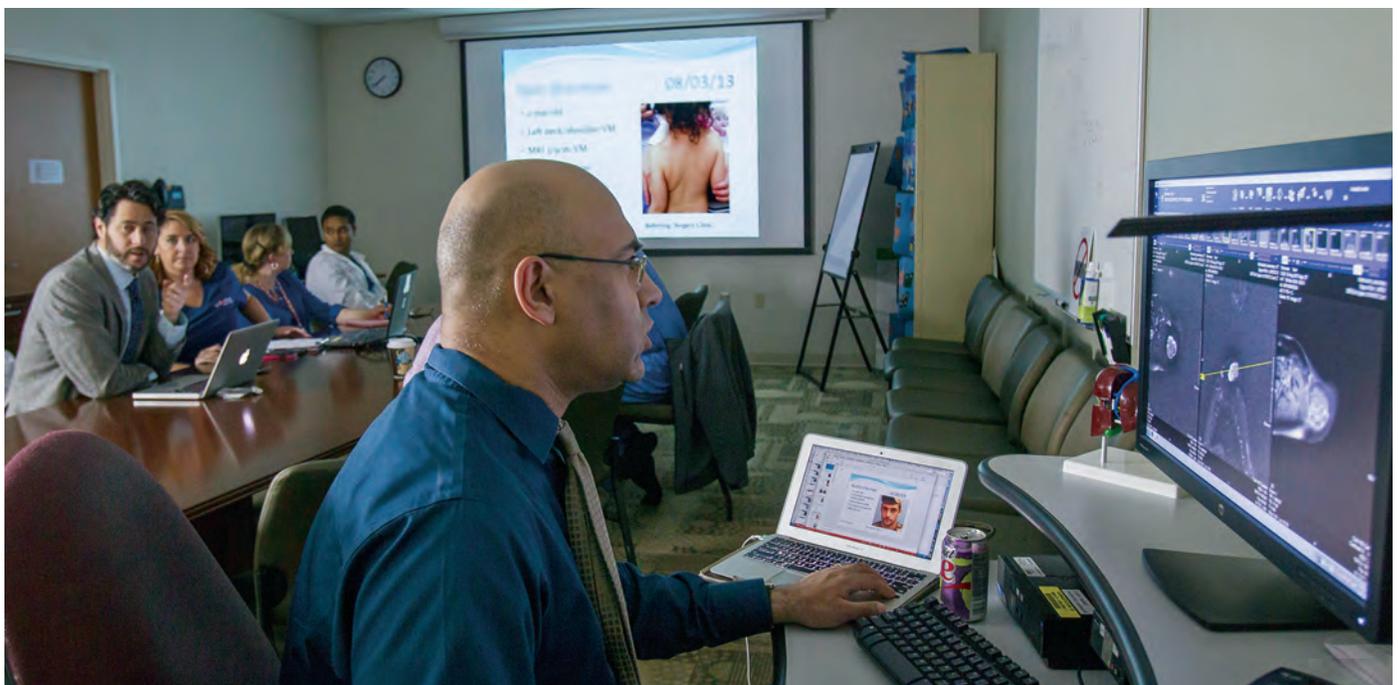
often associated with such lesions. And before she had even arrived in clinic, Sawyer's case was discussed

collaboratively by the entire Vascular Anomalies team – a group made up of subspecialists from eight hospital service lines.

## **A COLLABORATIVE APPROACH**

Bringing together a multidisciplinary team focused on managing these complex lesions has been the primary goal of the Vascular Anomalies Center. Crucial to that approach: a centralized clinic where patients can see all the specialists they need in one setting.

“Historically, it’s been hard to know where to send these patients. Kids might come in to different clinics as their entry point, and then it would be difficult to get all the specialists together needed to provide them with the

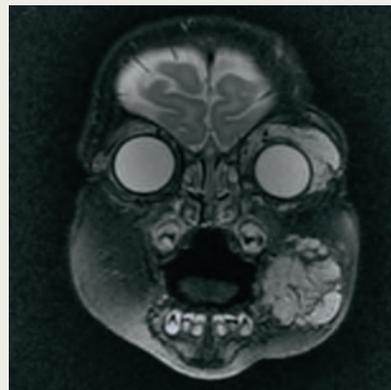


*Pediatric Neuroradiologist Asim Choudhri, MD, is an important part of the multidisciplinary Vascular Anomalies team. The team reviews images for each patient before clinic to discuss options.*

# Case Study: Sawyer Dembicky, 7 months

*Diagnosis: Segmental Facial Hemangioma*

*Treatment: Propranolol*



*Photos of Sawyer Dembicky, 8 weeks, show her segmental hemangioma at its worst. The MRI shows a multilobulated mass involving the left upper eyelid with retrobulbar extension. There is additionally large multilobulated mass in the cheek. An MRI shows the full extent of the masses, and their relationship to vital structures such as the eye, major arteries and veins of the face, and the airway, information which cannot be accurately determined by physical examination alone.*

By the time Sawyer Dembicky visited her pediatrician for her 6-week checkup, the facial hemangioma that was present at birth had drastically grown in size.

"It was red and purple, and you could all these blood vessels," said Amanda. "Her eye started swelling shut. We wondered what was going to happen to her eyesight."

Her pediatrician ordered an MRI, and results showed that the lesion had grown behind Sawyer's left eye and was pushing it forward, out of orbit. She was immediately referred to Le Bonheur's Vascular Anomalies Center, where the family met with Teresa Wright, MD, chief of Pediatric Dermatology, and Chris Fleming, MD, an ophthalmologist with Hamilton Eye Institute.

The physicians ordered additional imaging to rule out PHACE syndrome, a condition sometimes associated with segmental hemangiomas.

Sawyer was prescribed Propranolol, a beta blocker commonly used for hypertension. The drug was found to help reduce the size of infantile hemangiomas in 2008. Her parents noticed a drastic difference in just 24 hours.

Today, Sawyer's lesion continues to improve. Her swelling and hard spot under her cheek are gone, and her vision is the same in both eyes. She continues to follow up regularly in clinic.



*Sawyer's lesion has drastically improved. She follows up in clinic regularly to monitor her progress.*



Watch Sawyer's story – [www.lebonheur.org/promise](http://www.lebonheur.org/promise)



Program leaders Lucas Eljovich, MD, (left), Regan Williams, MD (center) and Teresa Wright, MD, see each new patient together in clinic. The group discusses options for Ella McCoy, 10 months, who was referred to the program for a lymphatic malformation.

best management plan,” said Teresa Wright, MD, chief of Pediatric Dermatology at Le Bonheur. Wright, who has spent much of her career treating vascular anomalies, was recruited to Le Bonheur in 2015 to help develop the Vascular Anomalies program.

The monthly Vascular Anomalies Clinic is regularly staffed by pediatric dermatology, pediatric surgery, pediatric plastic

surgery and two interventionalists. Other specialists, including pediatric orthopaedic surgeons, cardiologists,

hematologists/oncologists, ophthalmologists, interventional radiologists and otolaryngologists, come to the clinic as needed.

Specialists from Le Bonheur’s Fetal Center also come as

needed, as some patients’ vascular malformations are diagnosed prenatally. Patients’ care is coordinated

*“We tell the families, ‘We’ve seen your child’s imaging. We’ve all discussed your child’s case. Here’s what you’re dealing with. Here’s what we think we should do.’”*

Regan Williams, MD

## MEET THE TEAM

### LEADERSHIP



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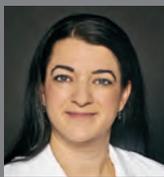


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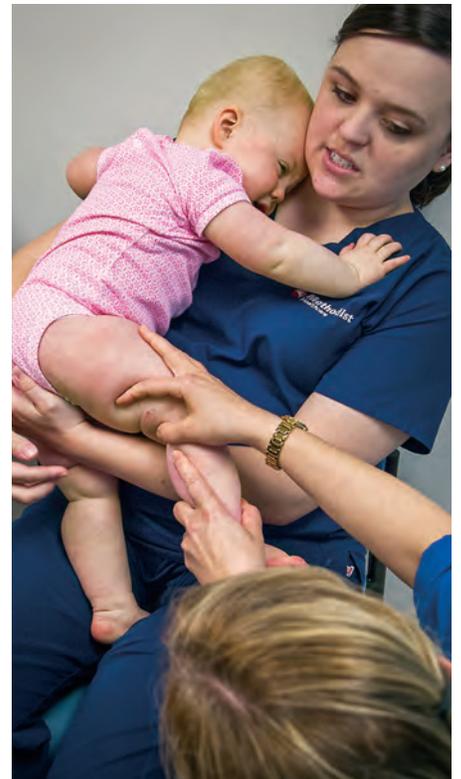
**Natasha Winders, RN**  
 Clinic Coordinator,  
 Vascular Anomalies Center,  
 Le Bonheur Children's Hospital

by a nurse coordinator who helps  
 schedule patients' clinic or procedure  
 appointments and guide families  
 through the process.

In the morning of clinic, every  
 subspecialist gathers for a conference  
 to discuss each patient on the schedule.

The physicians review all of the  
 patients' imaging and collaborate.

“Everybody sees an image of the  
 patient that's been sent over by the  
 parent. Everybody looks at the imaging,



*Claire Watson, 1, visits the Vascular Anomalies Clinic for a deep hemangioma. One in 10 babies is born with a hemangioma; half of those will require some sort of treatment.*

# Case Study: Eisleigh Bennett, 6 weeks

## Prenatal Diagnosis: Lymphangioma

### Treatment: Sclerotherapy

so it's not just one of us making an assessment," said Pediatric Surgeon Regan Williams, MD, co-director of the program. "And then we talk about the treatment options. What are the risks and benefits of those options? Sometimes we have friendly disagreements, but we really want to be able to give the parents all the information and all the options."

This focused, collaborative approach has allowed the Pediatric Vascular Anomalies team to not only weigh all of the treatment options for patients and families – but also to give them an accurate diagnosis and education on their child's condition. The broad spectrum of

Kaylee Switcher of Corinth, Miss., knew what to expect. Her daughter, Eisleigh, had been diagnosed with a lymphangioma in utero at 32 weeks. She met weekly with a maternal fetal medicine specialist at Le Bonheur's Fetal Center until delivery, where she also consulted with members of the Vascular Anomalies team.

When she delivered Eisleigh on April 3 at 38 weeks, the benign mass on the left side of her neck was there.

The family followed up in the Vascular Anomalies Clinic when Eisleigh was 2 weeks old and again four weeks later. By that time, the malformation had drastically grown. She underwent her first sclerotherapy session in May and a second in July. For each sclerotherapy treatment, Neuroendovascular Surgeon Lucas Elijevich, MD, co-director of the Vascular Anomalies Center, injects sclerosant, doxycycline, that will cause inflammation and subsequent scarring and collapse of the cyst.



Eisleigh Bennett, 6 weeks, with mom, Kaylee



Learn more about Eisleigh's story  
– [www.lebonheur.org/promise](http://www.lebonheur.org/promise)



Coronal image from MRI shows the extent of the macrocystic lesion that involves the left neck and posterior chest wall.



Corresponding MR angiographic view shows the relationship to surrounding vascular structures to help guide safe treatment.

vascular anomalies sometimes makes proper diagnosis a challenge.



*Patient Eisleigh Bennett, 6 weeks, undergoes her first sclerotherapy procedure performed by program Co-Director Lucas Eljovich, MD. Sclerotherapy injects a medication directly into the lesion to shrink it.*

“We’ve seen many frustrated families who’ve been told multiple different things from multiple different people and don’t really know what to do and or who was right,” said Williams. “If you’ve been told your child has an infantile hemangioma, and it’s going to go away, but then it starts to grow, it can be really concerning for families.”

When a new patient is seen in clinic, the core group of specialists visits the patient at once.

“We tell the families, ‘We’ve seen your child’s imaging. We’ve all discussed your child’s case. Here’s what you’re dealing with. Here are your options,’” said Williams.

## **Case Study: Cody Mitchell, 15**

**Diagnosis: Left Peri-orbital Lymphatic Malformation**  
**Treatment: Sclerotherapy**



*Pre-op*



*Post-op*

Cody Mitchell was 8 years old when a small lump the size of a pencil eraser first showed up on the inside corner of his left eye.

“He just woke up with it one morning,” said mom Candice Mitchell. “We thought maybe something had ruptured. We just didn’t know.”

The Mitchells were referred to a local oncologist who diagnosed him with a left peri-orbital lymphatic malformation, a benign vascular lesion. Because the lesion was asymptomatic, immediate treatment at that point was unnecessary.

By 2015, the lesion was starting to grow and was beginning to hinder his vision. Cody was referred to the Vascular Anomalies Center at Le Bonheur Children’s Hospital.

In June 2015, he received a sclerotherapy treatment to shrink the malformation. Since then, he’s had no issues, and the malformation remains unnoticeable.

Parents like Amanda McCorkle appreciate that kind of approach.

“It felt so good to know that all these doctors knew about my child and had talked about what to do,” said Amanda. “When that many people come together just for your baby, it just makes you relieved.”

## MEASURING OUTCOMES, QUALITY OF LIFE

With a coordinated program and centralized clinic in place, Le Bonheur’s Vascular Anomalies program is also focusing on measuring patient outcomes. Patient diagnoses are entered into a database, and outcomes are tracked.

“We’re following patients who’ve received treatment to see how the lesion is responding. We want to determine the best possible way to treat these vascular anomalies,” said Elijevich, who specializes in embolization

and sclerotherapy, a procedure that injects a medication directly into the lesion to cause inflammation that allows the lesion to scar and collapse.

The team is also focused on patients’ quality of life, collecting data through patient surveys to determine which therapies are associated with better or worse quality of life.

“Our whole program is really focused on a good experience for families and doing what’s best for them,” said Elijevich.



*Eisley Parker, 4 months, was referred to the program for a hemangioma with concern for airway compression.*

**MAGNET  
RECOGNIZED**



**AMERICAN NURSES  
CREDENTIALING CENTER**

# Badges of Honor

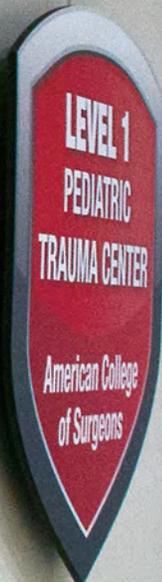
**W**hen Le Bonheur celebrated the hard-earned honor of achieving ANCC Magnet designation this spring, hospital staffers reveled in more than just a badge they could hang on the wall.

The real win for Le Bonheur and its families: increased use of evidence-based practices,

more highly trained and educated nurses and a more deliberate approach to quality improvement that improved outcomes for patients. Leaders say the designation was proof of a cultural shift that has permeated across physician faculty and clinical staff in the past several years – proof that this once community children’s hospital is

set on becoming a regional and national leader in pediatric care.

In the past seven years, Le Bonheur has added more than one badge to its hallways. It has been named a Best Children’s Hospital by *U.S. News & World Report* for six consecutive years, ranked in seven specialties for 2016-2017.



Last year, the hospital was re-designated as the region's only American College of Surgeons Level 1 Pediatric Trauma Center. And this past spring, the American Nursing Credentialing Center designated Le Bonheur a Magnet hospital – a designation only 7 percent of hospitals in the country hold.

“We use these processes as a way to improve the care we offer children,” said hospital President and CEO Meri Armour. “It is our responsibility as health experts to give our children every opportunity to grow up healthy and strong. We are committed to excellent clinical care, investigating the causes of our region's most pressing

care. “The steps we have taken on our Magnet journey have pushed us to be even better versions of ourselves,” she said.

Nursing Administrative Director Paula Dycus, DNP, RN, CPHQ, NEA-BC, meanwhile, can churn off a list of improvements that hospital staff has made as a result of the Magnet process: improved safety measures like lower catheter-associated urinary tract infection and central line-associated bloodstream infection rates, as well as decreasing device-related pressure injuries in critical care units.

The level of nursing education and national board certification rates – along with nursing satisfaction – has also dramatically increased in the past six years, a result of the push to become a Magnet-designated facility.

“Nurses are using evidence-based practice to improve patient outcomes and the nurse work environment,” Dycus said.

Le Bonheur Quality Director Donna Vickery also believes that work toward national designations creates higher engagement in quality projects among nurses.

“We already had strong quality initiatives, but this added more awareness for front-line nurses of what they do – and how it is related to quality,” Vickery said.

Similarly, in Le Bonheur's Heart Institute, registration in a handful of national quality and safety collaboratives – like The Society of Thoracic Surgeons and Children's Hospitals' Solutions for Patient Safety National Children's

Network (a hospital-wide initiative) – has helped clinicians benchmark themselves against other hospitals and join a larger discussion about making pediatric medicine safer.

The Heart Institute also is active in specific collaboratives that study conditions like hypoplastic left heart syndrome or even cardiac intensive care medicine. Membership in registries and collaboratives like these have helped establish practices that Le Bonheur didn't have



*Le Bonheur educators provide trauma training for nearly 30 adult facilities in the region, an added benefit of its push to become an American College of Surgeons Level 1 Pediatric Trauma Center.*

health problems and teaching the next generation of health professionals.”

## A BEST PRACTICE

Chief Nursing Officer Nikki Polis, PhD, RN, says the hospital's Magnet designation is an “ultimate credential for high-quality care” that families rely on. More than that, it is proof the staff is committed to a higher level of

before, leaders say.

A push to raise the game in the hospital's trauma care has also had unexpected benefits, said Trey Eubanks, MD, medical director of Trauma Services and surgeon in chief at Le Bonheur. In 2011, Le Bonheur began pursuing and later obtained American College of Surgeons (ACS) Level 1 Pediatric Trauma verification.

"Not only did it set us on par with every other pediatric trauma center, it made us raise our game," Eubanks said.

Today, thanks to the pursuit of the ACS designation, anesthesiology is in house 24/7, and the Emergency Department and operating rooms have specialized refrigerators that provide immediate access to blood products. Efforts are better coordinated throughout the hospital from the moment the patient arrives in the ED, to CT scan, to OR, to inpatient room.

Outside the hospital, Le Bonheur educators work with 28 adult facilities in the region to provide mock trauma codes, following up with training after a patient has been transferred – and serving as a 24-hour resource to that adult facility.

## CULTURE SHIFT

Hospital CEO and President Armour says that since the hospital's first national *U.S. News* ranking six years ago as a Best Children's Hospital hospital employees are prouder and sense the they are doing something extraordinarily different and important.

As a result of the Magnet journey, nurses have implemented a shared governance culture among themselves and are much more involved about decisions involving their work. In turn, nurse satisfaction is



*Le Bonheur's application for ANCC Magnet status improved clinical care across all levels of the hospital, nursing leaders say.*

dramatically higher, Dycus said.

The clout of staying on the list has also helped all Le Bonheur clinical and physician leaders recruit and retain top talent. In the past six years, Le Bonheur has recruited more than 100 new physicians – including a pediatrician-in-chief who also serves as the chair of the

Department of Pediatrics at the University of Tennessee Health Science Center and sought-after experts in fields like pediatric heart failure, pediatric cardiovascular surgery, tuberous sclerosis and pediatric obesity medicine.

Heart Institute Executive Co-Director Jeffrey Towbin, MD, joined Le Bonheur in 2015 because he wanted to help build "nationally recognized destination program with world-class expertise," he said. He saw the chance to expand his growing field and develop new areas of care – based on a foundation that had already been established.

The ability to recruit and keep talent – both among physicians and clinical staff, is just another benefit to the badges on the wall.



*Le Bonheur Heart Institute Executive Co-Director Jeffrey Towbin, MD, above left, joined the hospital last year because he saw an opportunity to build a nationally recognized destination heart program. Le Bonheur's ranking as a top-tier hospital has helped with recruitment and retainment.*

# Back to Le Bonheur

*Heart Surgeon Umar Boston, MD, leads growing transplant program*

When Umar Boston, MD, talks about his plans for building Le Bonheur Children's Hospital's heart transplant program, he is grateful that children suffering from heart failure can undergo heart transplantation here in Memphis without having to travel to other parts of the country.

That dream is what led him back to Le Bonheur Children's Hospital.

Boston, a pediatric cardiovascular surgeon, recently became Le Bonheur's surgical director of the Heart

Transplant and Mechanical Circulatory program and surgical director of the hospital's Adult Congenital Heart Disease program. He trained at the Mayo Clinic and began his career at Le Bonheur in 2006, before leaving for St. Louis in 2012, where he worked in the



Surgical Director of the Heart Transplant and Mechanical Circulatory program, Le Bonheur Children's Hospital



Surgical Director of the Adult Congenital Heart Disease program, Le Bonheur Children's Hospital

heart failure and heart transplantation program at Washington University. Boston returned to Le Bonheur in late 2015 to help develop the hospital's heart transplant program.

Coming back to Le Bonheur to build hospital's heart transplantation program was "an opportunity of a lifetime," Boston said. That opportunity, and the chance to work with prominent physicians like Chief of Cardiovascular Surgery Chris Knott-Craig, MD, and Chief of Cardiology Jeffrey A. Towbin, MD.

One of Boston's first goals is to build the infrastructure of the transplant

program, as well as to expand the number of physicians, nurses and staff.

Boston's extensive work, leadership and experience in heart transplantation will be vital to the program's success, said Towbin, who also serves as executive

co-director of the Heart Institute, along with Knott-Craig. Boston also is one of the best in his field, Towbin added.

“Dr. Boston is a highly experienced pediatric heart surgeon with special long-term interests, experience and expertise in heart transplantation, mechanical circulatory support and adult congenital heart disease. He also has expertise in congenital heart disease surgery of neonates and children,” Towbin said. “In order to develop elite heart failure, transplant and adult congenital heart disease programs, a top surgeon makes a huge impact.”

And making that impact will help hundreds of cardiac patients per year. Since 2009, Le Bonheur doctors have performed more than 350 cardiovascular procedures each year, and the

survival rates for most of those procedures are higher than Society of Thoracic Surgeons’ national averages.

While advancing the transplant program at Le Bonheur, Boston also plans to assist in recruiting three additional heart transplant cardiologists to the hospital’s nationally recognized Heart Institute. Providing expert heart care for children is what inspires Boston and is the motivation for his research.

“I like dealing with children, and I like being able to make a difference in a child’s and their family’s life on a daily basis,” Boston said. “It’s a very tangible feel in that you are working to fix a problem, and sometimes you have to come up with very creative means of fixing a problem. I find that exciting and challenging.”

*“Dr. Boston is a highly experienced pediatric heart surgeon with special long-term interests, experience and expertise in heart transplantation, mechanical circulatory support and adult congenital heart disease. He also has expertise in congenital heart disease surgery of neonates and children. In order to develop elite heart failure, transplant and adult congenital heart disease programs, a top surgeon makes a huge impact.”*

Jeffrey A. Towbin, MD  
executive co-director of the Heart Institute

## Umar Boston, MD

### Education and Training

- University of Toronto – (B.S. 1987-1991)
- Howard University – (M.D. 1991-1995)
- Mayo Clinic – General Surgery Residency (1995- 2002)
- Mayo Clinic – Cardiovascular Research Fellow (1997-1999)
- Mayo Clinic – Cardiothoracic Residency (2002-2005)
- Mayo Clinic – Chief Resident in Cardiothoracic Surgery (2004-2005)
- University of Alberta – Fellowship in Pediatric Cardiac Surgery (2005-2006)

### Recent Experience

- Surgical Director, Heart Transplant and Mechanical Circulatory Support, Le Bonheur Children’s Hospital
- Surgical Director, Adult Congenital Heart Disease Program, Le Bonheur Children’s Hospital
- Associate Professor, University of Tennessee Health Science Center



# Threads of Care

**B**ethany and Jonathan Chu never wanted Le Bonheur Children's palliative care team to visit their twin daughters' hospital room.

The Chus, whose daughters, Penny and Lydia, were born three

months premature, were terrified every time they saw the Palliative Care team walking the halls. Bethany and Jonathan said the team "felt like the angels of death."

"My first impression was, 'I hope

they never come and see me,'" Bethany said.

But those fears quickly subsided after a consultation with Palliative Care Medical Director Melody J. Cunningham, MD. The Chus benefitted

*(Above) Penny and Lydia Chu cuddle with Palliative Care Medical Director Melody J. Cunningham, MD, when the twins came back to Le Bonheur for a visit. The Chus are "graduates" from the hospital's Palliative Care program.*

from Le Bonheur's growing program, called Threads of Care, which helps guide families through their child's extended hospital stays by providing specialized medical care for those with chronic or complex illnesses, giving guidance and advice and planning long-term care and support.

Bethany and Jonathan sought support and advice from Threads of Care until both their daughters were finally home and "graduated" from the program. Lydia was hospitalized for two months because her underdeveloped lungs made it difficult for her to breathe. Penny was in the NICU for 10 months and was fitted with a ventilator and a G-tube and was under 24-hour nursing care. The Memphis couple credits Le Bonheur's palliative

care program with guiding them through their daughters' extensive hospital stays.

"For the team to come in and guide us through this was the difference between a terrible memory and a really treasured time where we were able to make the best decision for our children," Bethany said.

*"The most common myth is that we only take care of patients at the end of their life and we're the equivalent of hospice, and that's definitely not true. We follow many of our patients for years."*

Melody J. Cunningham, MD  
medical director of Palliative Care

In less than a decade, Le Bonheur's Threads of Care program continues to expand its program and further its goal of helping children like Penny and Lydia who are living with



*Palliative Care Medical Director Melody J. Cunningham, MD, leans in and visits with one of her patients during her daily rounds.*



life-threatening or chronic illnesses.

## *Dispelling palliative care myths*

Nationally, the number of palliative care programs continues to grow. According to a study by the Center to Advance Palliative Care, 67 percent of hospitals with 50 or more beds have a palliative care program.

As of 2014, the latest numbers, 400 hospitals have registered with the National Palliative Care Registry, but only 1.3 percent focus solely on pediatric patients. Launched in 2005, Le Bonheur Children's program is one of only three pediatric palliative care programs in Tennessee. The team was named Threads of Care to underscore the breadth of its service. The team sees patients in the hospital, clinics and homes in order to try to "stitch

the pieces of care together," says Cunningham.

Since its inception, the Threads of Care team has seen substantial growth in the number of patients they see each year. Cunningham said the team counseled approximately 250 children and their families in 2015, and in 2016, the team's on pace to see about 350.

While Threads of Care has seen steady growth in the last 10 years, Cunningham said pediatric palliative care is often misunderstood among families and physicians, with many believing her field of medicine only deals with the death of a child.

"The most common myth is that we only take care of patients at the end of their life, and we're the equivalent of hospice, and that's definitely not true," Cunningham said. "We follow many of our patients for years."

Although the team does handle end-of-life decisions with families,

the team's primary goal is to provide medical advice and support, said Threads of Life Program Coordinator Joanna A. Lyman, MA, CCLS. The Threads of Care team also aims to help coordinate a cohesive line of communication between Le Bonheur doctors, patients and their families.

"We're often asked to help (families) think through very difficult medical decisions and to be a sounding board for them as they are consid-

ering their options," Lyman said. "Very often we're an extra layer of support for a family that's walking a very difficult road and who needs additional support, ideas and comforts.

Providing that extra layer of support has been a comfort for Memphis residents Angela and Radale Pearson, whose son, Eric, has been in Le Bonheur's NICU for more than a year. Born at only 27 weeks, Eric weighed only 1 pound 1 ounce at

birth and suffers from chronic lung disease, pulmonary hypertension and pulmonary vein stenosis.

The Threads of Care team helped Angela and Radale understand and cope with their son's complicated medical conditions. Although Eric has graduated from Le Bonheur's NICU and remains in the hospital, the Pearsons said the Threads of Care team has provided the couple with hope that one day their son will go home.

*Before making its daily hospital rounds, the Palliative Care team meets with Le Bonheur doctors to discuss patient care and needs.*



## Continued support

When a child leaves Le Bonheur, the Threads of Care staff remains in contact with families. A team member calls families two and seven days after discharge for brief check-ups and provides parents with a list of phone numbers to use for concerns. In addition, Palliative Care makes home visits when necessary and sees patients in subspecialty follow-up clinic appointments.

If a child dies, the team will remain in contact for two years, and families are invited back to Le Bonheur for consultations to discuss any questions they have and to meet with their child's medical team.

"Almost all the families want to come back for clarity. They want their questions answered," Cunningham said. "There are some who don't want to come back for a medical confer-



Angela and Radale Pearson give Palliative Care Medical Director Melody J. Cunningham, MD, a hug when she stopped by their son's room.

ence, but they want to simply come back on the anniversary of the loss of their child so they can remember their child with us."

Building and maintaining a relationship with families is vital to the program's success, Lyman said, as is having an open line of communication between physicians, Threads of Care team members and their patients.

And that communication and support provided by the Threads of Care team is what Angela and Radale

Pearson rely on. Both said Eric's care at Le Bonheur has helped the 1-year-old to a better quality of life, and after extensive physical therapy, he's learning to sit up and is slowly growing stronger.

"I don't think my child would be to the point where we can talk about going home with him without Threads of Care," Angela said. "We needed a team to hear our side of the story, and Palliative Care was the glue that stuck it all together and made the puzzle complete."

## Le Bonheur named a Best Children's Hospital by U.S. News



Le Bonheur Children's Hospital has been named a Best Children's Hospital by *U.S. News & World Report* for the sixth consecutive year. The 2016-2017 lists were released on June 21, 2016.

"The U.S. News designation is further proof that Le Bon-

heur provides world-class pediatric health care to children in Memphis, the region and the country. This badge means that parents can trust that our experts work every day to be one of the best children's hospitals in the country," said President and CEO Meri Armour. "We use the *U.S. News* survey standard as a tool to continually advance the level of our pediatric care. We are honored that Le Bonheur has been recognized seven of the nine categories in which we could apply."

## Le Bonheur names Genetics chief

Chester Brown, MD, PhD, recently joined Le Bonheur as the Genetics Division chief. He will also serve as professor with the University of Tennessee Health Science Center. Brown comes to Memphis from Baylor College of Medicine where he served for 20 years as a faculty member in the departments of Molecular and Human Genetics and Pediatrics, and as training faculty in the Graduate School of Biomedical Sciences. He has spent much of his career focused on studying how genes control lean and fat body mass and more recently has studied how host genomic factors influence HIV and tuberculosis progression in African children, while training African scientists to carry out such studies independently.



Chester Brown, MD, PhD

Brown received his bachelor's degree from Howard University, and his medical and PhD degrees from the University of Cincinnati College of Medicine. He completed his pediatrics residency and medical genetics fellowship at Baylor College of Medicine.

## Heart Institute earns top quality rating

Le Bonheur's Heart Institute again received the highest possible rating, three stars, from The Society of Thoracic Surgeons (STS) in the Spring 2016 STS Congenital Heart Surgery Database Feedback Report. The STS Congenital Heart Surgery Database compiles data from pediatric heart programs across the country and publishes surgical outcome information twice a year. Participating programs receive a one- to three-star rating semi-annually.



## Le Bonheur to build new outpatient center in Jackson, Tenn.

Le Bonheur Children's Hospital recently announced plans to build a new outpatient center in Jackson, Tenn. The 30,000-square-foot facility, expected to open Fall 2017, will feature nine subspecialty clinics, 20 exam rooms, diagnostic services including X-ray, ultrasound, EKG, EEG, ECHO and pulmonary function testing, as well as a telemedicine link to Le Bonheur's downtown Memphis campus to allow access to even more subspecialists at Le Bonheur.



## Study finds controlled breathing affects brain functions

**S**low, deep breathing positively influences cognition, according to a recent study conducted by researchers at Le Bonheur Children's Hospital, University of Tennessee Health Science Center (UTHSC) and University of Memphis.

Results were published in the February 2014 edition of *Nature Communications* and in *bioRxiv* (049007) in 2016.

"When you take a breath, a lot of things happen. You trigger your olfactory senses but you also stretch your lungs, you stretch your skin, your intestines slightly move," said Primary Investigator Detlef Heck, PhD, associate professor in the Department of Anatomy and Neurobiology at UTHSC. "All of these things trigger sensory inputs in the brain, and those are the things that cause the change of activity in the brain. All these sensations are linked to respiration."

Researchers used mouse models and electrocorticography (ECoG) in humans to measure respiration's influence on brain activity. Results showed that controlled respiration affects brain activity known to be involved in performance cognitive brain function.

These findings provide the first possible neuronal explanation for how controlled breathing provides stress relief, reduces pain reception and generally affects cognitive function.

Understanding the link between respiration and brain activity will be beneficial for patients with neurological disorders such as epilepsy, Heck said.

"It has major implications because if our results are true, it means all the imaging experiments that doctors do should include measuring breathing," he said. "If you ignore breathing, you are ignoring a major source of variability in your data. It will change fundamentally the way imaging studies are done."

Heck performed these studies in close collaboration with James Wheless, MD, and Andrew Papanicolaou, PhD, co-directors of Le Bonheur's Neuroscience Institute.

