

DELIVERING ON A PROMISE

WINTER 2016

A Reshaped Life

Craniofacial program gives hope for congenital deformities

- ▶ New legislation aims to coordinate care, reduce costs for medically complex children
- ▶ Cannabidiol helps control seizures in children, study finds



THE UNIVERSITY OF
TENNESSEE
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DIRTY AIR

Researchers study how combustion-derived pollution can change metabolism, epigenetic makeup in the womb

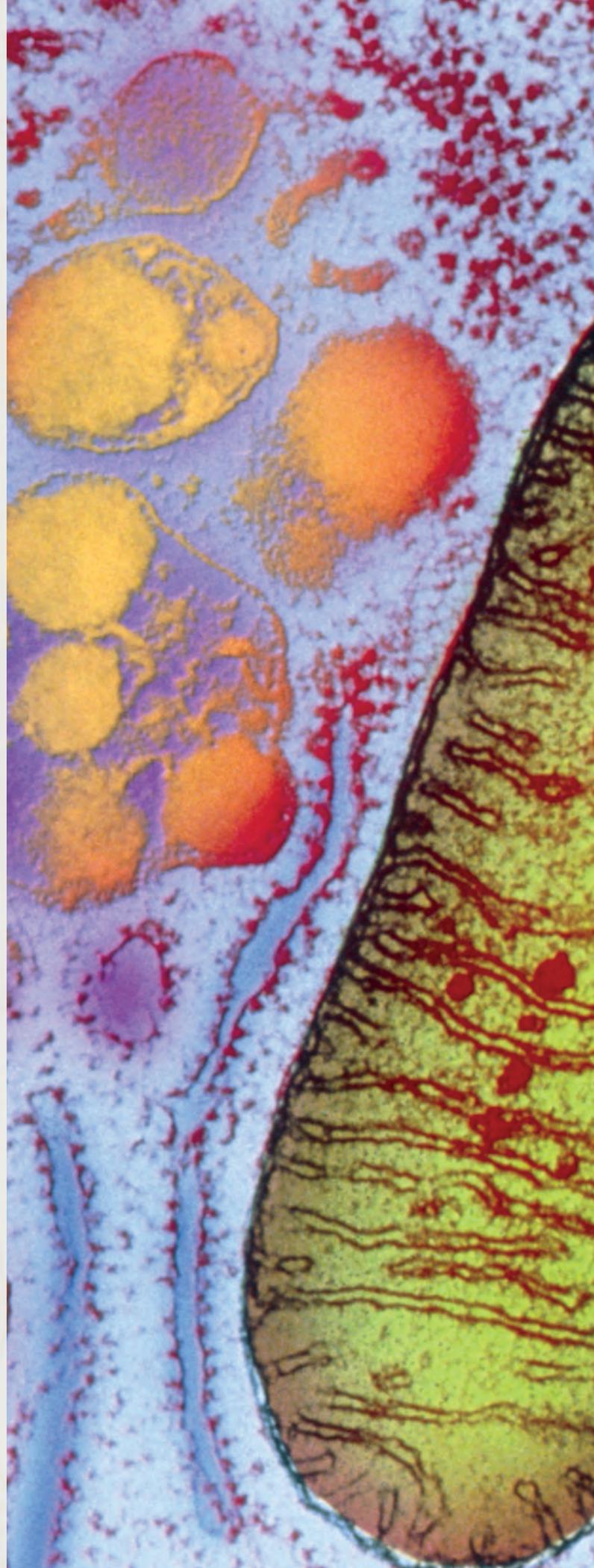
Gestational exposure to combustion-derived particulate matter can lower energy expenditure at least in part through alterations to mitochondrial metabolism, according to a new study from researchers at Le Bonheur Children's and the University of Tennessee Health Science Center.

The study, published in the *American Journal of Physiology, Endocrinology and Metabolism*, found that pregnant mice exposed to particulate pollution had larger pups – who stayed large throughout life – than pups born to mothers who weren't exposed to pollutants. Surprisingly, those large pups also ate less food than their control counterparts, said Stephania Cormier, PhD, director of the Pediatric Asthma Research Program and Plough Foundation Chair of Excellence in Pediatrics at Le Bonheur and UTHSC.

Cormier believes this work will translate to humans, particularly those in industrialized countries with high combustion pollution. It could also explain the rapid increase of obesity and diabetes among humans in industrialized countries – a rate that far outpaces evolutionary changes. Her goal is to learn more about how obesity and airway dysfunction correlate and eventually develop therapeutics to treat the condition.

The increased body size observed in mice exposed to the combustion-derived particulate matter was associated with reduced physical activity and lower energy expenditure. The reduced energy expenditure in pups indirectly exposed to the pollutants was associated with reductions in skeletal muscle, mitochondrial DNA copy number, lower mRNA levels of electron transport genes, and reduced citrate synthase (a marker of cellular oxidative capacity) activity.

Researchers also believe exposure increased oxidated stress and eventually changes the mitochondrial metabolism in the skeletal muscle of the pup. Cormier now wants to determine if exposure has transgenerational effects – and whether mitochondrial changes in the body can change genetic makeup and affect children for generations to come.





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 subspecialties.



LE BONHEUR LEADERSHIP

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Jon McCullers, MD – *Pediatrician-in-Chief*
James "Trey" Eubanks, MD – *Surgeon-in-Chief*
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The primary pediatric teaching affiliate of the University of Tennessee Health Science Center, College of Medicine

In this issue:

2 A RESHAPED LIFE

Craniofacial program gives hope for congenital deformities

13 MEDICALLY COMPLEX

New legislation aims to coordinate care, reduce costs for children with complex medical conditions

16 PROFILE: CHESTER BROWN, MD, PHD

Creating map for precision medicine brings Brown to Le Bonheur

18 CALMING SEIZURES

Cannabidiol helps control seizures in children, study finds

23 STAMP OF APPROVAL

Le Bonheur uses *U.S. News'* Best Children's Hospital survey to improve care

THE COVER:

Betzabeth Fajardo, 7, was born with a Tessier cleft palate and lip and has had 11 surgeries. Read her story on page 8.

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A RESHAPED LIFE

*Craniofacial program
gives hope for
congenital deformities*

Cynthia Fajardo doesn't remember much about the day her daughter was born.

She recalls arriving at the hospital and going into labor — a full week past her due date. Then came the shock when delivery room doctors handed Cynthia her little girl, Betzabeth. After that, the details of what should have been one of her most memorable days became a blur.



“When they put her on my stomach, the first time I looked at her I was in shock,” Cynthia said. “I remember everything up until I had her and the incubator process but after that I was sleeping and was pretty much out of it.”





Cynthia Fajardo plays with her children, Austin and Betzabeth, outside Le Bonheur Children's Hospital. Betzabeth, who was born with a Tessier cleft palate, has been a patient at Le Bonheur her entire life.

Betzabeth was born with a Tessier cleft palate and cleft lip, which caused a large portion of her upper lip and nose to not fully develop, leaving an inch-wide gap in the middle of her face. The hole was so large that she could see Betzabeth's tonsils. Prior to giving birth, Cynthia's ultrasounds didn't show any facial deformities.

A day after she was born, Betzabeth was transferred to Le Bonheur Children's Hospital where she would spend the next two months. At Le Bonheur, the Fajardo family got to know the hospital's craniofacial team — a group of pediatric neurosurgeons and plastic surgeons who performed life-changing facial surgery on Betzabeth.

In the last 17 years, Le Bonheur has continued to expand its craniofacial program, bringing together a team of multidisciplinary specialists who care for hundreds of children like Betzabeth born with severe congenital facial and skull deformities.

BUILDING A CRANIOFACIAL PROGRAM

At Le Bonheur, building a comprehensive craniofacial program involved formalizing a team of dedicated plastic surgeons, neurosurgeons, dentists, oral surgeons and other specialists, each focused on treating various skull and facial deformities.

Laying the foundation for the hospital's craniofacial program began, in part, with the recruitment of Frederick Boop, MD, co-director of Le Bonheur's

Neuroscience Institute, in 1999. Boop, a pediatric neurosurgeon and one of the country's leading experts on craniosynostosis, teamed with Robert Wallace, MD, medical director of Pediatric Plastic Surgery at Le Bonheur, to lead Le Bonheur's craniofacial program.



Frederick Book, MD, co-director of Le Bonheur's Neuroscience Institute, is one of the country's leading experts on craniosynostosis. He helps lead Le Bonheur's craniofacial program.

neurosurgery, plastic surgery, dentistry and oral surgery and attracts patients from across the country.

“We have a multi-disciplinary program at Le Bonheur that offers state-of-the-art management for

people with craniofacial deformities so that families who have children with these problems can be evaluated and get the care that they need,” Boop said.

Today, the program includes specialists from



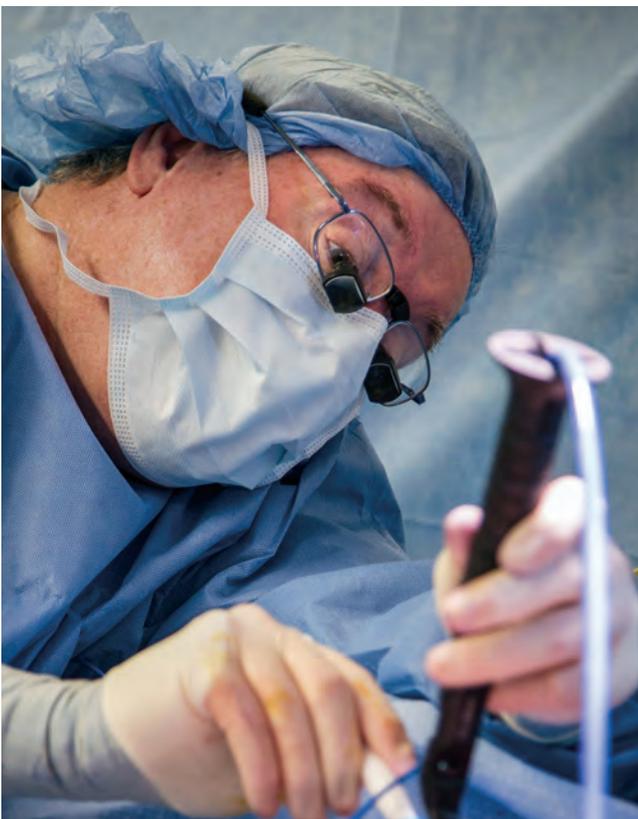
Learn more about Le Bonheur's craniofacial program — www.lebonheur.org/promise



Although there's no known cause, craniofacial deformities vary from craniosynostosis, microcephaly, congenital ear malformations, cleft palate and lip, hemifacial microsomia and more. Annually, more than 7,000 children are born with a cleft lip or palate, according to figures from the Centers for Disease Control and Prevention, and make up a



Every month, Robert Wallace, MD, medical director of Pediatric Plastic Surgery at Le Bonheur, helps lead the hospital's Craniofacial Clinic. Wallace and his team keep a photo gallery of his patients, pre- and post-surgery, to track their appearances as they age.



Each year, Robert Wallace, MD, medical director of Pediatric Plastic Surgery at Le Bonheur, and his team perform more than 40 craniofacial surgeries.

"For someone born with a facial deformity, they may need a plastic surgeon to fix the facial skeleton but they may also need dentistry or oral surgery to make sure their teeth are properly aligned. Or the patient may need surgery to fix the jaw so they can swallow properly or sometimes they may have problems with sleep apnea because their airway is compromised."

Frederick Boop, MD

majority of all craniofacial deformities.

Many of the facial and head deformities can be treated with surgery, including a craniectomy or implanting distracter plates. Surgeries are more than just cosmetic, however. The medical procedures also can help children with breathing disorders, speech impediments or feeding issues. In less serious cases, non-surgical



Case Study: Betzabeth Fajardo

Tessier cleft palate and cleft lip

When Cynthia Fajardo's daughter, Betzabeth, was born, she was "shocked" by her daughter's appearance.

Betzabeth was born with a Tessier cleft palate and cleft lip, which left an inch-long gap between her eyes and upper lip.

"It was like a big hole in the middle of her face," Fajardo said. "The hole was so large that you could see her tonsils."

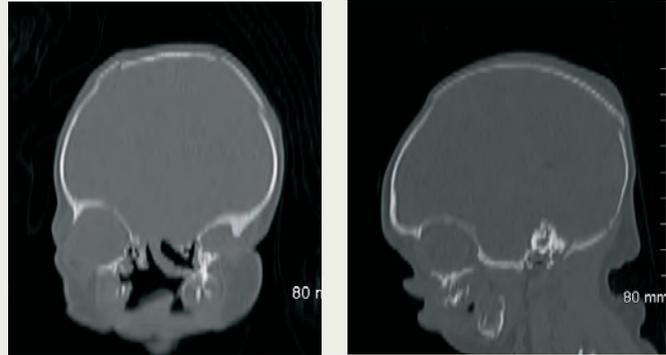
Betzabeth spent the first two months of her life in Le Bonheur's Neonatal Intensive Care Unit before finally going home. When she was 6 months old, she returned to Le Bonheur where surgeons from the hospital's craniofacial program repaired her

cleft palate and lip and closed the hole.

In the last seven years, Betzabeth, 7, has had 11 surgeries, including multiple lip repairs and adjustments to her orbital bones. She also had distracter devices implanted, which slowly repositioned her facial plates. Next summer, she's scheduled to undergo another surgery where Le Bonheur surgeons



Betzabeth Fajardo



Betzabeth Fajardo was born with a Tessier cleft palate, which caused her upper lip and nose to not fully form. The condition left an inch-wide gap in her face.

will cut the facial bones and move them closer together to form a more pronounced bridge for her nose.

"It's amazing how she talks because if you would have seen her when she was born, there's no way you would have thought she's able to speak as clearly and as well as she does right now," Fajardo said.

After 11 surgeries, Fajardo is confident Betzabeth will live a typical, healthy childhood.

"When we look at her baby pictures we're always, like, 'How did you do it?'" Fajardo said. "You would think that there's no way that they could possibly close a gap that big."



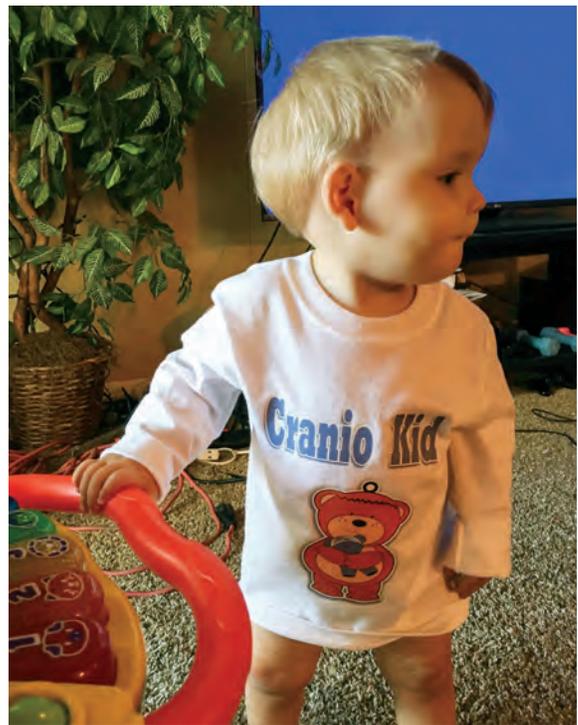
Watch Betzabeth's story –
www.lebonheur.org/promise



Most craniofacial surgeries are performed when the patient is between 6 to 12 months old. During a routine check-up, Robert Wallace, MD, measure's Parker Vance's skull growth.

positional molding has proven to be an effective method to reshape the skull. Most Le Bonheur craniofacial patients have surgery when they are between 6 to 12 months old, Wallace said. Annually, Le Bonheur performs more than 40 craniofacial surgeries.

“For someone born with a facial deformity, they may need a plastic surgeon to fix the facial skeleton but they may also need dentistry or oral surgery to make sure their teeth are properly aligned,” Boop said. “Or the patient may need surgery to fix the jaw so they can swallow properly or sometimes they may have problems with sleep apnea because their airway is compromised.”



Braxton Ganus was born with sagittal suture synostosis. Le Bonheur surgeons removed the prematurely fused suture in August.

ONE-STOP CLINIC VISIT

Every month, Boop, Wallace and Paul Klimo, MD, chief of the Division of Pediatric Neurosurgery, lead the hospital's Craniofacial Clinic, where patients and their families can meet with Le Bonheur neurosurgeons and plastic surgeons to discuss any medical questions or concerns.

Combining multiple disciplines into one comprehensive clinic is a benefit to all patients, Wallace said, as parents and their children can see multiple

"It's not just a cosmetic problem. If a child's brain development is not allowed to happen then they are not going to recover from that."

specialists in one visit. The dentistry and oral surgery specialties also hold a separate, monthly clinic to help treat children with facial deformities. The two clinics collaborate when deciding a patient's best surgical option.

During clinic days, the team sees more than 15 patients and meets after each one to discuss the child's medical condition and surgical options. Having various subspecialties in one cohesive clinic not only saves families time but also ensures they stay informed about treatment options and outcomes, said Le Bonheur Oral

Robert Wallace, MD

MEET THE TEAM



Frederick Boop, MD

Co-director, Neuroscience Institute, Medical Director, Neurosurgical ICU, Le Bonheur Children's Hospital; Professor and Chairman, Department of Neurosurgery, University of Tennessee Health Science Center; Chief, Division of Pediatric Neurosurgery, St. Jude Children's Research Hospital



Paul Klimo, MD

Chief, Division of Pediatric Neurosurgery, Assistant Professor, University of Tennessee Health Science Center



Robert Wallace, MD

Medical Director, Pediatric Plastic Surgery, Le Bonheur Children's Hospital; Chairman and Professor, Plastic Surgery, University of Tennessee Health Science Center



Russell Peck, DDS

Oral Maxillofacial Surgeon, Le Bonheur Children's Hospital

Maxillofacial Surgeon Russell Peck, DDS.

“When a patient has to bounce from one appointment to another, the explanation and ideas given by doctors can be disjointed,” Peck said. “The biggest benefit of the clinic is that it gives parents an explanation of their child’s problem. The beauty of the team concept is that it ties it all together and prevents any loose ends.”

EVALUATING PATIENTS AND OUTCOMES

After surgery, Le Bonheur physicians follow their patients for years, many until they are at least 5 years old. All patients’ surgical procedures and outcomes are entered into a database, and Wallace keeps a photo library of the children, pre- and post-surgery, to compare their appearances as they age.

“It allows us to assess the overall results because we do these operations at a very early age,” Wallace said. “The

Case Study: Braxton Ganus

Sagittal suture synostosis

Brittany and Jordan Ganus weren’t overly concerned when they noticed their son, Braxton, was born with a large bump on the back of his head.



Braxton Ganus

It wasn’t anything to be worried about, the doctors assured Brittany and Jordan – maybe it was from the stress of labor and the birth canal that caused Braxton’s head to grow to an irregular shape. The doctors in Blytheville, Ark., told the couple to closely monitor his skull growth over the next few months and to let Braxton lay on the back of his head. Eventually the skull would flatten and grow normally, they were told.

At Braxton’s 6-month check up, the pediatrician noticed the back of his skull had grown larger and was elongated and narrow. An X-ray showed that his skull sutures had prematurely fused. Braxton was diagnosed with sagittal suture synostosis.

“His head was long and pointy in the back and was cone-shaped,” Brittany said. “When I began researching sagittal suture synostosis online I was really scared because the first thing I thought was surgery.”

After his diagnosis, the Ganus family was then referred to Le Bonheur Children’s Hospital where surgeons Paul Klimo, MD, chief of Pediatric Neurosurgery, and Robert Wallace, MD, medical director of Pediatric Plastic Surgery, were able to perform a craniectomy on Braxton in August.

“The change in head shape is dramatic,” Wallace said.

Every six months, Braxton will return to Le Bonheur where Wallace will monitor his skull growth.



In August, Le Bonheur surgeons removed Braxton Ganus’ fused suture. “The change in head shape is dramatic,” said Robert Wallace, MD.



skull and brain growth is not complete, and the only way to know if what you are doing is correct is by following these children for many years. We have many children who come back to our clinic five or six years post operation.”

Following patients for several years also allows Le Bonheur doctors to determine whether additional surgeries are required.

Such is the case for Betzabeth, now 7, who will undergo her 12th surgery next summer to move her orbital and nose bones closer together to create a bridge for her nose. Mom Cynthia said Le Bonheur’s craniofacial program has dramatically improved her daughter’s appearance.

“When she was born it was a shock, but as the days went by I thought, ‘This is my little girl and we’re going to get through

it.’ Somehow, somehow she’s going to grow up, and she may be America’s Next Top Model. You never know,” Cynthia said.



Betzabeth Fajardo has undergone 11 surgeries to fix her Tessier cleft palate. She will have her 12th surgery next summer to move her orbital bones and nose closer together.



Medically complex

New legislation aims to coordinate care, reduce costs for children with complex medical conditions

Diagnosed with a congenital heart defect and bilateral hearing loss, Lizzie Kate Gray has had two major surgeries, nearly 30 hospital stays and hundreds of follow-up and therapy appointments in her five short years.

It's a journey Lizzie Kate's parents, Josh and Laurie Gray, never expected after a healthy pregnancy and smooth delivery. The heart diagnosis came first

– within hours of Lizzie Kate's birth on a Friday night in May. She looked ashen, Laurie said. Her coloring, a "bit off."

The Grays were grateful for Lizzie Kate's relatively smooth recovery from heart surgery, but another devastating blow was around the corner. Lizzie Kate failed her newborn hearing screening, and a second test a couple weeks later confirmed the Grays' fears: she was deaf.

"We were just learning how to be

parents for the first time," said Laurie.

"Let alone parents of a heart baby who couldn't hear."

The Grays are one of nearly 3 million families in the United States facing the hard road of caring for a medically complex child – coordinating multiple specialty appointments, keeping track of medications, staying on top of therapy to make sure their child doesn't fall behind.

A bipartisan bill called the Advancing Care for Exceptional Kids Act of 2015 (ACE Kids Act) aims to improve the delivery of care for children like Lizzie Kate. Reintroduced this year, the ACE Kids Act proposes a system of care designed around the unique health care needs of children with complex medical conditions.

The term “medical complexity” describes those with chronic health conditions affecting multiple organs and requiring a lifetime of care.

“These kids need experts in many different disciplines, which means they are best cared for only in the most comprehensive centers with a full range of services like large children’s hospitals,”



ACE Kids Act

[S. 298 (Grassley/Bennet)/H.R. 546 (Barton/Castor)]

At a glance

- **Optional for states that want to improve and better coordinate care for children with medical complexities with accountable teams of pediatric providers**
- **Works within a state’s existing Medicaid structure**
- **Cost savings and improved quality for medically complex patients, according to published studies**
- **Bipartisan support with 39 cosponsors in the Senate and 227 cosponsors in the House**

Source: Children’s Hospital Association

Learn more at www.acekidsact.org.

said Jon McCullers, MD, pediatrician-in-chief at Le Bonheur Children’s

definition of medical complexity. The

Hospital and chair of the Department of Pediatrics at the University of Tennessee Health Science Center.

The majority of medically complex children – nearly 2 million – rely on Medicaid to help them access care. They account for only 6 percent of those who use Medicaid, but nearly 40 percent of all Medicaid costs.

The goal of the ACE Kids Act: to better coordinate multidisciplinary care for these children and reduce costs.

The model proposed under the ACE Kids Act establishes a medical home for children who meet the

Medically complex children account for only **6 percent** of those who use Medicaid, but nearly **40 percent** of all Medicaid costs.

medical home – like a children’s hospital or other equipped entity -- would serve as a hub and partner with other specialists to provide the full range of care. This enhanced coordination reduces the burden on families and improves efficiencies, says McCullers. Advocates of the legislation estimate

a cost savings of nearly \$13 billion in 10 years for Medicaid through reduced hospital admissions and emergency room visits and fewer duplicated tests and procedures.

The new legislation would also make it easier for families to travel across state lines for care – as is often necessary due to the limited number of experts who can care for these kids’ unique conditions.

The Grays, for instance, were living in rural Missouri where Josh

worked as a pastor when Lizzie Kate was born. She underwent heart surgery 120 miles from home

“The number of children with medical complexities is rising thanks to advances in medicine that allow children born prematurely or with a congenital health condition to survive to childhood. This legislation is needed. It’s the right thing for these kids.”

Jon McCullers, MD, pediatrician-in-chief at Le Bonheur Children’s Hospital

at Le Bonheur Children’s Hospital, where the Grays felt confident doctors had the experience and expertise needed to help their daughter.

“We knew we were where we needed to be, and the last thing we wanted to have to worry about was whether we would be covered (by insurance) because we crossed state lines,” said Laurie. “For many families, that’s the case.”

The ACE Kids Act currently

has the support of more than 250 legislators nationwide.

The Grays were one of 47

families who traveled to Washington, D.C., this past July to advocate for the ACE Kids Act on Capitol Hill as part of the Children’s Hospital Association’s Family Advocacy Days.

Now is the best time

to take a hard look at how care is delivered to these children, says McCullers.

“The number of children with medical complexities is rising thanks to advances in medicine that allow children born prematurely or with a congenital health condition to survive to childhood,” said McCullers.

“This legislation is needed. It’s the right thing for these kids.”

Creating map for precision medicine brings Brown to Le Bonheur

Chester Brown, MD, PhD, says one day he'll be able to study a child's genetic blueprint and assess his or her risk for certain diseases. He'll be able to create a roadmap of precision-based medicine that helps physicians develop the most effective treatment options for children.

Brown recently joined Le Bonheur as its Genetics division chief in June. He also serves as chief of genetics at St. Jude Children's Research Hospital, and is a professor and the St. Jude Chair of Excellence in Genetics for the Department of Pediatrics at the University of Tennessee Health Science Center.

He comes to Memphis from Baylor College of Medicine where he helped build one of the world's largest and most respected genetics programs. Brown spent 20 years as a faculty member in the departments of Molecular and Human Genetics and Pediatrics and as a research faculty member in the Graduate School of Biomedical Sciences.

Brown said one of his first goals at Le Bonheur is to expand the hospital's genetics program, focusing on clinical vision, research and education.



Chief, Genetics, Le Bonheur Children's Hospital



"It's clear that there's an important need in the community for genetics and genomics education," Brown said. "We really need to help people understand the power of these technologies — what they do, what they can't do, not just in the hospital's bubble but in the broader Memphis community."

Brown's vision for educating the community about the importance of genomics will be vital to the program's success,

said Pediatric Endocrinologist Joan Han, MD, director of Le Bonheur's Pediatric Obesity Program. Han and her team members work closely with the genetics program to study and find the best treatments for obese children.

With his extensive background in genetics, Han said Brown is one of the most prominent researchers in his field.

"Genetic factors greatly contribute to a patient's predisposition for developing obesity and obesity-related health complications. With his expertise in the genetics of body composition, Dr. Brown has been a wonderful partner and enthusiastic supporter of the Pediatric Obesity Program and our mission to advance personalized approaches for the prevention of treatment of childhood

obesity,” Han said. “He has infused our program, as well as the genetics division, with vital new ideas for improving patient care and designing cutting-edge research studies that could impact how physicians worldwide diagnose and manage genetic disorders.”

And designing state-of-the-art research studies includes expanding Le Bonheur’s efforts in collecting and storing a child’s DNA to create precision-based medicines that will allow physicians to provide better care for their patients. Collected DNA will be stored in Le Bonheur’s biorepository and that information will be used for future research studies.

“With our biorepository efforts, we want patients to come in and give permission to use their leftover blood samples so that their DNA samples can be used for research purposes,” Brown said. “We can take their DNA information to inform doctors how to take care of their patients.”

He has spent much of his career focused on studying how genes control lean and fat body mass, more recently studying how host genomic factors influence HIV and tuberculosis progression in African children, while training African scientists how to carry out such studies independently.

Brown also is a co-investigator with the Collaborative African Genomic Network (CAfGen) and Human Heredity and Health in Africa (H3Africa) consortium, funded

by the National Institutes of Health, which aims to use genomic approaches to discover factors that influence the progression of HIV and HIV-TB in African children. He has co-authored more than 30 publications in various scientific and medical journals.

Another area Brown said he will focus on is expanding genomic research studies in African Americans in the Memphis area. Although African Americans are a majority in Memphis, Brown said that population is underrepresented in research studies that use genomic science.

“We are offering a unique opportunity to contribute to the

broader picture of genomics and how genes might impact the care of patients in this community,” Brown said. “Is there anything different that we can learn from African ancestry and how can we inform everyone about mechanisms that can contribute to different diseases.”

While advancing Le Bonheur’s growing Le Bonheur’s genetics division, Brown also plans on recruiting additional practitioners and developing new genetics-based programs that will rely heavily on DNA sequencing.

“With growing the clinical side, our practitioners will be able to take care of patients with genetic disorders, and our institution as a whole will be able to develop programs that allow us to do world-class research,” Brown said. “Our ultimate goal is to generate data that will inform doctors how to best take care of our patients.”

“Our ultimate goal is to generate data that will inform doctors how to best take care of our patients.”

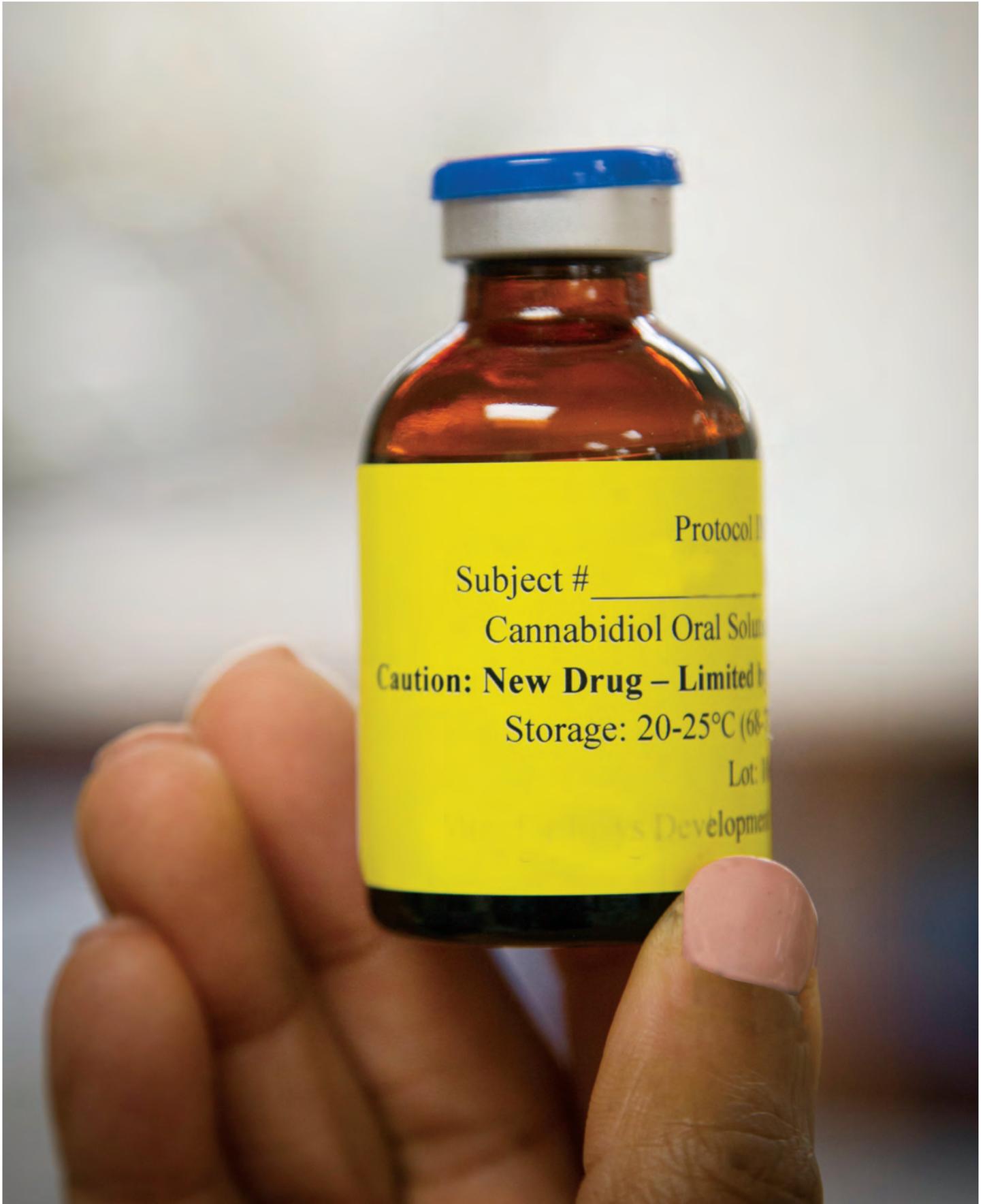
Chester Brown, MD, PhD
Genetics Division Chief

Chester Brown, MD, PhD

Education and Training

Baylor College of Medicine – Residency Medical Genetics
Baylor College of Medicine – Residency Pediatrics

University of Cincinnati College of Medicine – Medical School
University of Cincinnati College of Medicine –
Howard University – B.S. Zoology/Chemistry



Le Bonheur recently enrolled its patients into a clinical trial of cannabidiol (CBD), a compound extract from a cannabis plant. Neurologists hope CBD will minimize the amount of seizures for children with epilepsy.

Calming seizures

Cannabidiol helps control seizures in children, study finds

Neurologists at Le Bonheur Children's Hospital are leading a new pediatric clinical trial of cannabidiol (CBD), a compound extract from a cannabis plant, which they hope will help minimize the frequency and length of seizures for children with epilepsy.

The new trial, currently in its third phase, studies the potential benefits of CBD for children with epilepsy. Le Bonheur started its study of CBD drug treatment in 2015 and is the only children's hospital in Tennessee to provide such care.

Results are promising. Researchers

have found some children who have been using CBD have had fewer seizures and that those seizures are shorter in duration, said James Wheless, MD, chief neurologist and co-director of Le Bonheur's Neuroscience Institute.

"In our CBD trials, some of

James Wheless, MD, chief neurologist and co-director of Le Bonheur's Neuroscience Institute, said some patients have had fewer seizures since taking the CBD compound.



the children have had a sustained reduction in seizure number, with one child doing well enough to lower the other seizure medication," Wheless said.

To enroll in the trial, each child must be treatment resistant to at least three epilepsy medications, parents must record their child's seizure frequency and quality of life and the patient can't have any other medical issues that would interfere with the monitoring and clinical drug trial.

During the first phase of the drug trial, children were hospitalized at Le Bonheur for 11 days and given the oral medication daily. The second phase began when the children were released from Le Bonheur and their parents began administering the medication. The children will be monitored by their doctors for one year.

The Neuroscience Institute's lead

Clinical Research Coordinator Tracee Ridley-Pryor, MSN, RN, CCRC and her team have closely monitored the new drug's effects on children. The CBD compound contains less than 1 percent of tetrahydrocannabinol (THC), the chemical responsible for most of marijuana's psychological effects, and does not contain enough to cause psychoactivity, Ridley-Pryor said. Researchers see CBD as a supplemental treatment for children suffering from epilepsy.

"There has been a significant change in the number of seizures the patients report experiencing," Ridley-Pryor said. "Not only have the seizures decreased in frequency, they have also been shorter in duration. Our families are quite happy about this and so are we."

Stephanie and Danny Pearson's 15-year-old daughter, Sydnie, is one of

Le Bonheur's first epilepsy patients to receive CBD.

Sydnie had her first seizure when she was 4 months old. Since then, Sydnie would suffer from more than six convulsive seizures a day



and required 24-hour care. When Le Bonheur doctors suggested the Pearsons try the hospital's new CBD drug trial, the Fort Smith, Ark., residents immediately signed up. Prior to CBD treatment, epilepsy

medications did little to slow down Sydnie's seizures. At 16 months, a vagus nerve stimulator was implanted, which helped reduced the number of seizures but did not stop them completely.

"It's devastating to watch your child suffer from seizures, and there's nothing you can do about it," Stephanie Pearson said. "When they asked if we wanted to participate in the new trial, we were thrilled."

Stephanie Stanley administers medication to her son, Peyton, during a recent visit to Le Bonheur. Peyton is one of several children currently enrolled in Le Bonheur's CBD drug trial.



After Sydney's first dose of CBD, 12 hours passed before she had her next seizure – the longest period that she had ever been seizure free. Stephanie said her daughter's health continues

“It’s devastating to watch your child suffer from seizures, and there’s nothing you can do about it. When they asked if we wanted to participate in the new trial, we were thrilled.”

Stephanie Pearson, mother of Sydney

to improve with the new medication and her seizure frequency and length have reduced dramatically.

Children enrolled in the drug trial are required to return to Le Bonheur for multiple follow-up visits where researchers will record seizure activity

data, as well as any side effects or concerns from parents.

Ridley-Pryor said the children will most likely continue to take CBD in addition to other anti-seizure medications. While epilepsy medications have proven to help some children, the drug's side effects often can make a child sluggish, Ridley-Pryor said. The side effects of CBD are less severe and are easier to tolerate compared to most epilepsy medications.

“Cannabidiol seems to have a milder side effect profile,” Ridley-Pryor said. “With other medications, if you want to calm the seizures, you have to calm the brain, and this may unintentionally lead to decreased energy, sleepiness or behavior changes. While taking CBD with other epilepsy medications, our kids seem to be more interactive, a positive outcome

we like to see.”

In the past 20 years, the use of medical marijuana to help with pain management, neurological disorders and other medical conditions has gained popularity. As of July, 25 states and Washington D.C. permit the use of medical marijuana. In August, the Drug Enforcement Agency said it will allow researchers and drug companies to grow research-grade marijuana.

With Le Bonheur leading the way to finding more effective treatments for epileptic children, the Pearsons remain hopeful that CBD will one day help their child to a better quality of life.

“The entire family feels overwhelmingly blessed because there’s finally hope that she’s going to make it to her 18th birthday and beyond,” Stephanie Pearson said.



STAMP OF APPROVAL

Le Bonheur uses *U.S. News*' Best Children's Hospital survey to improve care

When Pediatric Neurologist James Wheless, MD, told the Drash family of Atlanta he thought he could help their son, Billy, they didn't hesitate to travel nearly 400 miles to Memphis, Tenn.

The Drashes, who had met with numerous neurologists throughout the country for Billy's seizures, jumped at the chance to consult with Wheless, one of the country's leading experts on pediatric epilepsy.

The Drash family of Atlanta travel to Le Bonheur's Children's Hospital for their son's care. Billy has epilepsy.

Since their initial visit two years ago, the Drashes have continued to make that drive two to three times a year for Billy's care at Le Bonheur Children's Hospital, where Wheless has built a world-class epilepsy program focused on outcomes and research.

They know they are with one of the best, thanks in large part to the *U.S. News & World Report* "stamp of approval" that has recognized Le Bonheur's Neuroscience Institute as one of the top pediatric neurology and

neurosurgery programs in the country for six straight years.

The work that Wheless, and the rest of Le Bonheur, puts in to make that list is a concerted effort to implement best practices and improve outcomes for patients like Billy. *U.S. News* recognized Le Bonheur in 2016 specifically for its comprehensive multidisciplinary programs, clinical best practices and patient outcomes.

JOURNEY TO RECOGNITION

Since it first applied in 2007, Le Bonheur has used *U.S. News'* Best Children's Hospital survey as a standard bearer for best practices.

"[The rankings] allow us to verify that our programs are at or above the level of other top children's hospitals and reassure parents and families about quality of care and dedication to improvement," said Le Bonheur President and CEO Meri Armour.

U.S. News & World Report has ranked hospitals for 25 years, and its Best Children's Hospitals survey remains the only comprehensive survey of pediatric hospitals to date. The survey uses hospital quality metrics, infrastructure, programs and clinics and national reputation – among other measures.

Each year, hospital leaders use the tool to analyze and identify improvements and gaps, says Armour.



James Wheless, MD, chief neurologist and co-director of the Neuroscience Institute, has built a world-class epilepsy program at Le Bonheur Children's Hospital.



Above, Pediatric Neurologist Namrata Shah, MD, treats patients in the Muscular Dystrophy Association Clinic – one of several coordinated, multidisciplinary programs Le Bonheur has strategically developed.

The initial focus in 2007: build the infrastructure needed to support strong programs, including top-tier talent and multidisciplinary programs.

The hospital focused on developing coordinated programs and clinics, including a Tuberous Sclerosis Center of Excellence, Muscular Dystrophy Association Clinic and Pediatric Vascular Anomalies Center. Le Bonheur also grew its hospitalist, palliative care and acute pain/sedation services for patients.

Proper staffing was also a first focus, driving the hospital to adopt a fully integrated physician practice

plan, appoint service line-specific advanced practice nurses and add four ACGME-accredited fellowships. In the last two years alone, the hospital has added more than 50 pediatric specialists, including leading experts in heart failure, pediatric obesity and tuberous sclerosis.

With infrastructure in place, hospital leaders and clinicians have focused on implementing best practices and improving outcomes.

Le Bonheur invested in cutting-edge technology, like transcranial magnetic stimulation and functional MRI that help physicians understand a patient's brain

LE BONHEUR'S PROGRESS

structure and function when making surgical decisions for patients with epilepsy. Now, EOS imaging ensures that scoliosis patients receive significantly smaller doses of harmful radiation, and an intraoperative MRI significantly reduces the need for additional operations or sedations for children undergoing brain tumor surgeries.

Clinician leaders implemented programs centered on infection prevention, including mandatory flu vaccines for high-risk patient populations, an antimicrobial

stewardship program and hand hygiene compliance measures. New family-oriented services were put into place, like a parent mentor program, Family Resource Center and a highly engaged Family Partners Council.



Le Bonheur has invested in cutting edge technology, like a 3T intraoperative MRI that significantly reduces the need for additional operations and sedations for children undergoing brain tumor surgeries.

In a push to improve quality for patients, Le Bonheur joined a handful of national quality and safety collaboratives, changed physician rounding models to encourage better continuity of care, and applied for specialty certifications areas like EEG, epilepsy, radiology and adult congenital heart disease.

SEEING RESULTS

Le Bonheur's efforts to challenge physicians and other staff members to become better have paid off.

Since 2007, Le Bonheur has improved outcomes in several key areas, including reduced readmissions for neonatal, neurosurgical and asthma patients, fewer unplanned returns to the operating room for spinal fusion surgeries, shorter lengths of stay and best-in-class surgical outcomes in cardiac, neuroscience and orthopaedics.

Best-in-class patient outcomes – like seizure-free

Since 2007, Le Bonheur has improved outcomes in several key areas, including **reduced readmissions** for neonatal, neurosurgical and asthma patients, **fewer unplanned returns to the operating room** for spinal fusion surgeries, **shorter lengths of stay** and **best-in-class surgical outcomes** in cardiac, neuroscience and orthopaedics.



Top notch technology — like transcranial magnetic stimulation — is part of the reason Le Bonheur's Neuroscience Institute attracts patients from around the country.

rates for epilepsy and survival rates for complex heart procedures – are attracting patients from across the country. In 2015, patients from all 50 states and 14 countries came to Le Bonheur seeking its exceptional care.

Further proof of Le Bonheur's journey to be recognized among the best is its recent Magnet designation by the American Nurses Credentialing Center (ANCC). Magnet is considered one of the



ultimate credentials in high quality nursing care, and in March, Le Bonheur joined the ranks of

only 7 percent of hospitals in the country to have earned that distinction.

The hospital's patient satisfaction scores have also improved. For the past two years, 85-90 percent of families have ranked overall care at Le Bonheur a 9 or 10 on a 10-point scale.



Le Bonheur's reputation as a leader in pediatric care has helped recruit top tier talent. John Bissler, MD, was recruited to help lead the Tuberous Sclerosis Center of Excellence.

“When you find that level of care, you’ll do whatever it takes to return. Even if it means driving seven hours for a check-up.”

Wayne Drash, Billy's dad

Le Bonheur's commitment to bettering care for patients is palpable, says the Drash family.

“When you find that level of care, you'll do whatever it takes to return,” said Wayne Drash, Billy's dad. “Even if it means driving seven hours for a check-up.”

WHY IS LE BONHEUR A “BEST CHILDREN'S HOSPITAL”?

- American College of Surgeons Level 1 Pediatric Trauma Center designation
- Magnet designation
- Infection prevention best practices, including hand hygiene, antimicrobial stewardship and measures to prevent central line-associated blood stream infections
- Quality and safety best practices, including simulations, training, root cause analysis
- Best-in-class complex surgical outcomes in cardiac, neuroscience and orthopaedics
- Participation and benchmarking with national quality registries
- National certification in ECMO, adult congenital heart disease, radiology, epilepsy and EEG
- Seizure-free rates 12 months after epilepsy surgery
- Prevention of surgical complications including readmissions and returns to the operating room

Cohen awarded as 2016 Honored Educator by RSNA

Le Bonheur's Chief of Radiology Harris Cohen, MD, recently received the 2016 Honored Educator award from the Radiological Society of North America (RSNA). This achievement recognizes dedication to furthering the profession of radiology and commitment to radiology education by delivering high-quality educational content for RSNA endeavors.



Harris Cohen, MD

CEO Armour speaks at U.S. News leadership summit

Le Bonheur President and CEO Meri Armour spoke on "Stepping Up Pediatric Patient Safety" at the 2016 U.S. News Healthcare of Tomorrow National Leadership Forum in Washington D.C. on Nov. 3. The summit is the first forum of its kind to bring together the nation's most distinguished hospital executives, medical experts and thought leaders to examine the industry's critical challenges and identify optimal solutions.



Meri Armour

Le Bonheur HIV Network awarded for excellence in testing

Le Bonheur's Community HIV Network received the Outstanding HIV Testing Program award during the Tennessee

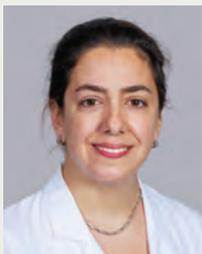


Department of Health's HIV Prevention Services' statewide meeting in September. The Community HIV Network was recognized for "excellence in HIV testing in 2015." Since 2009, the program has tested more than 100,000 people for HIV.

Dubin recruited as Pulmonology chief

Patricia Dubin, MD, recently joined Le Bonheur as chief of Pediatric Pulmonology and Sleep Medicine. Dubin comes to Memphis from West Virginia University School of Medicine, where she was chief of Pediatric Pulmonology and Sleep Medicine and director of the Mountain State Cystic Fibrosis Center.

She completed her medical school training at the University of Rochester School of Medicine and Dentistry, pediatric residency at Yale New Haven Children's Hospital and pediatric pulmonology fellowship at the Children's Hospital of Pittsburgh.



Patricia Dubin, MD



Le Bonheur opens East Memphis outpatient center, breaks ground in Jackson

Le Bonheur opened its new outpatient center at 100 N. Humphreys in East Memphis, providing convenient access to 13 pediatric specialty clinics and diagnostic and rehabilitation services for families in the eastern portion of Shelby County.

The location features state-of-the-art diagnostic equipment and services, including a 640-slice CT scanner and the quietest MRI in the region with largest bore – all designed to offer the safest, most comfortable options for pediatric patients.

Le Bonheur also recently broke ground on its new 30,000-square foot outpatient center in Jackson, Tenn. Expected to open Fall 2017, the facility will feature 20 exam rooms for nine subspecialty clinics and a full range of diagnostic services, lab, X-ray, ultrasound, EKG, EEG, ECHO and pulmonary function testing.



Study evaluates RSV vaccine strategies

Vaccinating children younger than age 5 is the most efficient and effective way to prevent respiratory syncytial virus (RSV) in both children and older adults, according to a recent study published in the *Proceedings of the National Academy of Sciences*.

Co-authored by Le Bonheur's John DeVincenzo, MD, the study used a transmission model to evaluate the age-stratified population effectiveness of a vaccination program in the United States. The model integrated data on daily infectious viral load and behavior changes while symptomatic — the two main drivers of RSV transmission. Findings showed that children are disproportionately responsible for transmission due to higher viral loads, longer durations of infection and greater frequency and duration of contacts.

RSV is a leading cause of lower respiratory tract infections worldwide and a leading cause of infant hospitalization. The World Health Organization estimates a vaccine will be available in the next five to 10 years.



John DeVincenzo, MD



New heart heralds new era at Le Bonheur

Lyrice Everhart, 20 months, of Memphis, Tenn., received a life-saving heart transplant at Le Bonheur Children's Hospital on Oct. 22. Diagnosed with idiopathic dilated cardiomyopathy only a month before, Lyric had limited time without a new heart.

For Le Bonheur, Lyric's transplant signifies the culmination of years of work, recruitment and strategy to house a transplant program within its world-class Heart Institute.

"I am proud to be part of the Heart Institute transplant team and expect that we'll be able to eventually perform 10-12 transplants per year," Umar Boston, MD, surgical director of Heart Transplant and Mechanical Circulatory Support, said. "The transplant is an important milestone for the Heart Institute program and for Le Bonheur as a center of excellence for the care of children in our community. We know that this will help families in our community who have children with end-stage heart disease."

Earlier this year, the Heart Institute received a three-star rating — the highest possible — from The Society of Thoracic Surgeons (STS) in the Spring 2016 STS Congenital Heart Disease Database Feedback Report.

"The heart transplant program is the final piece in the puzzle of building a world-class Heart Institute at Le Bonheur," said Meri Armour, Le Bonheur president and CEO. "The families we care for are the real winners here, as they now have yet another level of stellar pediatric care available to them."