

DELIVERING ON A PROMISE



A Devastating Diagnosis

Le Bonheur launches Infantile Epilepsy Center



Le Bonheur Neurosurgeon wins CNS Pediatrics Paper of the Year for 2nd consecutive year

Le Bonheur Neurosurgeon Paul Klimo, MD, MPH, was awarded the Pediatrics Paper of the Year by the Congress of Neurological Surgeons (CNS) during the annual meeting in San Francisco, Calif., for the second year in a row. The paper, “The Preventable Shunt Revision Rate: A Multicenter Evaluation,” was published in *Neurosurgery* in March 2019.

The Preventable Shunt Revision Rate (PSRR) was introduced in 2016 as a quality metric to determine which shunt failures were avoidable. Shunt surgery is the most common procedure performed in neurosurgery, and shunt malfunction is the second most common cause of rehospitalization in children.

“PSRR goes directly to the heart of the current quality movement in health care,” said Klimo. “Quality metrics

lead to the implementation of processes to avert negative consequences and maximize positive results.”

The paper evaluated two years of consecutive shunt operations data from nine participating centers in North America to determine the PSRR across institutions as well as the most common etiologies that lead to shunt failure. Of the 5,092 shunt operations performed, 861 failed within 90 days, an overall failure rate of 16.9%.

Of the 861 failed shunts, 307 were determined to be potentially preventable – an overall 90-day PSRR of 35.7%. Preventability was defined as cerebrospinal fluid (CSF) infection, wound breakdown or infection, suboptimal position of the proximal or distal catheter or an improperly assembled or inadequately secured shunt that resulted in postoperative



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 45 subspecialties.

LE BONHEUR LEADERSHIP

Michael Wiggins, MBA, FACHE – *President*
Jon McCullers, MD – *Pediatrician-in-Chief*
Barry Gilmore, MD, MBA – *Chief Medical Officer*
James "Trey" Eubanks, MD – *Surgeon-in-Chief*
Harris Cohen, MD – *Radiologist-in-Chief*
Kathleen Seerup, BSN, MSHA, RN, NE-BC – *Chief Nursing Officer*



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

disconnection, migration, kinking or obstruction. The most common etiologies of preventable failure were shunt infection, malposition of the proximal catheter and judgment errors.

The study showed that a significant proportion, approximately one third, of early shunt failures are preventable. The paper suggests that the overall shunt infection rate for any major children's institution should be 5% or less. Predictors of preventable failure included lack of endoscopy, recent shunt infection, shunt type and participating center.

"Direct involvement and oversight by staff is critical and can help reduce the risk of all causes for preventable shunt failures," said Klimo. "PSRR allows practitioners and institutions to identify areas that may be improved such as investing in image guidance technology, implementing a shunt surgery checklist and reaching out to general surgeons to assist in accurate distal catheter placement."

Future efforts with PSRR include creating a real-world registry as well as re-evaluating centers that have implemented changes in an effort to lower PSRR.

Klimo also won the CNS Pediatrics Paper of the Year in 2018 for his research on survival rates for pineoblastoma tumors.

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A DEVASTATING DIAGNOSIS

Le Bonheur launches Infantile Epilepsy Center

When 14-month-old Westin's head began dropping unexpectedly, his mom, Jennifer Hopper, knew she was watching more than just infant reflexes.

"I had a gut feeling that something wasn't right," said Jennifer. "I knew that infantile spasms was the worst case scenario for Westin."

After several days of these movements, Jennifer took her son to the Emergency Department at Le Bonheur Children's Hospital. Within 24 hours Westin was diagnosed with infantile spasms – a type of infantile epilepsy that can wreak havoc on a child's development.

Le Bonheur's Neuroscience Institute recently launched the Infantile Epilepsy Center



Pediatric Epileptologist and Assistant Professor of Pediatrics, University of Tennessee Health Science Center, Sarah Weatherspoon, MD, (right) conducts a follow up visit with patient Mia Lorino.

to help children like Westin get a quick diagnosis and individualized, multidisciplinary treatment. Thanks to this approach, early intervention is saving the lives of infants and improving their developmental outcomes.

MORE THAN JUST SMALL KIDS

Infantile epilepsy is a group of rare seizures that typically affect children younger than 2 years old. The seizures typically present as small involuntary movements, crunches or spasms and require a rapid diagnosis to curb

potential developmental delays.

“Infants are not just small children,” says Pediatric Epileptologist and Director of the Infantile Epilepsy Center, Sarah Weatherspoon, MD. “Infantile epilepsy requires specific techniques, diagnostics and treatments.”

As the only Infantile Epilepsy Center in the Southeast and one of only three centers dedicated to the condition in the country, Le Bonheur’s standardized approach provides efficient and rapid access to expert care. Infants with suspected epilepsy are quickly admitted for monitoring,



Le Bonheur’s Infantile Epilepsy Center is the only center in the Southeast and one of only three in the country.

diagnosis and treatment.

When children enter the center, they see a wide array of experts. These include members of the Neuroscience Institute such as pediatric epileptologists, pediatric neuroradiologists who interpret brain imaging studies, neuropsychologists for neurodevelopmental assessments and a neuro-ophthalmologist.

Care for these infants may even extend into a wider range of disciplines than neuroscience – general pediatricians, geneticists, as well as clinical nutritionists and speech therapists to monitor feeding and growth.

“In order to find the underlying etiology of an epilepsy, it is important to provide state-of-the-art neuroimaging and genetic testing. We are trying to consolidate our resources so that every patient has access to what they need.”

Sarah Weatherspoon, MD, Director of the Infantile Epilepsy Center

With these resources, the Infantile Epilepsy Center is able to provide for the whole child and address the spectrum of ways their health has been impacted by infantile epilepsy.

“In order to find the underlying etiology of an epilepsy, it is

important to provide state-of-the-art neuroimaging and genetic testing,” says Weatherspoon. “We are trying to consolidate our resources so that every patient has access to what they need.”

AN EARLY DIAGNOSIS

Westin Hopper’s diagnosis of infantile spasms is a

Infantile spasms typically:

- Are small, involuntary movements such as a drop of the head, arms curling inwards or arms flailing outward
- Occur between ages 4-12 months
- Do not appear to be severe
- Only last a few moments
- Occur in clusters of five to 10 in a row
- Happen when going to sleep or waking up
- Occur daily



condition which Weatherspoon often sees only after it has gone untreated for much too long.

“Unfortunately, many children are not diagnosed with infantile spasms until their brains have been severely impacted,” says Weatherspoon. “They need to be evaluated and initiate treatment within a week of when their spasms start.”

Infantile spasms typically arise between the ages of 4 to 12 months. These seizures are small and seemingly innocuous. While they don’t have the visual impact of a tonic-clonic seizure, these spasms have a large impact on development. Each week of untreated spasms leads to permanent worsening in development.

The Infantile Epilepsy Center has a variety of resources to ensure early diagnosis. Infants require an electroencephalogram (EEG), a brain wave test,



Infantile Epilepsy Center



59%
*patients from
out of state*



105 miles
*average distance
patients travel to
Le Bonheur*

Meet the Infantile Epilepsy Center Team



Sarah Weatherspoon, MD
Pediatric Epileptologist
Director of the Infantile Epilepsy Center



Amy Patterson, MD
Pediatric Epileptologist



Christen Holder, PhD
Neuropsychologist



Lauren Ditta, MD
Pediatric Neuro-ophthalmologist



Asim F. Choudhri, MD
Pediatric Neuroradiologist



Roozbeh Rezaie, PhD
Clinical Neuroscientist

Lindsay Walsh, MS, RD, CSP, LDN, CLC
Ketogenic Dietitian

Amy Claire Petro, MS, CCC-SLP
Speech Therapist

in order to assess their brain activity and determine the type of seizure or event in order to choose the most appropriate treatment.

Following an EEG, an infant may undergo further testing from the Neuroscience Institute's suite of imaging modalities including a 3T MRI, magnetoencephalogram (MEG), transcranial magnetic stimulation (TMS) and functional MRI (fMRI). These diagnostic tests allow pediatric epileptologists to localize brain lesions, determine the source of the seizures and assess an infant's critical motor and language functions.

Fortunately for Westin, quick diagnosis preserved his motor and verbal development.

"Most children with infantile spasms are passed over in ERs and pediatrician offices," says Jennifer. "Thanks to the team from Le Bonheur, we have a little boy who continues to improve developmentally."

Caught quickly, treatment options can stop infantile epilepsy in its tracks. The treatment consists of adrenocorticotrophic hormone (ACTH) and vigabatrin, often used in combination. With these medications, spasms can disappear in as little as a few days. The Infantile Epilepsy Center also uses other treatments such as ketogenic diet and epilepsy surgery to help control infantile epilepsy.

IMPROVING OUTCOMES

Le Bonheur's outcomes for infantile epilepsy continue to improve, thanks to early detection and individualized therapies.

Of the patients with infantile spasms

who were treated with a combination of ACTH and vigabatrin, 91% were spasm free at two weeks and 73% were spasm free after six months.

“Time to treatment makes a huge difference in long-term outcomes,” says Weatherspoon. “Anything that shortens this time is critical for positive outcomes for development and seizure relief.”

One of Weatherspoon’s goals is to continue education for families and pediatricians around the country of the effects of infantile epilepsy so that infants are diagnosed faster. Babies change, and their development can deteriorate rapidly. If families know what to look for and doctors know how to recognize it and refer appropriately,

the treatment process for infantile epilepsy will flow smoother and quicker.

Westin Hopper is just one child who has benefited from the Infantile Epilepsy Center’s efforts for early diagnosis and treatment. Although his verbal development is still in progress, he is making strides in his physical, occupational and speech therapies.

“With a rare diagnosis like Westin’s, we were grateful to have a team providing a variety of options and answers,” says Jennifer. “Because of correct tests and treatments, we have a little boy who you can’t tell has infantile spasms.”



Le Bonheur’s new Infantile Epilepsy Center is helping children younger than 1 battle epilepsy, when diagnosed early. Above, Epileptologist and Assistant Professor of Pediatrics, University of Tennessee Health Science Center, Amy Patterson, MD, treats LeJend Ford.

Marty Smiley, Huntsville, Ala. | Time to treatment: 10 months

Before Danielle Smiley ever met her adopted son, she knew he was going to be special.

"I fell in love with him the first time I was asked to come hold him in the NICU," said Danielle. "Love had already begun before I could even see him. When I met that beautiful sweet boy, it was instant connection."

Marty was 3 weeks old and recovering in a Huntsville, Ala., neonatal intensive care unit from a hypoxic brain injury from birth when Danielle first met him.

Marty already had significant damage to his brain from the birth injury and had seizures during his first few days of life. However, his seizure activity resolved on its own. About five months after Danielle took him home from the hospital, he had a 24-hour bout of seizure activity that was quickly and fully managed with one medication.

But when Marty was just over a year old, he began to have multiple seizures at a time. Danielle rushed him to the local emergency room where he was transferred to a regional children's hospital, diagnosed with multifocal epilepsy and put on multiple medications.

"It was like an avalanche," said Danielle. "His epilepsy was uncontrolled, and he was on unbelievable doses of medication."

Danielle noticed that Marty's EEGs and seizures didn't look like they had before. Expressing her concern about infantile spasms, she was told that wasn't the issue at hand. During a second stay at the hospital, infantile spasms was again dismissed.

"I had done my research on EEGs and brain waves," said Danielle. "I knew that his EEG pattern was changing, and my biggest concern was infantile spasms."

But doctors continued to tell Danielle that this wasn't the case. Marty's injury from birth had left its mark distinctly, they said.

Thanks to a local neurologist, Danielle was given the hope she was looking for – a referral to Le Bonheur Children's Neuroscience Institute.

At Marty's first Le Bonheur appointment, he had another EEG. Within 15 minutes pediatric epileptologist Sarah Weatherspoon, MD, was in the room confirming Danielle's fears – it was infantile spasms, and Marty needed to be admitted immediately.

"It was really a feeling of relief," said Danielle of his diagnosis. "Finally somebody believes me and sees what I'm seeing. We're going to get help."



"It was really a feeling of relief. Finally somebody believes me and sees what I'm seeing. We're going to get help."

Danielle Smiley, Marty's mom

Treatment with the medications ACTH and vigabatrin began within 48 hours, and it took three weeks for the infantile spasms and coinciding erratic brain activity to get fully under control. Unfortunately, Marty had 10 months of undiagnosed infantile spasms. His brain was significantly and negatively impacted because of the delayed diagnosis.

The severe side effects of untreated infantile spasms mean that Marty has to relearn everything. But he is slowly improving and redeveloping his skills, gaining muscle control and strength. He currently spends time in physical, occupation and speech therapies to help encourage further developmental strides. Danielle and Marty continue to see Weatherspoon in clinic and alternate longer inpatient stays for more extensive monitoring.

"The attention that Le Bonheur has given to Marty is an investment to help him as much as possible and give him the best quality of life," said Danielle. "Marty was born outside of the box, but Le Bonheur's doctors are invested in learning about Marty and not making assumptions that dictate their care. That has truly and literally been life-saving for us."



Marty Smiley is currently in physical, occupation and speech therapies to encourage further developmental strides.

Westin Hopper, Walnut, Miss. | Time to treatment: 2 weeks

Fourteen-month-old Westin Hopper was enjoying playtime when his mom, Jennifer, noticed his head briefly drop and then snap up. She watched this continue for a few minutes and then suddenly stop.

It was unusual, Jennifer thought, but maybe he was just playing.

The next evening she watched the same scene play out two more times. She didn't know what it was, but she knew something wasn't right.

Her local emergency room doctor and pediatrician didn't know what was wrong either, but Jennifer had a gut feeling she needed to get another doctor's opinion. After doing research, she learned infantile spasms was the worst case scenario for her son. Knowing the severe consequences of delayed treatment, she drove him 70 miles to the emergency department at Le Bonheur.

Westin was admitted immediately to the epilepsy monitoring unit (EMU). He was diagnosed with infantile spasms the next day and immediately began adrenocorticotropic hormone (ACTH) – the most effective treatment for infantile spasms.

Three days into his stay at Le Bonheur, he went 24 hours without a seizure. Three weeks later, Westin returned for follow up testing where Pediatric Epileptologist



Sarah Weatherspoon, MD, confirmed that Westin was in remission from infantile spasms.

"So many children are passed over in ERs and pediatrician offices," said Jennifer. "Most children with this diagnosis have serious developmental delays. Thanks to Le Bonheur his condition was caught and treated quickly enough that today he is a rambunctious 3-year-old."

Eight months later, Westin briefly returned to Le Bonheur after Jennifer noticed slight jerking movements again. After six months on a new medication, Westin's infantile spasms were in remission again.

With such a rare diagnosis, the Hoppers found Le Bonheur's team approach comforting and effective. The current knowledge available regarding infantile spasms is sparse, and the team provided a variety of options and answers to give Westin the best possible outcome, said Jennifer.

Today, Westin enjoys playing with his siblings, running and jumping. His infantile spasms left him with some developmental delays, but he was treated quickly enough to prevent a devastating decline in his ability to function.

"Because of correct testing and treatment, we have a little boy who you can't tell had infantile spasms," said Jennifer.

Mia Lorino, Memphis, Tenn. | Time to treatment: 3 days

Although Mary Lorino, Mia's mom, is a pediatric nurse, she had never heard of infantile spasms.

"After doing research into infantile spasms, I was completely surprised by the severity of what we could be dealing with," said Mary. "My gut instinct was that something wasn't right with Mia, and I needed to advocate to get the care she needed."

The Lorinos had noticed that Mia, then 10 months old, was making an unusual upward gaze. After capturing the movements on video, they took Mia to their pediatrician the following day. His opinion – wait a week to see if the movements continue and then perform an EEG.

But as a nurse and a mom, Mary felt like waiting wasn't an option for Mia.

"I left the appointment and immediately began to start researching her symptoms because I knew something was wrong," she said.

Thanks to an internet search, she found a video of a child with the same eye movements – and a diagnosis of infantile spasms. Her research showed that infantile spasms was a medical emergency, and she needed to act quickly to prevent damage to Mia's brain.

Fortunately, Mary called Epilepsy Coordinator Karen Butler, RN, BSN, to get an appointment for Mia to be seen by Le Bonheur's epileptologists the following day. At the clinic, she was taken back for an EEG immediately.

"It was quickly apparent that Mia's EEG was abnormal," said Epileptologist Sarah Weatherspoon, MD. "Mia was admitted to the hospital for a 24-hour EEG plus an MRI and other testing to determine the cause of her unusual movements."

After a series of tests, it was confirmed – Mia had infantile spasms.

Fortunately for Mia, it was only three days from the onset of her first spasms to treatment, lowering her risk of permanent brain damage. She immediately started ACTH and vigabatrin. Her spasms dissipated within a week of their onset, and she was off medication after a few months.

"Because of early intervention, Mia had no serious regressions and no pause in her development," said Weatherspoon. "Her success shows the crucial need for pediatricians to be able to recognize potential cases of infantile spasms as a medical emergency and the importance of quickly referring children to a center than can offer the best treatment options."

Currently, Mia is 21 months old, medication-free and enjoys exploring the world around her. While she has mild delays in speech and gross motor skills, she is quickly closing that gap thanks to early intervention speech and physical therapies.

"Thanks to Le Bonheur we were able to get a fast diagnosis for Mia," said Mary. "The staff was attentive to all of our fears, and we hope that Mia's story can help primary care doctors learn to recognize the first signs of infantile spasms to help other children have better outcomes."





“We treat illnesses that lead to hospitalization, but we also want to improve their quality of life and get kids and families what they need – medical or not. At Le Bonheur, I can show that I care, walk through this with them and listen to them.”

Cynthia Cross, MD
Director, Le Bonheur Hospitalist Program
Assistant Professor of Pediatrics, University of Tennessee Health Center

PROFILE: CYNTHIA CROSS, MD

Founder of Le Bonheur Hospitalist Program creates better futures for Memphis children

Cynthia Cross, MD, believes she's always been traveling toward her current work at Le Bonheur Children's.

As a native Memphian, she understands firsthand how socioeconomic factors and disparities can affect a child's health. As a mother of a child with special needs, she identifies with parents who are in and out of hospital rooms, doctor's offices and therapy appointments. And as a medical care provider across several disciplines, she understands the experience of nurses, community pediatricians and now hospitalists.

But her path wasn't easy. Growing up in the segregated South, her obstacles were many.

"My grandfather taught me that the way out of poverty for African Americans was education," said Cross. "At the time I didn't know any black women who were doctors, but from childhood I knew I wanted to pursue medicine."

As a child, Cross saw medicine up close and personal thanks to her next door neighbor — a nurse who encouraged her medical interests.

But she also saw the impact that desegregation and busing had on her neighbors and fellow Memphians. Desegregation didn't remove health care disparities — it negatively affected health and access to care.

"Neighborhoods changed because people left, which led to disparities in access to health care among the people of Memphis," said Cross. "Health affects education, employment and more."

After graduating high school, Cross attended Methodist Nursing School, but even then she knew this wasn't the end of her medical education.

Following nursing school, she worked briefly in adult urology before taking a position in the neonatal intensive care unit where physicians encouraged her to go to medical school. So she promptly pursued her undergraduate degree, attended medical school at the University of Tennessee Health Science Center and completed two years of pediatric residency at Baylor College of Medicine before returning home for the final year of residency due to her mother's cancer diagnosis.

She worked for five years in private practice as a pediatrician and then in a position combining emergency and hospital medicine before joining Le Bonheur. "I have always loved kids," she said. "They are accepting, resilient and have so much potential. Improving their health can have wide-reaching impacts for years to come."

In 2008, then Le Bonheur President and CEO Meri Armour, former Pediatrics Chair Russell Chesney, MD, former Chief Medical Officer William May, MD, and local Pediatrician Robert Riikola, MD, approached Cross about forming a hospitalist program at Le Bonheur. The program would help community pediatricians manage admission of their patients. The hospitalists then follow the patient through their treatment at Le Bonheur before discharging back to the pediatrician for follow up.

"Hospitalists care for children with a variety of illnesses and increased medical complexity," says Cross. "We are uniquely suited to care for these children — we know all team members across subspecialties who have a hand in providing the best care for our kids."

At the launch of the hospitalist program, administrators thought Le Bonheur could include about 15 pediatricians in the program. When word got out that Cross was leading the program, the number exploded. Now more than 60 pediatricians in the community utilize Le Bonheur's hospitalist program for their patients.

One of Cross's favorite parts of working as a hospitalist is the opportunity she has to build relationships with families and walk with them through the difficulties of a hospital stay.

"We treat illnesses that lead to hospitalization, but we also want to improve their quality of life and get kids and families what they need — medical or not," said Cross. "At Le Bonheur, I can show that I care, walk through this with them and listen to them."

Cross is also involved in several initiatives at Le Bonheur that focus on reducing health care disparities in the Memphis area. She is medical director of Le Bonheur on the Move, a mobile unit that travels to rural areas to provide affordable, accessible health care for kids without pediatricians. She is also medical director of the School Nurse Program — a pilot program in Shelby County Schools intended to decrease health care disparities by providing a resident nurse in five elementary schools in Memphis. She is also involved in the multidisciplinary Center for Health Equity.

At the end of the day Cross wants to create better futures for all children in Memphis.

"I enjoy taking care of kids, plain and simple. I get to help my town and mentor future generations," said Cross. "Many people don't have adequate resources for health care or daily needs. Our Le Bonheur team is here to make sure this happens less and less. I'm honored to be part of the solution."

Cynthia Cross, MD

Chief, Division of Hospital Medicine

Education and Training

Le Bonheur Children's Medical Center — Pediatric Residency
Baylor College of Medicine — Pediatric Internship/Residency
University of Tennessee Health Science Center — Medical School

Board Certifications

American Board of Pediatrics



EXIT Strategy

Team plans, executes rare EXIT procedure and in-hospital delivery

Ananasa Mobley needed a miracle team. A recent ultrasound had shown a mass compressing the trachea of the infant she was carrying. Doctors were worried for her near-term baby's life – the infant's young airway could be so compressed by the growing tumor that she'd be unable to breathe at birth.

What followed was several weeks of planning by the team at Le Bonheur Children's Hospital to ensure baby Aubree Mobley had the best chance. Her birth, and subsequent surgery to remove the mass, would require a handful of specialists all ready to play their part.

This is the story of Aubree's miraculous birth.

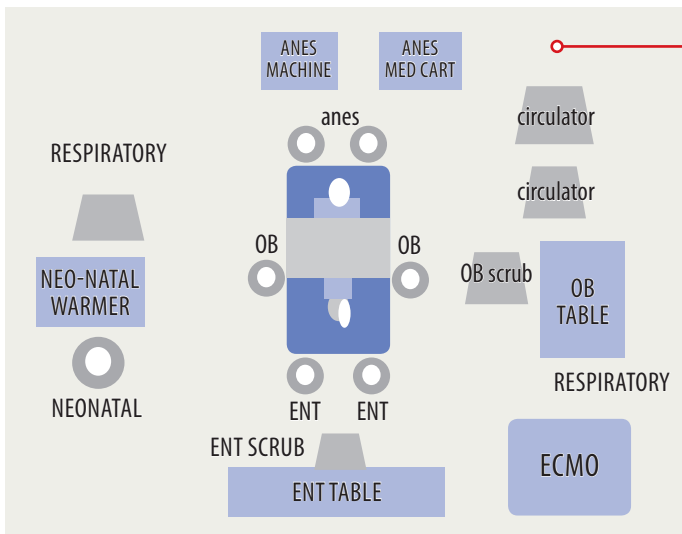


TROUBLING ULTRASOUND

Memphis Perinatologist Roy Bors-Koefoed, MD, calls Le Bonheur Pediatric Surgeon Trey Eubanks, MD, and asks Eubanks to see one of his patients in clinic. A recent ultrasound on a near-term baby girl showed a mass compressing the infant's trachea. "When I saw the mass, I knew we'd need an EXIT procedure," Eubanks said. An EXIT procedure, or ex utero interpartum treatment, is a specialized surgical delivery procedure for babies who have neonatal emergencies, such as an airway obstruction, that require an immediate procedure while still attached to the umbilical cord. Images showed that a teratoma was blocking the airway of Aubree Mobley, the infant.

A PLANNED DELIVERY

Eubanks and Le Bonheur's team of surgeons and Operating Room staff begin building a plan to deliver and open the baby's airway at Le Bonheur. "When we built the new operating rooms in 2019, we designed them with room so that we could deliver babies here, if needed," Eubanks said. This would be Le Bonheur's first planned delivery since adding four new operating rooms. The procedure would require a handful of specialists – pediatric surgeons and otolaryngologists, pediatric and adult anesthesiologists, Ananasa's obstetrician, and a host of labor and delivery and pediatric operating room nursing teams. The teams met to walk through the procedure several times, developing a plan and contingency plans for all scenarios.



THE CURVEBALL

The plan hit a snag early on when Ananasa, in her fifth pregnancy, suffered a mild preoperative stroke that left weakness in one side of her body. She was admitted to an adult hospital and the team moved their procedure date up a week – to Memorial Day weekend. Team members planned on operating at Le Bonheur, but developed backup plans to do an EXIT procedure at the neighboring hospital, if necessary. That required endless checks with both hospitals' pharmacy and nursing staffs to ensure safe deliveries could occur in either operating room, if needed.



DELIVERY DAY

With mom and baby stabilized, Ananasa was transferred to Le Bonheur Children's on the day of her surgery, Friday, May 24. Le Bonheur's surgical team met her there and prepped her for the EXIT procedure.



A TWELVE-MINUTE PLAN

Twelve minutes. Ananasa's surgical team figured they had 12 minutes once baby Aubree was delivered to access an airway for her. The team's best option was to intubate baby Aubree, but the team also was prepared to create a surgical airway or even put her on heart-lung bypass if necessary. Those scenarios meant that a minimum of 16 people – and all of the necessary equipment – needed to be in the Operating Room.

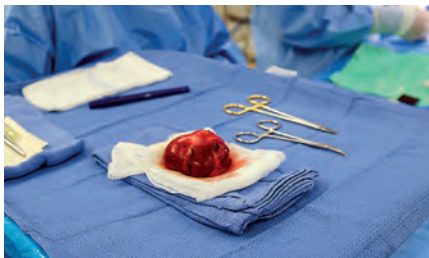




As part of the EXIT procedure, only the upper portion of Aubree’s body was delivered outside the placenta, to optimize the mother-baby connection for as long as possible. Pediatric Otolaryngologists Jennifer McLevy, MD, and Jerome Thompson, MD, were able to intubate Aubree quickly, establishing an airway in less than five minutes. Once intubated, the team – including Bors-Koefoed and Obstetrician Corey McGlothan, MD, assisted by Pediatric Surgeon Tim Jancelewicz, MD, delivered Aubree.

SUCCESS

Aubree was then moved to Le Bonheur’s Neonatal Intensive Care Unit, while mom Ananasa was transported back to the adult hospital for recovery. Two weeks later, Pediatric Surgeon Eubanks removed the teratoma (pictured below) from Aubree’s airway. “The availability of excellent subspecialists really helped us,” Eubanks said. “We are able to do this because of our breadth of expertise, and we’re proud to have built a team at Le Bonheur that was able to help this family.”



Registry to study transcatheter PDA closures

Le Bonheur Interventional Cardiologist Shyam Sathanandam, MD, will be the principal investigator for a national registry that will study long-term outcomes of a device used to close patent ductus arteriosus (PDAs) in extremely low birth weight (ELBW) infants.

The device, Abbott's Amplatzer Piccolo Occluder, received FDA approval in January 2019 to treat PDAs in ELBW infants. It is the first transcatheter cardiac device to receive FDA approval for premature infants.

Sathanandam, medical director of Le Bonheur's Interventional Cardiac Imaging and Interventional Catheterization Laboratory, perfected the technique to close PDAs in ELBW babies in Le Bonheur's hybrid catheterization lab before joining a 10-site FDA device trial for the Amplatzer Piccolo Occluder.

The registry, funded by Abbott Structural Heart, will be housed at Le Bonheur's Children's Foundation Research Institute. It will enroll babies in collaboration with the Congenital Cardiovascular Interventional Study Consortium (CCISC), a non-profit organization dedicated to advancing treatments for those requiring surgical and interventional treatment of congenital heart disease.

Babies who weigh less than 2 kg and receive the Amplatzer Piccolo Occluder device will be part of the study. Researchers hope to enroll 500 children within five years from 50 participating centers.

"We want to move the field forward and understand all we can about this technique and long-term outcomes for these babies," Shyam said. "Our goal is to find even better ways to give premature babies a great start."



ORIGINAL STUDY

Role of Transcatheter
extremely

Shyam Sathanandam, MD

Kristen Washburn

Benjamin Rush

Study comparing

Comparing

Comparing



Interventional Cardiologist and Associate Professor of Pediatrics, University of Tennessee Health Science Center, Shyam Sathanandam, MD, presents the Le Bonheur Heart Institute's work in transcatheter PDA closures on extremely low birth weight infants at the International PDA Symposium in May. The Memphis symposium attracted 200 providers from all over the world.

Standing up to Sepsis

Le Bonheur researchers pioneer pediatric tool





Critical Care Chief and Professor of Pediatrics, University of Tennessee Health Science Center, Samir Shah, MD, and Kimberley Giles, Le Bonheur Director of Decision Support, have been working to find ways to flag sepsis as soon as possible.

Nine years ago, Kimberley Giles, Le Bonheur’s Director of Decision Support, and Samir Shah, MD, Chief of Critical Care, realized they shared a vision: flagging sepsis as soon as possible.

“Every minute counts,” says Shah. “If you don’t intervene early, there’s a much higher risk of a negative outcome, whether it’s complications or mortality. Every hour that passes by without starting goal directed therapy increases the odds of mortality. If you miss the golden hour, you’ve missed a critical window.”

Giles and Shah brought their departments together to build a tool to screen patients for severe sepsis in real time. Le Bonheur’s clinicians, decision support, information services and critical care staff have worked for nearly a decade refining an algorithm which integrates with a patient’s electronic medical record (EMR): the “first tool of its kind to be used in a pediatric center,” Shah says.

Sepsis, a suspicion of infection plus systemic inflammatory response syndrome, escalates to severe sepsis if left untreated. Severe sepsis, signaled by acute organ dysfunction and clinical signs such as low blood pressure, kidney failure and increased need for oxygen, leads to multiple organ dysfunction syndrome and death.

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Samir Shah, MD, Chief of Critical Care

As care providers enter documentation and lab results into a patient’s EMR, the algorithm immediately scans for red flags.

The algorithm checks for combinations of criteria that may indicate severe sepsis, from patient age to lab results and vital signs. The moment a combination suggesting severe sepsis occurs, the algorithm fires an alert directly to an intensive care unit (ICU) nurse’s phone. The nurse and a physician then visit the patient, confirm severe sepsis and decide on treatment.

“Our job is to bring the team that can manage a child with severe sepsis in order to intervene quickly in a busy tertiary care children’s hospital,” said Shah.

THE COST OF SEPSIS

Swift intervention reduces cost, morbidity and mortality. The national pediatric treatment cost for severe sepsis rose from \$4.8 billion in 2005¹ to \$7.31 billion in 2016². In addition, sepsis, if allowed to progress, can cause residual damage from organ shutdown.

“If we don’t intervene early, these patients become severely septic, they

¹ Hartman et al: Pediatric Critical Care Medicine. 14(7):686-693, September 2013.

² Carlton et al: JAMA Pediatrics. August 12, 2019. doi:10.1001/jamapediatrics.2019.2570.

stay in institutions longer, and even at the end of that, they have a lot of morbidity,” says Shah. “There’s lung, kidney and liver injury.”

Giles and Shah’s initial goal was to curtail sepsis-related mortality.

“Sepsis was the leading cause of preventable death at this hospital, and it was really the highest type of pediatric mortality where we could make an impact,” said Giles. “There are some conditions in children that you can’t change. But this group jumped off the page as an opportunity for change.”

After reviewing potential explanations, Shah and Giles concluded the mortality rate was a result of insufficient sepsis recognition.

DETECTING SEPSIS

Several barriers exist on the road to detection.

One pediatric challenge is age. A 1-year-old and an 18-year-old have different heart and respiratory rates; care providers with varying levels of experience may miss signs that suggest escalating sepsis in one age group versus another.

“For adults, a healthy heart rate and respiratory rate

are about the same across all ages,” says Shah. “But a brand new nurse or resident may not pick up subtle signs that this child has a heart rate that’s too high.”

The time frame of sepsis progression is erratic with no set pattern. Where one patient proceeds to severe sepsis in a matter of hours, another may present later based on immune defenses. Severe sepsis also has no set biomarkers or lab values which define it.

Finally, patients face an array of unique challenges that complicate detection. Young children are unable to communicate exact symptoms slowing diagnosis. Some patients are admitted with comorbidities, which can alter immune defenses and render them more vulnerable. Other patients live with complex developmental disabilities or depend on organ system support. These conditions can shift vital signs, making sepsis even harder to pin down.

“Their temperatures may not be normal, or their respirations are more like a child of another age, or their technological dependence skews their vital signs,” says Giles. “Kids with disease or developmental disability may not display the typical vital signs you see in a healthy child.”

To create a reliable pediatric tool, Shah and Giles had to account for these scenarios.

“Sepsis was the leading cause of preventable death at this hospital, and it was really the highest type of pediatric mortality where we could make an impact. There are some conditions in children that you can’t change. But this group jumped off the page as an opportunity for change.”

Kimberley Giles, Le Bonheur’s Director of Decision Support



Left to right: Kimberley Giles, Samir Shah, MD, Lindsay McElroy, PCC, Shannon Riley, MD, and Nico West, MD

They began by sifting through data from Le Bonheur gold standard cases of severe sepsis, retroactively pinpointing symptoms.

“What we had was information,” Shah said. “Heart rate, blood pressure, oxygen numbers and lab results. We put those together and ran an iterative model to create a rough tool.”

Giles and her decision support team, alongside Amy Guynn Bagwell in Information Services and her IS team, began coding their tool to fit within the framework of Cerner, Le Bonheur’s EMR software. They also incorporated age-specific thresholds for abnormal heart rate and respiratory rate, as well as a linear temperature correction for each age category.

In 2014, after a pilot trial and repeated PDSA (Perform, Do, Study, Act) cycles, the tool was ready for use.

GOING LIVE

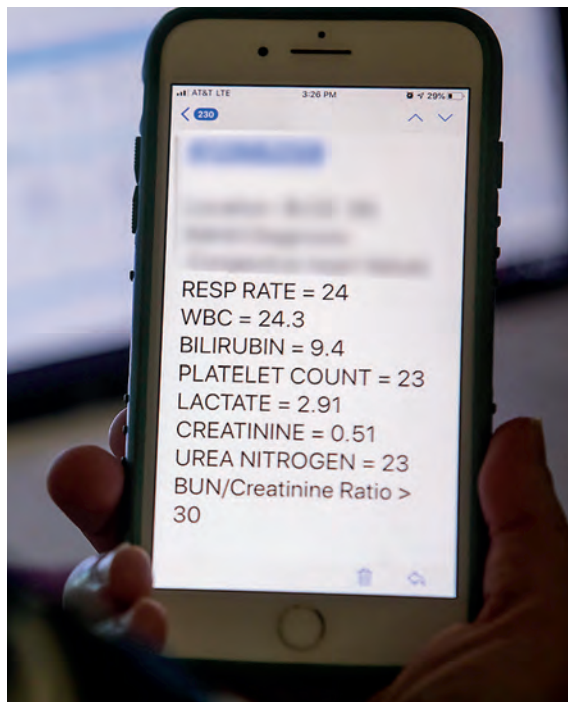
The tool went live in age-based batches, first used in 2014 for patients 13 to 18 years.

From 2014 to 2015, 2,646 adolescents were screened. In its first year, the algorithm’s positive predictive value (PPV) was 53.9%. In 2016, the algorithm rolled out to patients aged 6-12. The algorithm’s PPV jumped to 71.5%.

As the team gained insight, they created filters to stop alerts from overfiring: for example, accounting for “sepsis mimics” such as epilepsy, post-operation periods, new trauma and asthma. The algorithm was suppressed on patients with these conditions until 48 hours after admission, reducing false positive alerts.

In February 2019, the algorithm went live for patients ages 1-5. Now, it runs on all Le Bonheur patients ages 1-18.

“Our mortality is down, our response time is better, antibiotics are being delivered in a timely fashion and in general, it has helped overall ICU mortality,” says Shah.



The moment potential sepsis is detected in Le Bonheur’s Intensive Care Unit (ICU) an alert is sent directly to an ICU nurse’s phone.

The algorithm has aided clinicians in administering antibiotics during the “golden hour”: the first in a three-hour window within which antibiotics best combat infection. In 2018, 135 patients had antibiotics administered an average of 1.2 hours after a true positive alert.

As of 2018, pediatric sepsis had dropped to Le Bonheur’s fifth leading cause of death. Excluding the neonatal intensive care unit (NICU), pediatric septic mortality has fallen from 7.6% in 2014 to 4.9% in 2018 – below the national pediatric average of 8.4%.

Shah is quick to explain that the algorithm is not the only reason for that improvement. “The tool is also helping raise the level of awareness,” he says. “Opening a clinician’s mind’s eye to the possibility of severe sepsis.”

THE FUTURE OF SEPSIS PREVENTION

Le Bonheur’s critical care and bioinformatics teams are utilizing the algorithm in a new project – not simply catching sepsis, but predicting it via physiometers.

The teams analyzed physiologic data that was constantly gathered from PICU patients two to 24 hours before the algorithm fired a true positive alert. The teams then used artificial intelligence to investigate the data for physiometers which reliably predicted sepsis. Several potential physiometers were discovered, such as standard deviation (SD) of heart rate and SD of systolic and diastolic blood pressure. These physiometers could forecast sepsis in advance of the current clinical signals.

In the future, the teams hope to develop technology both sensitive to physiometers and integrated with bedside monitors. Where the algorithm relies on intermittent, manual data entry for information, a monitor-integrated tool could continuously update and scan for second-to-second variations in vital signs.

Early Answers

Study analyzes how gestational age influences gut microbiome

Microbial DNA is present in the gut of developing fetuses and differs by gestational age at birth, according to a study published in *The FASEB Journal*. Using advanced culture and DNA sequencing techniques, researchers at Le Bonheur Children's Hospital/University of Tennessee Health Science Center analyzed samples of meconium to explore neonatal gut microbial communities.

"For the last hundred years, scientists have believed that the human fetus developed, protected from the outside world, in a womb that — unless something went terribly wrong — remained sterile and completely isolated from the host of bacteria, fungi and viruses that waited to make us sick when we emerged into the outside world," said Lead Author and Le Bonheur Researcher Kent Willis, MD. "This belief was largely based on the fact that it was very difficult to grow cultures of live microorganisms from this part of the body."

Recent studies have challenged that theory, and scientists are learning more about the early colonization of microorganisms inside the womb.

Willis's team collected meconium samples from both very low birth weight preterm and term-born infants to study how gestational age affects a newborn's microbial DNA. Factors considered in data collection included prenatal and postnatal antibiotic exposure, prenatal steroid exposure, delivery mode and illness severity. Researchers characterized microbial findings using both culture-independent and culture-dependent techniques.

"We found that the largest determinant of the amount and type of fungi detected is the infant's gestational age at birth," said Senior Author and Le Bonheur Researcher Joseph F. Pierre, PhD. "This suggests that the fungal DNA we detected is not the result of random contamination of the uterus or colonization following birth but rather is highly associated with the age at which the infant leaves the womb."



Researchers Joseph F. Pierre, PhD, (left) and Kent Willis, MD, (right) used meconium samples to explore neonatal gut microbial communities.

Understanding the order and timing in which microorganisms colonize in the intestines is important, the researchers say, because therapeutic interventions, like perinatal antibiotics, may affect the gut's mature microbiome at birth and play a crucial role in disease development.

For instance, findings showed that preterm birth was highly correlated to the presences of *Candida*, a potentially pathogenic type of fungi.

"This suggests that, unlike the majority of the fungi we studied, these fungi might contribute to the disease process of preterm birth," said Willis.

In recent years, the gut's microbiome has received a lot of attention, as scientists discover more about the role it plays in an individual's health. Studies have linked diversity of gut bacteria and fungi to everything from food allergies and obesity to cancer and mental health.

The UTHSC team is continuing to follow study participants to determine whether the meconium samples or additional samples collected in the weeks following are correlated with later disease risk and growth parameters

View the full text article at <https://doi.org/10.1096/fj.201901436RR>.

Research included in this report was funded by the Children's Foundation Research Institute.



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Joseph F. Pierre, PhD, senior author



Innovative Interventions

Le Bonheur's Fetal Center provides unique treatments for babies in utero

For some children and families, medical intervention needs to happen before a child is born. For these unique cases, Le Bonheur has the Fetal Center – the only center of its kind in the area to care for babies from prenatal diagnosis to fetal intervention. In partnership with the University of Tennessee Health Science Center and Regional One Health, the Fetal Center treats babies diagnosed in utero with a congenital anomaly.



The Fetal Center offers the following fetal interventions:

- Laser for twin-to-twin transfusion syndrome
- Placement of shunts
- Cordocentesis and infusion therapy
- Radiofrequency ablations for twin reversed arterial perfusion (TRAP) sequence
- Amniocentesis
- Amniopatch for latriogenic PPROM
- Amniotic band syndrome intervention
- Chorionic villus sampling
- EXIT procedures
- Fetal anemia treatment
- Fetoscopy
- Pleurocentesis
- PUBS
- Vesicoentesis

Thanks to the Fetal Center, physicians can intervene before birth to provide a chance at life for children with unique conditions in utero.





The Fetal Center at Le Bonheur Children's:

- Is the only center in the region to offer laser treatment for twin-to-twin transfusion syndrome
- Has written the current guidelines on treating fetal anemia
- Gives families access to all specialties in one setting
- Partners with families and their primary obstetrician to determine the best course of treatment
- Is accredited by the American Institute of Ultrasound in Medicine in Obstetric Ultrasound

Asher Tasma, Tupelo, Miss.

Diagnosis: Pleural effusions

Treatment: Thoraco-amniotic shunt

When Jenifer Tasma looks at her son Asher, now 2 years old, she can't believe how lucky she really is.

"He's a walking miracle," Jenifer said. "We know how blessed we are to have him."

Two years ago, Asher was given a 35% chance of surviving birth. Innovative procedures while in utero performed by the Le Bonheur Fetal Center's team saved Asher's life.



During a regular obstetrician visit, the doctor found a massive amount of fluid on Asher's right lung, a condition known as severe pleural effusion. Jenifer was referred to a maternal fetal medicine specialist in Tupelo, Miss., who recommended genetic testing. While the genetic testing did not reveal the cause of the fluid, it did come back 99.9% positive for trisomy-21 – Down syndrome.

Down syndrome was the furthest thing from Jenifer's mind. That day her specialist referred her to Le Bonheur's Fetal Center because the fluid accumulation was so severe it was compressing Asher's heart.

Le Bonheur Fetal Center physicians developed a plan to get Asher safely to delivery day. First, doctors performed a procedure to remove the fluid from around Asher's lungs. While it looked to be successful, fluid quickly accumulated again, dropping Asher's survival rate.

"Asher had very severe fluid accumulation in his chest pushing on his organs," said Fetal Therapy and Surgery Specialist Mauro Schenone, MD. "Pressure like this can be high enough to impair fetal heart function or lung development. It was crucial to come up with a plan to help the lungs reclaim that space and to allow the heart to work properly."

At 31 weeks, Schenone placed a thoraco-amniotic shunt in between Asher's ribs to help drain fluid. The minimally-invasive procedure inserts a shunt through a needle that is less than 2mm

in diameter. The fluid exits on its own. "It's almost the equivalent of placing a chest tube in the fetus," said Schenone.

With five other children at home, the time away started to take its toll. With Schenone's approval Jenifer went home. Monitoring would continue until she reached 39 weeks, and Asher could be born safely under Schenone's care.

But Asher came sooner than planned. The night she went home, Asher was born at a hospital near their home in Tupelo, Miss. Weighing 6 lb. 3 oz., Asher was alert, could breathe on his own and had his shunt easily removed.

"The shunt provided the critical relief in pressure for the heart to work properly and avoid hydrops fetalis – fetal heart failure. It also allowed Asher's lung to reclaim space and better develop before birth," said Schenone.

Asher spent 15 days in the neonatal intensive care unit in Tupelo but has had no issues with fluid accumulation since his birth. He has a structurally perfect heart, and his only present health condition is acid reflux for which he is currently undergoing testing.

"We would not have Asher today if not for the Fetal Center team," said Jenifer. "We had the most amazing experience anyone could ask for – it took each one of the doctors, specialists, surgeons and anesthesiologists to bring my baby into the world."



Heart Institute opens Cardiac Care Unit

Recently, Le Bonheur's Heart Institute opened a new 12-bed Cardiac Care Unit dedicated to providing high-quality care to patients with congenital and acquired heart disease. This unit allows patients with cardiac diagnoses and active cardiac issues to be cared for on a unit by cardiac nurses specially trained to care for this fragile patient population.



Primary ciliary dyskinesia program receives accreditation

The Primary Ciliary Dyskinesia (PCD) Foundation recently granted Le Bonheur's PCD program full accreditation. The PCD Foundation works to create infrastructure and processes to address the unmet needs in the PCD patient community.

Samarasinghe named Plough Foundation Chair of Excellence

Le Bonheur researcher Amali Samarasinghe, PhD, was awarded the Plough Foundation Chair of Excellence. As a part of this chair she is now the Director of the Pediatric Asthma Research Program. This chair of excellence was established in 1986 by the state of Tennessee.



Amali Samarasinghe, PhD

Director of Injury Prevention receives award from Safe Kids



Susan Helms

Le Bonheur's Director of Injury Prevention, Susan Helms, was honored by Safe Kids Worldwide for her work developing Splash Mid-South, the community coalition that provides free or low-cost swim lessons for kids and CPR training in the community.

Pediatricians honored with awards from TNAAP

The Tennessee Chapter of the American Academy of Pediatrics (TNAAP) has named two Le Bonheur pediatricians as honorees for the 2019 Excellence



Tim Gillespie, MD, FAAP



Elisha McCoy, MD

in Pediatrics Awards. Tim Gillespie, MD, FAAP, received the Lifetime Achievement Award, and Elisha McCoy, MD, received the AAP Special Achievement Award at the awards ceremony held in September. The annual TNAAP Excellence in Pediatrics Awards recognize and honor pediatricians and community members who have made exceptional contributions to children's health advocacy in Tennessee.

Sathanandam, Memphis CHiLD nominated for the Memphis Business Journal's Health Care Heroes



Memphis CHiLD

Each year the *Memphis Business Journal* honors organizations and health care professionals who continue to advance the reputation of Memphis as a place of medical innovation. Shyam Sathanandam, MD, medical director of Interventional Cardiac Imaging and Interventional Catheterization Laboratory, was nominated in the Health Care Provider – Physician category.



Shyam Sathanandam, MD

Memphis CHiLD, a medical-legal partnership of Le Bonheur, University of Memphis School of Law, Memphis Area Legal Services and UTHSC, was nominated in the Community Outreach category.

Le Bonheur neurosurgeon named President Elect of the International Society for Pediatric Neurosurgery

Neuroscience Co-Director Frederick Boop, MD, has been named President Elect of the International Society for Pediatric Neurosurgery (ISPN). ISPN's mission is to improve the health and welfare of children requiring neurosurgical care throughout the world by scientific research and close international cooperation. Boop is professor and chairman of the Department of Neurosurgery at the University of Tennessee Health Science Center and Chief of the Division of Pediatric Neurosurgery at St. Jude Children's Research Hospital.

