

SECURING THE PROMISE

WINTER 2016

A Grateful Heart

*Family finds complex heart care at home,
looks to tomorrow*

- ♥ Memphis Grizzlies forward inspires young patient
- ♥ Chocolatier creates "Heart of Le Bonheur"

Le Bonheur
Children's Hospital

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.

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Securing the Promise is a publication of Le Bonheur Children's Hospital, produced by Le Bonheur Institutional Advancement. If you have any questions or wish to be removed from the mailing list, please contact us at 901-287-6308 or info@lebonheur.org.

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In this issue:



2 A GRATEFUL HEART *Family finds heart care at home*



16 A SPECIAL GIFT *Family honors son, Le Bonheur*



18 CAMP CONFIDENCE *Cardiac camp changes child's outlook on heart condition*



22 ALL HEART *Grizzlies player inspires heart patient*



26 A HOLE IN ONE *Local golf teaching professional finds passion for Le Bonheur*



32 CHOCOLATE FOR A CAUSE *Memphis chocolatier creates "Heart of Le Bonheur" chocolate*



36 A GOOD FIT *From jewelry-maker to dragon slayer, volunteer meets the needs of Le Bonheur children*

Support Le Bonheur

For more information about ways to support Le Bonheur Children's by volunteering, attending events, developing partnerships and giving financially, please visit lebonheur.org/ways-to-help or call 901-287-6308.

www.lebonheur.org/secure



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MESSAGE FROM MERI

Dear Friends,

One of the greatest gifts I receive from working at Le Bonheur is watching children take back healthy childhoods. Ten-year-old Madeline Flack (below right) is one of those kids. She was born with a hole in her heart and has undergone several procedures – including open-heart surgery – to repair her condition. Those surgeries and regular check-ups have given Madeline a happy, full childhood.

Twenty years ago, Madeline might not have had that chance. Pediatric cardiology and cardiac surgery are relatively new fields that are always changing with innovation and new technology. Every year we find better ways to care for congenital heart conditions that allow children to remain active into adulthood and even have children of their own.

Your gifts help give children a chance at a full life.

Today, we are on a new frontier of pediatric cardiology. Le Bonheur's growing team of cardiologists and cardiac surgeons are discovering new ways to mend the most complex heart conditions. Our nurses, doctors, therapists and other specialists work furiously to find better treatments. They know children depend on them.

Those children also depend on you. Investments in our Heart Institute have made all the difference for these children and their families. When you give to Le Bonheur, you provide hope for so many families.

We depend on your generosity, and we're so grateful for the ways you continue to meet these needs. For every child like Madeline who needs your continued support, we say thank you.

Sincerely,



Meri Armour, MSN, MBA
President and CEO





A Grateful Heart

Theirs is a story of gratitude.
Of a blue-eyed, curly-haired boy, born on Thanksgiving Day.
Of a healthy pregnancy and a smooth delivery.
Then, a terrifying diagnosis turned their lives upside down.



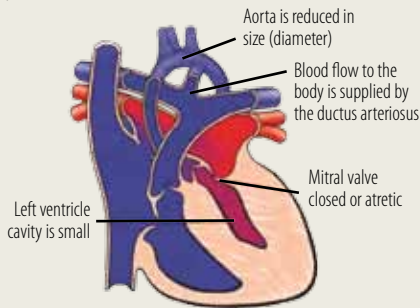
The fear came first. And then the gratitude. For people who took them in and cared for them. For a place that understood healing is more than medicine. For experts who knew how to mend a broken heart.

Just hours after the birth of their first child, Jack, Mark and Saralyn Crowell learned the devastating news that their son was born with a heart



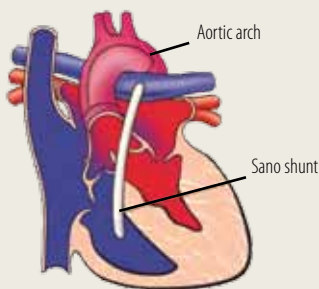
HYPOPLASTIC LEFT HEART SYNDROME

Shortly after their first son, Jack, was born, Mark and Saralyn Crowell learned that he had a life-threatening condition: hypoplastic left heart syndrome (HLHS). Hypoplastic left heart is a congenital condition where the left side of the heart is underdeveloped, affecting normal blood flow. The defect is usually fatal unless treated within the first few days of birth.



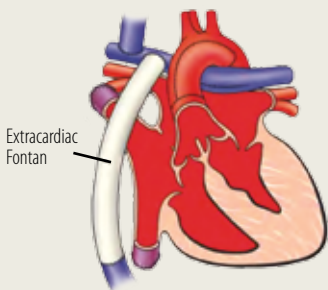
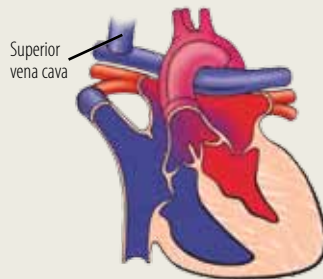
Cardiologists and cardiac surgeons at Le Bonheur Children's were able to provide the care that Jack needed quickly. Their approach: three planned surgeries staged throughout more than two years to replumb his heart.

THREE PLANNED SURGERIES



1. 6 days old: Surgeons performed the most complex and riskiest stage of Jack's heart reconstruction, known as the **Norwood procedure**. Jack's doctors enlarged the aorta and hooked it to the right ventricle, allowing blood to pump to both the lungs and the body without keeping the ductus arteriosus open. Blood traveled to the lungs through a small tube, called a Sano shunt, that allowed blood to bypass the underdeveloped left side of the heart.

2. 4 months old: Surgeons performed the second staged procedure, the **bidirectional Glenn**, to connect the superior vena cava to the right pulmonary artery, allowing deoxygenated "blue" blood to travel from the upper part of the body to the lungs. The Sano shunt is disconnected and half of the blood is directed directly to the lungs without going through the ventricle.



3. 32 months: Surgeons performed the last of the three stages, the **Fontan procedure**, to connect the inferior vena cava (the vessel that drains deoxygenated blood from the lower part of the body into the heart) to the pulmonary artery. They created a channel to direct blood through the pulmonary artery — allowing all de-oxygenated blood to now flow passively through the lungs.



Mark Crowell with his infant son, Jack.

defect. **His diagnosis:** Hypoplastic left heart syndrome (HLHS), a condition where the heart's left ventricle is underdeveloped and can't pump blood to the left side of the body. The condition is usually fatal unless treated within a few days or weeks after birth.

"We were totally at the mercy of God's will," said Mark. "But that's what saved Jack's life: All those people were in place the day we walked in the door of the hospital. We were thankful for the foresight Le Bonheur had to put a team in place that could care for kids like our son."

That team spent the past three years caring for Jack, as he underwent three major heart surgeries, extensive hospital stays and dozens of doctors' visits. Given the chance to seek care elsewhere, the Crowells knew that Memphis and Le Bonheur Children's offered their son the best chance. And for that, they are grateful.

Illustrations by the American Heart Association

BLUE BABY

After a normal delivery – and no previous need for concern – the Crowells thought they were bringing their son home. But after Jack struggled several times to feed, his oxygen levels started to fall.

He was beginning to look blue and grey, and he was quiet. Then came the diagnosis of HLHS.

“Immediately your heart sinks. Because, that’s not what you want to hear,” Saralyn said. “I had a normal, healthy baby less than 24 hours ago, and now they are talking about surgery.”

In a field of medicine where outcomes matter most, the Crowells started studying up on HLHS and their options. They rested easy knowing the Le Bonheur Children’s Chief of Cardiac Surgery and Heart



Jack Crowell was diagnosed shortly after birth with HLHS, a condition in which part of his heart is underdeveloped.

Institute Co-Director Christopher Knott-Craig, MD, was one of best in the field – a pioneer for some of the most complex congenital heart defect procedures.

Jack had more than the fighting chance he needed.

The Crowells remember those six long days between Jack’s birth and his first surgery.





“He wasn’t doing well when he got to Le Bonheur, and we couldn’t really interact with him,” Saralyn said. “The beeping and buzzing of the monitors, I remember thinking, ‘That beeping means he’s going to die. What if he doesn’t make it?’”

Six days after his diagnosis, Jack underwent the Norwood surgical procedure, the first of three planned surgeries Jack would need.

The Norwood is the most complex and highest-risk procedure in the planned staged surgeries. With it, Knott-Craig enlarged Jack’s aorta, and hooked it to the right ventricle – which allowed blood to pump to the body. Knott-Craig is one of few surgeons in the country who perform this

delicate procedure – and his success rate is higher (90 percent) than the national average (84 percent).

The Crowells were discharged a few days later,

left to take their fragile, only child home. Now they were alone with him. Tired and stressed, they held tightly to a handful of cell phone numbers from their cardiologists and Knott-Craig. Those numbers, they say, became their lifeline – the steady reassurance they relied on when they were most scared. They called and texted Jack’s doctors when they were unsure



Le Bonheur Chief of Cardiac Surgery Christopher Knott-Craig, MD, is a pioneer in repairing congenital heart defects.



The Crowell family says Le Bonheur’s expert heart care saved their son, Jack. Above, Saralyn and Mark Crowell discuss Jack’s case with Surgeon Christopher Knott-Craig, MD, following surgery.



Jack Crowell's cardiologist Dr. Jean Ballweg has cared for Jack since he was an infant. The two have a special bond.

what to do, and they always heard the support and encouragement they needed on the other end of the line.

"We offer a unique kind of care here," said Knott-Craig. "I believe that children heal faster when we care for the entire family and pay attention to the whole child. It's important to me that those families are at ease."

Four months later, Knott-Craig performed

the second staged procedure, a bidirectional Glenn procedure that allowed deoxygenated or "blue" blood to travel from the upper part of the body to Jack's lungs. The second surgery provided a more "stable physiology" for Jack, said Dr. Jean Ballweg, his cardiologist.

Ballweg became a friend to the Crowells, as they lived as "normal" of a life as they could with Jack for the next two years.

"He looked normal," Saralyn said. "He looked healthy. But he wasn't really."

This past July, Jack underwent the final planned surgery, the Fontan, which allows all deoxygenated blood to flow passively through the lungs. This "fix" should slowly increase Jack's energy and exercise levels, Ballweg said.

"We are fortunate that we have the expertise to be able to care for patients like Jack here and offer the staged procedures," Ballweg said.

A GROWING TEAM

The "foresight" that Mark spoke of to have the right experts in place when Jack needed them most is part of a growing Le Bonheur Children's Heart Institute

team focused on transforming the way it cares for children and adults with congenital heart disease.

Earlier this year, Le Bonheur recruited pediatric cardiologist and cardiac researcher Jeffrey Towbin, MD, to be the new Heart Institute executive co-director and chief of Cardiology. Towbin came from Cincinnati Children's Hospital Medical Center, where he built one of the country's most respected pediatric cardiology programs. He is an expert in the field of heart disease and heart failure, and has a clear vision of growing a program in Memphis that can meet the needs of children and adults who are living longer with heart defects.

"Today, most patients can survive with a heart defect," Towbin said. "Now, our challenge is to improve the quality of life for these children and adults."

In the next five years, the Heart Institute will expand the foundation with more depth of talent, technology and research. Leaders plan to develop 10 new super-specialized heart programs,

Jeffrey A. Towbin, MD, was recruited to lead the Heart Institute at Le Bonheur Children's Hospital in 2015. Towbin's vision for the program includes building destination programs, recruiting specialized talent, adding advanced specialty fellows and developing new areas of research.



recruit 25 new cardiologists, cardiac surgeons and researchers, and develop new areas of study.

In the areas of research, Towbin is building laboratories that focus more on personalized medicine for heart disease – using genetics to understand the best individual fix for each child.

The result: improved care for a fast-changing field that focuses on the needs of children and adults with congenital and acquired heart conditions.

NEW PROGRAMS

With your support, Le Bonheur will expand super-specialized programs like:

- Mechanical Circulatory Support
- Cardiovascular Genetics
- Adult Congenital Heart Disease
- Heart Transplantation
- Neurodevelopment
- Single Ventricle
- Sports Cardiology
- Obesity
- Cardio-Oncology, in conjunction with St. Jude Children's Research Hospital

INNOVATION FOR TOMORROW

While Saralyn worries most about today – whether her beautiful 3-year-old boy is healthy today – her husband only thinks about tomorrow.

Mark knows that science hasn't found a permanent fix for Jack's condition yet. The staged rewiring will help Jack live into adulthood, but eventually, his heart will grow tired.

Mark thinks about how he'll teach Jack to take care of his body – to eat and drink well and exercise enough, but not too much.

"HLHS is something that unfortunately is part of Jack," Mark said. "He will have to operate strategically and carefully on the edge of a physiological envelope. I don't ever want Jack to feel sorry for himself. I want him to enjoy life, but I don't want him to hurt himself in the process. It saddens me that he cannot *not* think about HLHS and the impact it will have on him daily. My goal is to do whatever I can to help Jack and other children like him live and thrive not just into adulthood but to age 100 and beyond." Mark considers scientists all over the world, including those at Le Bonheur, who are developing new mechanical devices, shunts or even growing new hearts. And he hopes that they can find better options for Jack before he needs them.

"Dr. Knott-Craig and Le Bonheur's cardiologists



Mark Crowell, right, hopes that advancements in science will allow Jack, left, to live a long full life. He and his wife, Saralyn, give to Le Bonheur to support Heart Institute innovation.

have been able to get these children into adulthood, so they have bridged the first major hurdle,” Mark said. “But what about the next 40 or 50, 60, 70 or 80 years? There is going to come a point when Jack needs a transplant.”

In her relatively short career, Ballweg says she’s seen great strides already in how cardiologists


treat children like Jack. Fifteen years ago, only about 10 percent of HLHS patients survived – most were just given comfort in their last days. Today, doctors

are getting them into adulthood.

“I think we are a ways away from an artificial heart, but there is a lot of focus now on mechanical support – in

“Dr. Knott-Craig and Le Bonheur’s cardiologists have been able to get these children into adulthood, so they have bridged the first major hurdle. But what about the next 40 or 50, 60, 70 or 80 years? There is going to come a point when Jack needs a transplant.”

Mark Crowell, father of Le Bonheur heart patient, Jack



"Sometimes, you don't really realize what a resource you have in Le Bonheur until you need it. Le Bonheur is the children's hospital for this city and this region. That's what saved Jack's life."

Mark Crowell, father of Le Bonheur heart patient, Jack



developing implantable devices that can improve quality of life,” she said.

Mark knows that advancements like this only come with supported innovation. He and his wife support the Heart Institute as monthly givers, donating what they can to help spur those discoveries. He has asked his friends and family to do the same.

“It’s all about the money coming in behind the skill and the talent,” Mark said. “Nothing moves without money.”

This fall, a job transfer for Mark moved the Crowells from Memphis to North Carolina. They continue to entrust Le Bonheur with Jack’s care – and know the investments the hospital is making in the Heart Institute will only build more expertise.

“Sometimes, you don’t really realize what a resource you have in Le Bonheur until you need it,” Mark said. “Le Bonheur is the children’s hospital for this city and this region. That’s what saved Jack’s life.”



Watch Mark and Saralyn share Jack’s story
www.lebonheur.org/secure



Your support in Le Bonheur helps support the team that cares for kids like Jack. Le Bonheur's Heart Institute includes:

- 3 pediatric cardiac surgeons
- 16 cardiologists
- 6 training fellows
- 3 cardiac anesthesiologist
- 80 specially trained heart nurses
- 5 cardiac researchers

The Heart Institute provides care for 12,800 pediatric visits a year.

Le Bonheur's Heart Institute



Le Bonheur's Heart Institute is a resource for all children in our community and region. Our doctors evaluate and treat all forms of congenital and acquired heart disease such as:

- Anomalous coronary artery (ACA)
- Aortic stenosis
- Atrial septal defects (ASD)
- Atrioventricular canal (AV canal or AVC)
- Bacterial endocarditis
- Cardiomyopathy
- Coarctation of the aorta
- Dilated cardiomyopathy
- Ebstein's anomaly
- Genetic cardiac conditions
- Heart murmurs
- Heart tumors
- Hypoplastic left heart syndrome (HLHS)
- Hypertrophic cardiomyopathy
- Myocarditis
- Patent ductus arteriosus (PDA)
- Pulmonary hypertension
- Pulmonary stenosis
- Rhythm disorders (arrhythmia)
- Tetralogy of Fallot (TOF)
- Transposition of the great arteries
- Ventricular septal defect (VSD)



Dr. Knott-Craig,
We wanted to thank you for all you've done for us and Jack. You have not only performed the most delicate and intricate of surgeries on our son with amazing results, but you have been patient with our endless questions and concerns. We feel as if you are a gift from God. Your selfless pursuit of excellence in your field, your compassion, your skill, and the way you connect with your patients is wonderfully unique. How blessed we are to have you caring for our son! Thank you for all you've done for Jack and the countless other children who have been fortunate enough to have you as their surgeon.

Love,

Mark, Saralyn, & Jack Crowell

With thanks ...

Saralyn and Mark Crowell know that the experts at Le Bonheur Children's Hospital saved their son – and were there when they needed them most. Those experts need you. Your gifts allow Le Bonheur's Heart Institute to grow and continue to find new ways to care for kids like Jack.

Who are we thankful for? You.



Zach Monaghan, 18, was set to attend Oklahoma State this fall with his two brothers.

A special gift

Family honors son, Le Bonheur by giving back

Zachary Monaghan had a special heart but was determined to live a full life.

His heart was, in some ways, an anomaly – holding some of medicine’s most complex conditions. But Zach’s family never let him think of it that way. God had made it special.

Zach was born with a complex congenital heart condition and from an early age, doctors didn’t give Zach’s parents, Kelly and Chris of Tulsa, Okla., much hope for his survival. The couple continued to search for doctors who thought differently. After Cardiac Surgeon Christopher Knott-Craig performed Zach’s first surgery at age 1, he thrived.

“He had a normal childhood,”

said his dad, Kelly. “He played soccer, baseball, basketball and was active in Boy Scouts. He never wanted people to have sympathy for him. He wanted to be like any other kid.”

By the time he was 15, Zach had joined his high school track and cross country team in Oklahoma. Doctors were amazed that he was as active as he was – that his special heart could work so hard. He accomplished what many others with normal hearts couldn’t. Then, last fall, Zach began to notice his endurance level wasn’t what it had been before.

What followed were long discussions, and then a decision, to repair a leaking valve between two chambers of his heart.

They traveled to Memphis to see Knott-Craig, the surgeon who had repaired his heart so long ago.

“The expectation was he would be hospitalized for a week,” Kelly said. “We thought he would be able to run competitively in Spring 2015. His goal was to run the 800 meters in under two minutes. The doctors were optimistic and excited for him.”

Zach ended up spending 31 days at Le Bonheur after a lengthy surgery and complications, an unexpected detour for a teenager during Christmas and New Year’s break.

“We never left Memphis,” Kelly said. “I made a promise to him that I wouldn’t

leave him. And I didn't."

Throughout the stay the Monaghans became especially attached to not only Zach's doctors and nurses – but also Child Life specialists Molly Pearce and Anne Von Lanken who "went out of their way to make sure it was as pleasant as it could be," Kelly said. Child Life specialists are pediatric health care professionals who work with children and families to help them cope with the challenges of hospitalization, illness and disability.

"We just had a special connection with them and I think they saw in us how strong our family was and how much we cared about one another," Kelly said.

"It's just a way of me being able to help the hospital and really help the Child Life Program continue its mission – to provide help to children and their families during stressful times."

Kelly Monaghan, father of Le Bonheur heart patient Zachary Monaghan

Monaghan remembers one day when Pearce made special arrangements for Zach and his brothers, who had traveled from college in Oklahoma to spend the break with family. Zach received a new Xbox for Christmas, and the brothers wanted to play Halo 3. Molly quickly made arrangements for them to use the Room of Magic, Le Bonheur's movie theatre, to play the game together on the big screen.

"All the positive memories we provide in the hospital can help to wash away the harder ones," Pearce said.

At another time, when the Harlem Globetrotters came to visit, Von Lanken made sure they came by Zach's



The Monaghan family, pictured outside of Oregon's Black Crater Trail in summer 2012, love vacationing in the mountains, where they can ski, hike and mountain bike. The youngest of three boys, Zach didn't let his complex heart condition slow him down.

room to visit.

"We found it refreshing to have someone other than doctors and nurses to come in and be attentive to the needs of the child and the needs of the family," Kelly said. "And that really had a lasting impression."

Zach returned to school to finish his senior year of high school in the spring. But on a mountain bike ride during the Spring Break family vacation in Arizona, Zach grew tired quickly.



Zach Monaghan running the 4x800 relay in spring 2014. The race was the last track meet at which Zach was able to run.

Tests back home in Oklahoma showed that his oxygen saturation numbers had dropped far below their normal range. He underwent another heart catheterization in Spring 2015 – but as he continued to get worse, Dr. Knott-Craig called them back to Memphis for another surgery to replace the faulty valve.

"They admitted us in the same CVICU room. There was a lot of mixed emotions," Kelly said. "We aren't naïve by any means. We are a very faithful family. We had a tremendous number of people praying for Zach – that he would come through this and God was going to heal him. We never thought we would leave Memphis without our son."

In the weeks that followed Zach underwent three open heart surgeries and two catheterizations, but his heart proved too weak. He died on June 27, 2015.

"My hope is that science continues to develop and that researchers continue to give hope to families," said Kelly. "When you are told that your child has a severe heart condition, it takes your breath away."

Kelly is also giving hope to those families through his work on the Thomas Eugene Bentley Foundation. Thomas Bentley was a long-time client of Monaghan who cared deeply for youth. He serves as a director – along with Bentley's daughters – to the foundation.

The Foundation recently gave a gift to Le Bonheur designated for Child Life, a service that is not reimbursed by insurance but solely funded through the hospital.

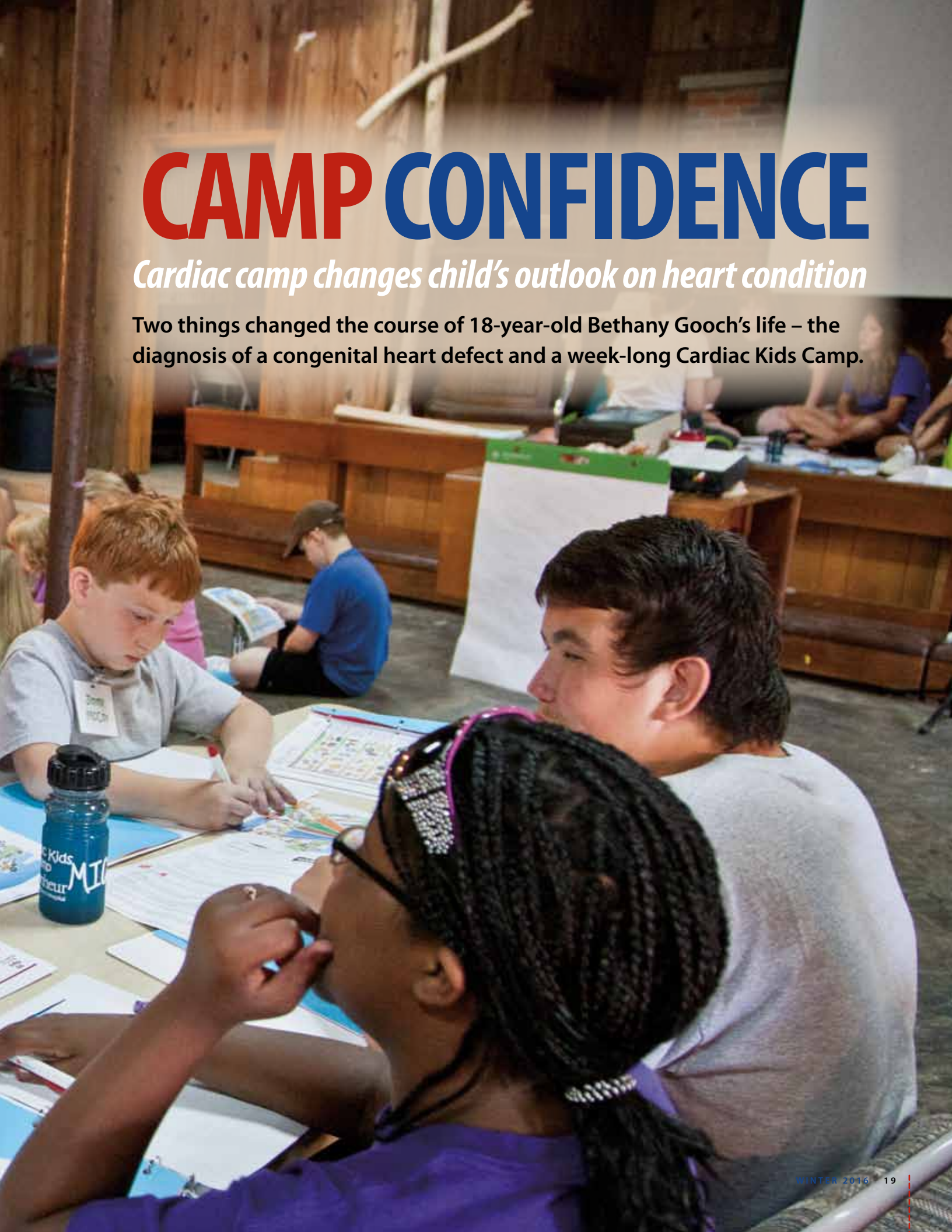
"During the time we spent at Le Bonheur, we learned about the uniqueness of how the hospital was started and saw that it was providing a tremendous service," Kelly said. "It's just a way of being able to help the hospital and really help the Child Life Program continue its mission – to provide help to children and their families during stressful times."



CAMP CONFIDENCE

Cardiac camp changes child's outlook on heart condition

Two things changed the course of 18-year-old Bethany Gooch's life – the diagnosis of a congenital heart defect and a week-long Cardiac Kids Camp.





At just 10 weeks old, Bethany turned blue at a family Christmas celebration.

At the hospital, the family learned their youngest daughter had three heart conditions. For the first six years of her life, Bethany couldn't do many of the things her friends and siblings did.

"I remember when she was in kindergarten, she couldn't go to school all day. When they would do recess, the teachers would make her sit and watch because she was still turning blue.



Bethany Gooch

Bethany would tell me, 'Mama, I just want to go out and run with the other kids,' said Bethany's mother, Serena Gooch.

That school year, Bethany had a major surgery that suddenly gave her a lot more freedom.

"She came home and said 'I ran at recess and I beat

those boys,'" Serena said. "We've come a long way and I'm grateful for that."

Life changed again when Bethany was 8 years old and finally old enough to attend Le Bonheur's Cardiac Kids Camp, an annual summer camp for children with heart conditions. The week-long camp, which started in 1998, serves about 50 children ages 8-16 each year. It's free to families thanks to generous donors.

Cardiac Kids Camp is staffed by physicians, nurses, pharmacists, sonographers, EKG team members, respiratory therapists, child life staff and chaplains. About 10 adult congenital heart patients serve as mentors during the week of camp. There is a high staff-to-camper ratio, because for many of these children, Cardiac Kids Camp is their



only opportunity to be away from home for a week.

"For some parents, they're so afraid of something happening to their child, that this is their only break all year. It's a well-deserved break they really need," said Camp Director Crystal Thomas.

At camp, Bethany learned about her heart. Four hours each day is dedicated to education. Doctors and nurses teach the children about anatomy, blood flow and different diagnoses. This intense time gives children more information about their hearts than they can get during a clinic visit. Understanding the diagnosis can save a child's life, Thomas said.

"My goal is for 100 percent of kids to know the scientific name of their defect, their medications and why they take them," Thomas said. "We've seen teenagers go to athletic events and pass out on field. Their mom and dad may not be there. It has happened more than once with our patients. It's so important that they can easily communicate their diagnosis and treatments to any first responder."

The rest of each camp day is spent on self-esteem building activities and time for the kids to connect and build friendships.

"These kids have a really hard journey," said Thomas.

"It's challenging to stay motivated and encouraged to take their medication. They have to have a great self esteem to know they're worth taking care of. The better they take

care of themselves, the better chance they will have long-term success."

The Gooch family says camp has also given them a support system of people who really understand what they're facing.

"We really felt alone after Bethany's diagnosis. We had Le Bonheur, but we didn't have a support system. Heart camp has brought families together. Not only does she have the support system, so do I," said Serena Gooch.



"We've come a long way and I'm grateful for that."

Serena Gooch





ALL HEART

Grizzlies player inspires heart patient

The doctor's warning rocked Angela and Steven McCarter's world. She told the athletic couple that their baby probably wouldn't be able to play sports. Matthew had three surgeries to repair his coarctation of the aorta before he was 3 months old.

"We were devastated," Angela said. "The movie I had in my mind was that he'd be able to do anything and everything he wanted to do. There would be no limitations. Then it hit me. He's going to have limitations in his life."

The news that their son may not have a normal childhood was hard to stomach for the McCarters. They had to adjust their expectations for their son who couldn't sustain a blow to the chest.

As 8-year-old Matthew, a sports fanatic, has grown, he has learned what sports he can play. Golf and tennis first, and now his heart has proven strong enough for baseball and basketball.

Matthew exceeded

everyone's expectations on and off the court.

That progress makes his new-found friendship with another Memphis basketball player all the more meaningful.

Power forward Jeff Green joined the Memphis Grizzlies in January 2014, and one of his first orders of business was a visit to Le Bonheur Children's Hospital. Green knows all too well what the kids in the Cardiovascular Intensive Care Unit are experiencing.

Green sat out the 2011-2012 season with the Boston Celtics while he recovered from surgery on his aortic valve.

At Le Bonheur, Jeff met Matthew. The pair compared scars. Later at FedExForum, Jeff told Matthew they were like the superhero Ironman, who suffered a chest injury and now has protective padding around his heart.

"By Matthew seeing me play hard and have fun

doing it, it can also inspire him to enjoy life and be happy," Jeff said. "And I know basketball isn't everything, but I appreciate it a little bit more [since the surgery]. You don't take it for granted."

Angela and Steven watched their son and the towering 6'9" basketball player talk to each other. They had renewed hope for their son.

"I can say Matthew, 'Look at Jeff. He had surgery on the



Memphis Grizzlies forward Jeff Green (left) and Le Bonheur heart patient Matthew McCarter (right) share a bond built on similar heart conditions.

same part of the heart that you had surgery on and look what he's doing today," Steven said.

Angela echoes, "From a heart mom, watching a heart patient play in the NBA, as well as Jeff plays in the NBA, it makes me rethink what Matthew is going to be able to do in his life. I don't know that he'll play in the NBA, but he won't be as limited as I thought he was going to be when he was 4 months old."



Steven, Lainey, Matthew and Angela McCarter with Jeff Green

A hole in one

Local golf teaching professional finds passion for Le Bonheur

Rob Akins wanted to be a cowboy. At an early age, he raced and cared for quarter horses. But when he got tired of washing and feeding 13 horses every day, he took to his backyard – the 16th hole of a municipal golf course in Shreveport,

La. At age 11, Akins got serious about golf, and now he's wrangling some of golf's top teaching professionals to Memphis to benefit Le Bonheur Children's Hospital.

Rob Akins, director of Golf Instruction at The Academy at Spring

Creek Ranch in Collierville, Tenn., is considered one of the top teaching professionals in the world. Seven years ago, using his connections in the golf world, he created Gurus of Golf, which has raised more than \$1 million for Le Bonheur.



“You are whatever you deeply believe you are,” Akins tells his players — meaning people find a way to make their deeply-held beliefs come true. Akins’ deeply-held belief: that he could make a difference for Le Bonheur.

His idea, Gurus of Golf, has created a win for the teaching professionals who come to Memphis, a win for the teams and team sponsors who pay to participate, and

a major victory for the children and programs of Le Bonheur.

A WINNING IDEA

Gurus of Golf started with a conversation between Akins and his friend, Mike Pera. Pera had been asked to chair the Le Bonheur Celebrity Pro-Am. Professional golfer Loren Roberts ran the tournament for 10 years, bringing in touring pros from the PGA Tour and Champions Tour and matching them



with local players for a five-hour fund-raiser.

But Akins had a new idea. “Rob is an idea guy, idea after idea after idea.



But this one was a pearl,” said Pera, former managing director at Marsh



Gurus of Golf pairs teaching pros with amateur golfers to raise money for Le Bonheur.

USA in Memphis, former Le Bonheur board member and founding board member of Spring Creek Ranch.

Akins described a tournament that brought the best teaching pros in the world to spend a day working with amateur players. He envisioned

well-known, accomplished teachers working on every aspect of the game, taking films, giving instruction and spending eight or more hours engaging with the players.

“My vision was to change a vanilla format to something totally unique and different, an event with much greater value than a pro-am,” Akins recalls.

“We wanted players to walk



away from this event with more than just golf. Pairing Top 50 and Top 100 teaching professionals with a foursome to provide eight hours of active, hands-on instruction makes this event as unique and special, just like Le Bonheur.”

When Akins calls, they come – and all it took was a few phone calls. Soon Akins recruited 15 top teaching professionals, many of his



The country's best golf instructors flock to Spring Creek Ranch in Collierville, Tenn., each year to help support Le Bonheur.

closest friends and all with a history of teaching tour golfers, and a few corporate sponsors to commit to

the first Gurus of Golf in 2009.

Sponsors paid \$10,000 a team, and 15 foursomes were matched with a pro.

Pera asked Akins, “What do we do now?”

Akins replied, “Sit back and let my group take care of it. You’ve got the world’s best here to entertain, teach and put their heart and soul into it.”

Everyone had a great time – the



“This year’s roster was a virtual who’s-who of the Golf Digest 50 Best Teachers list ... During the lunch break, players actively cross-pollinated, moving from [Stan] Utley’s short game clinic at the practice green to [Chuck] Cook and [Mike] Adams’ stations at the range. Out on the course [Randy] Smith and the other teachers mixed concrete swing tips with strategy advice and volumes of stories about tour life behind the scenes. Smith made quick work of his team, tuning up turns and fixing grips early in the day and seeing immediate results.”

— Golf Digest Blog, June 9, 2015



players and the pros. In its first year, the event netted \$95,200 for Le Bonheur, double what the previous pro-am tournaments had raised. And everyone wanted to come back next year. The return rate for pros and team sponsors is more than 90 percent.

BIRDIES, BOGIES AND BBQ

Gurus of Golf is now one of the most anticipated times of the year for the teaching professionals involved. It is the only opportunity this elite group has all year to network, learn from each other and build camaraderie with their friends and peers. Akins' now famous, end-of-the-event barbeque for the pros at his

home seals the deal for most of them. Most importantly, Akins' passion is infectious, and the teaching pros all believe in Le Bonheur and its mission to help children. "Rob is passionate. He really cares about whom he's working with and sincerely wants them to improve their game. He's very smart, versatile in his teaching approach and one of the hardest working people I've ever known," said Jennifer Hudson, head golf professional at Spring Creek Ranch.

As a boy, Akins won the city golf championship three years straight. He was enamored with the golf swing and started to study it with intensity. He began teaching at age 15 and

turned pro at 21, after playing for Louisiana Tech University.

By the time he was 24, he knew he was meant to be a teacher and started dreaming of getting players on Tour. He has mentored and taught PGA Tour players who have won three Majors, 17 Tour events, one national amateur championship and four state amateur championships. Akins also prepares aspiring junior players for collegiate careers.

Akins shares that passion for teaching with Gurus of Golf participants.

Perhaps renowned teaching professional and repeat guru Stan Utley sums up Akins the best: "Every day I go out to teach golf or encourage a young player, I take lessons that I have learned from Rob and pass them on to my students. This is why I call Rob my friend and also a great coach. He has not only helped me to become a better player and person but also gave me the knowledge and passion to make others better."



Guru Rob Akins

- Director of Instruction, The Academy at Spring Creek Ranch
- *Golf Magazine's* Top 100 Teachers
- *Golf Digest's* Top 50 Teachers
- Two-time Tennessee Section PGA Teacher of the Year
- Four-time West Tennessee Chapter Teacher of the Year
- Students include 2001 PGA Champion David Toms, eight-time Tour winner Loren Roberts and David Gossett, 1999 U.S. Amateur Champion



Gurus at a Glance

At Gurus of Golf, amateurs learn from and play with a Top 50 *Golf Digest* or Top 100 *Golf Magazine* teaching professional.

- Twenty amateur foursomes and 20 of the country's top teaching professionals
- \$10,000 per foursome for unlimited access to their pro as well as access to the other instructors; playing lesson in the morning, private instruction in the middle of the day and a playing lesson to finish out the afternoon
- Pre-event "Par-tee" where teachers are paired with their teams, featuring a silent and live auction which includes golf packages and vacations offered and/or attained by the pros
- Committee: Chair Mike Pera and Barbara Pera, Deborah and Rob Akins, Nancy and Ed Barnett, Debbie and Ken Edmundson, Mimi and Greg Gibson, Neco and Ben Livingston, and Barbara and Stefan Smith
- Major Sponsors: Lexus of Memphis, Ring Container Technologies, Thomas & Betts, The Barnett Group and Semmes Murphey
- Gurus of Golf raised \$220,000 in 2015 and more than \$1 million in the last seven years to help ensure that Le Bonheur Children's Hospital can serve sick children and their families, no matter their ability to pay.

For more information on Gurus of Golf, contact Joanie Taylor at 901-287-5988 or joan.taylor@lebonheur.org.





CHOCOLATE *FOR* A CAUSE

Growing up in a family of creative minds, Chef Phillip Ashley Rix understood the importance of following dreams at a young age. He often found himself caught up in his own world, constantly drawing and daydreaming. The freedom to dream led to greater things than he could have ever imagined.





Chef Phillip Ashley Rix helps Le Bonheur Heart Institute patient Madeline Flack, right, make chocolate during one of Rix's visits to Le Bonheur.

After 10 years in corporate sales, he knew he really wanted to be an entrepreneur, but that he wanted to create something unique and outrageous to offer the world.

That's when chocolate found him. At the time, there were no real options for someone who wanted to learn the art of chocolate — which can be a temperamental ingredient. With determination, passion, a few books and an airbrush painter he found on eBay, Phillip Ashley set out to conquer the world of chocolate.

Ten years later, Phillip Ashley, who is often

compared to the great fictional character, Willy Wonka, is an accomplished chocolatier. He's known throughout culinary circles across the country for the designer chocolate he and his team of artists create from his shop in the Cooper-Young district in the heart of Memphis.

He has made a name for himself by creating more than just chocolate candy. His edible art includes everything from sweet treats to decadent, savory flavors, like the Mama Jean — a sweet potato infused nod to his grandmother — and his personal favorite, French bleu cheese.

Of all his accolades and awards, he's most proud of using his platform to help others and give back to the community. A Memphis native, he's always known about Le Bonheur Children's Hospital and its impact on countless families. After being invited to a Le Bonheur 101 class by a customer, he was blown away by everything he learned. The chef knew he wanted to do something to help such a vital landmark in his own backyard.

The result: the Heart of Le Bonheur, an orange marmalade and tarragon acacia honey concoction featuring an artfully airbrushed Le Bonheur heart on each piece. Each confection is delicately wrapped in



a gift box aimed at raising awareness and funds for the Le Bonheur Heart Institute, which provides care for patients with congenital heart defects from before birth to adulthood.

Chef Phillip Ashley Rix is a Memphis treasure, and he says he's determined to give back while making a name for himself, especially to "places like Le Bonheur that make the city great."



The special Heart of Le Bonheur chocolate was crafted by Chef Phillip Ashley using ingredients with a history of healing. For every box sold, \$4 is donated to the Le Bonheur Heart Institute.

To order your own box, visit www.phillipashleychocolates.com and click Shop. Heart of Le Bonheur chocolates make great holiday gifts!



A GOOD FIT

From jewelry-maker to dragon slayer, volunteer meets the needs of Le Bonheur children

Le Bonheur
Children's Hospital
VOLUNTEER

Vadim Sinitsyn, 30, doesn't come from a medical background. He doesn't have children, and he's the youngest of his siblings. He wakes up each morning and goes to work at an investment company, trading commodity futures.

He's an unlikely Le Bonheur Children's Hospital volunteer.

And yet, Vadim plays a key role in the success of his community's children's hospital. Each week, he spends at least three hours at Le Bonheur as a "unit buddy" – walking up and down inpatient floors, visiting and playing with patients who are by

themselves, offering respite to parents and support for staff.

Volunteers like Vadim help Le Bonheur take care of more than 250,000 children a year.

Vadim grew up in St. Petersburg, Russia, and moved to the United States when he was 13. He majored in mathematics in college and landed a job in Memphis after graduation. When he moved to Memphis, he began looking for ways to connect to the community through volunteering. A friend suggested Le Bonheur, so he decided to give it a try. That was two and a half years ago.

"Before my friend told me about Le Bonheur, I didn't know this was something I could even do," he said. "I thought you had to be in medical school or something like that."

Anxiety about his ability to help children in a hospital setting was cast aside as soon as he visited his first patient. Vadim said he quickly realized that the patients would tell him what they needed, not the other way around.

"As long as you are there, the kids will make good use of you and your time," he said.


Vadim is part of a community of more than 188 volunteers who spend at least one day a week helping patients. There are as many ways to help as there are numbers of patients who come to Le Bonheur every day. As a non-profit, Le Bonheur relies on the generosity of people to meet the needs of the community's pediatric population.

*"As long as you are there,
the kids will make good use
of you and your time."*

— Vadim Sinitsyn, 30, a Le Bonheur Children's volunteer who spends three hours a week as a "unit buddy"

Vadim's volunteering activities have ranged from jewelry-making to dragon slaying. He has also volunteered as a baby hugger, gently rocking and soothing our smallest patients.

"There was a moment once, when I came to help with a baby who was blind and deaf, and alone," Vadim recalled. "He was crying so much, but as soon as I held him, he calmed down. It was really emotional, and something like that, it really puts life in perspective."



Volunteers serve an important role at Le Bonheur, and there's a need for more "unit buddies" on our floors. A few hours of your time could make a real difference in the life of a child. Often, as a volunteer, you will benefit just as much, if not more, than the patients and families you help. Volunteer opportunities include creating crafts with patients, helping at special events, supporting patients and siblings in the Emergency Department, hosting game days and more. For a complete list of volunteer opportunities, visit lebonheur.org/ways-to-help.



Every Gift Matters.



Eighty-six-year-old Clint Trusty has given more than 20,000 hours to the patients and families of Le Bonheur Children's Hospital in the past 22 years. He volunteers in the Neonatal Intensive Care Unit where he hugs, rocks, changes and nurtures very sick babies.

Not only does Clint give generously of his time now, but he has also planned to give generously in the future. He has been so moved by his experiences with the babies in the NICU that he has donated his entire estate to Le Bonheur. With Clint's gift, he is ensuring the highest quality health care services for future generations of children. According to Clint, "If I can help somebody, then my living is not in vain."

lebonheur.org/giftplanning

In the spirit of the season, see how your planned gift can make a difference in the lives of children today and tomorrow. Please contact:

Roberta "Sue" Matthews, J.D.
Director of Gift Planning

roberta.matthews@lebonheur.org
901-287-6308

Le Bonheur
Children's Hospital

Where Every Child Matters



Don't miss the
Enchanted Forest
Now through Dec. 31



Children of all ages will be charmed by the animated characters set in the magical snowy setting of Enchanted Forest. Elves are busy at work and penguins play in the snow while Santa cheerfully greets guests at the end of the Forest and poses for holiday photos.

Stroll through the avenues of the beautifully decorated trees which glisten throughout the Pink Palace Museum.



theenchantedforest.org

Recent Events



Hospital ball brings joy

The Le Bonheur Children's Hospital Ball, a fun night of dinner, dancing, a children's choir and live and silent auctions, raised more than \$435,000 for Le Bonheur. Hosted by the Le Bonheur Club, the event supported Bunny Lane, where patients receive a new toy before going to surgery, and the rehabilitation unit at the new Le Bonheur Outpatient Center East currently under construction. Special gratitude to 2014-15 Le Bonheur Club President Peggy Lovell, Event Co-Chairs Sally Perry and Lauren Barnett and Honorary Chairs Hamp and Nancy Holcomb.

Date night for dads and daughters

Little girls wore their fanciest party dresses for a date with their dads to support Le Bonheur Children's Hospital. More than 1,200 people attended the event of the summer hosted by the TWIGS of Tupelo. The event, complete with dancing and Disney princesses, raised nearly \$60,000. Many thanks to Gumtree TWIGS, BancorpSouth and Magnolia Business Centre for a memorable night for dads and their daughters.



Halloween festivities kick off with the Pumpkin Run

More than 1,500 runners gathered together in East Memphis in mid-October in support of all the children treated at Le Bonheur. Families and children dressed in costumes enjoyed the Pumpkin Run 5k, 400 meter kids' fun run and post-race celebration. Many thanks to the teams and individuals who raised \$115,000 for the hospital.

Hats off to Big Wig Ball



More than 300 fans of Le Bonheur flipped their wigs to show their support of the children's hospital. The June event at Annesdale Mansion raised more than \$60,000. A portion of the proceeds funds the Children's Foundation Research Institute's Young Investigator Award. This year's recipient is Amali Samarasinghe, PhD, an asthma researcher. Special thanks to the title sponsor Independent Bank, event co-chairs Liza Routh and Kyle Cannon and the planning committee.



Go Jim Go keeps on going

In Go Jim Go's 10th year, WREG News Channel 3 Meteorologist Jim Jagers rode more than 333 miles on his bicycle for Le Bonheur Children's Hospital. The weeklong "telethon on wheels" visited more than 77 schools across the region to thank the students who raised money to help sick kids at Le Bonheur. Surpassing previous years, Jim raised \$343,000 bringing the total to \$1.75 million. To see photos and videos from every school visit, check out Go Jim Go on Facebook or visit www.gojimgo3.org.

Gala makes the house a home

More than 500 gathered at The Peabody last spring to lend their support to FedExFamilyHouse, a home for families while their child is treated at Le Bonheur. The FedExFamilyHouse Gala raised more than \$600,000 so families do not have to pay for their accommodations. Le Bonheur parents Genny and Wayne Drash shared the story of son Billy's treatment for epilepsy at Le Bonheur. Many thanks to Honorary Chairs Justin and Jenny Fuente and Event Chair Vicki Carayiannis.



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ALL HEART

***NBA player, Le Bonheur
patient compare scars,
form friendship***

See more inside, page 23



"From a heart mom, watching a heart patient play in the NBA, as well as Jeff plays in the NBA, it makes me rethink what Matthew is going to be able to do in his life,"

Angela McCarter, mother of Le Bonheur Children's heart patient Matthew McCarter, right.

Matthew and Memphis Grizzlies forward Jeff Green both had heart surgery to correct a congenital defect.