Book of Hope

children's health℠

To our patient families.

Over the years, advances in the diagnosis and management of complex congenital heart disease have been truly astounding. Prenatal diagnosis, advanced imaging and novel interventional and surgical procedures have allowed for what was one day considered “impossible” to be “possible” – particularly for our tiniest and sickest babies.

Our multidisciplinary approach to each child’s care not only makes us unique but has resulted in outstanding outcomes and quality of life for our patients undergoing even the most complex procedures. We are the ones to say “yes” when others may say “no.”

As a surgeon, there is no greater satisfaction than seeing these little ones, whose families have entrusted us with their lives, not only just growing up but truly thriving. Follow-up visits, photographs, emails and letters are constant reminders of how far we have come.

Having a younger brother with congenital heart disease reminds me of what it is like to be “on the other side,” so I hope that in reading these compelling stories you will find comfort and strength when you embark upon your own personal journey.

Please know that our team is here to walk alongside and support you the entire way. You are part of our heart family, and I know the future will be bright!

Kristine J. Guleserian, M.D.

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The progress that our field has made in the general care of children born with congenital heart defects has been remarkable. This has been especially true with those kids born with complex single ventricle anatomic situations, such as hypoplastic left heart syndrome.

For those babies, the operative survival for their first stage has improved dramatically over the past several years so that it is now greater than 90% at Children’s Health. In addition to this improved short-term survival, we have made dramatic inroads on intermediate-term survival with our Safe at Home program.

Nothing pleases me more than receiving the notes and pictures from my patient families showing these children growing and developing throughout their childhood, whether it’s swimming with their siblings, going to the zoo or even riding a horse. These courageous children are showing us that the boundaries of the “possible” have been pushed beyond what many of us would have considered realistic just several years ago.

We are now moving beyond concerns about just “survival” and are now heavily focused on improving the quality of life for these kids. I hope you find these personal stories inspirational.

Joe Forbess, M.D.

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Ethan's story

Although all "heart kids" have different stories, different diagnoses, a different set of tricks up their sleeves, they share one thing: they're unique. The same goes for their parents and caregivers. They have no choice but to experience fear and uncertainty and in the process learn a few things about what really matters in life.

We knew before he was born that Ethan had hypoplastic left heart syndrome (HLHS), so his life began with interventions, tests and monitors to ensure he remained alive despite his heart defect. He spent the first week of his life in the cardiac unit stabilizing and had his first of the three HLHS surgeries, the "Norwood," when he was just over a week old. It was tough; there were complications. But the surgery went well, and Ethan recovered, if not a little slowly. Sometimes, for every two steps forward, Ethan would take three back. We spent eight weeks in the hospital recovering from the Norwood, during which we dealt with an injured phrenic nerve (resulting in a diaphragm that wouldn't let Ethan's lung expand), an MRSA colonization and a biliary tract blockage in addition to all of the normal post-op breathing, feeding and basic survival hurdles. But we made it, and we finally made it home because of our enrollment in the "SAFE at Home" program.

Though we made it home, we still had a very fragile kid. Sometimes, the at-home monitoring and routine clinic visits weren't enough for the nurses, doctors, and team members who cared fiercely for Ethan and who wanted to see him thrive.

Ethan had plenty of grueling inpatient admissions. We got through it; however, and Ethan had his second HLHS corrective surgery, the "Glenn," after just three months in the program. Compared to the Norwood, the Glenn was a breeze. We were home again just eight days following surgery. The hard part was over. We could finally start living life like a normal family – start doing normal things. All of the difficulties experienced during the previous months became a distant memory. Hang in there – you'll experience this, too.

But as I said earlier, heart kids come complete with a bag of tricks. Ethan showed us his latest trick about six months after his Glenn surgery: his heart, despite best efforts, began to struggle, and there was no fix for it. Ethan was listed for a transplant in December 2012, where we spent the next four months hoping for a miracle.

Our prayers were answered in April 2013 when Ethan received a new, working heart. He is now as normal as he can be – so normal that no one can tell he no longer has the heart he was born with or that he spent the first 18 months of his life in and out of the hospital. As much as our own efforts and care contributed to Ethan's tremendous success, so did the efforts of the men and women of Children's Health℠. They are our heart story!

Josiah's story

Josiah is our sweet, full-of-life, blonde-haired and blue-eyed little boy. His name means "Jehovah saves" – which did not truly resonate until our 23-week ultrasound when we found out that he has hypoplastic left heart syndrome. This news came three days before our big move from Nebraska to Texas. Life all of a sudden became a blur.

We moved to Dallas on June 1, when I was 23 weeks pregnant. It took about five or six weeks for the news to sink in. Our baby had a very serious condition. Right about the time that we came to terms with our news, my water broke. I was 30 weeks pregnant, and I spent the next two weeks in the hospital praying that our precious boy would just stay put! Eleven days later, our sweet Josiah Michael was born. He weighed an astounding 5 lbs. 2 oz. I got about 45 precious seconds with him laid on my chest before he was whisked away to be taken care of. The next 89 days were some of our scariest days, but they were rewarding as we watched Josiah get stronger and ready to come home.

Since Josiah was premature, he was too small for the Norwood operation that was originally planned for him within his first weeks of life. On the fourth day, he was taken in for the pulmonary artery banding operation. It was successful, and Josiah did great. Three weeks later, he was brought to the cath lab to have a stent placed. From that point, we waited for Josiah to steadily gain weight and strength for his Norwood operation. Our big day arrived on September 24, which also happened to be Josiah's due date. He had met his goal weight of 4 kg (about 8.8 pounds) and was taken into the operating room once again. It was a long 8-hour day in the waiting room that was met with sweet relief when he was brought out of surgery. Once again, he did great, and the long process to recovery started. Those next few days felt like some of the longest days of our lives, but Josiah fought through with the help of all of his wonderful nurses and doctors at Children's Health. We were discharged on October 29 to finally bring Josiah home!

Those 89 days were not easy. There were a lot of tears and worry, but there were also times for smiles and laughter. Being premature, Josiah had weak lungs, causing collapsed lungs and breathing issues. He was small and spent many weeks in the preemie Isolette. I also remember the hours I spent holding him and cherishing the moments with him in my arms. We were grateful for our nurses and doctors' ability to joke and laugh, yet be on point when needed.

Once we were home, we started the Safe at Home program. What a blessing! It was a huge sense of relief to know there was always someone available if the need arose. Josiah did well during those few months at home as we waited for his Glenn operation. We checked his weight and oxygen levels every day and met the challenges of having a baby with a feeding tube. In our minds, a feeding issue was small in comparison to what Josiah had just conquered.

Josiah had his successful Glenn operation on February 10. Complications arose during the days following when doctors discovered that Josiah's right diaphragm had been paralyzed during surgery. He was taken for emergency surgery on February 14. My husband and I enjoyed a "romantic" Valentine's Day meal in the waiting room that was delivered by someone cheering Josiah on. After the diaphragm plication surgery, Josiah turned around for the better. He came home the following week.

The following months gave us a breath of fresh air. Life began to feel "normal." We still met with his cardiologist every couple of weeks, due to his lack of weight gain, but we felt a sense of relief that we made it through the hard stuff. We were able to travel back to Nebraska several times throughout the summer to visit family and celebrate Josiah's first birthday.

Josiah has come a long way! He has fought through battles that many wouldn't even dream of! We are still working on his feeding. Josiah has a g-button for feeds, but he has recently started to eat by mouth; we are beyond thrilled! In the next couple of years, Josiah will have his Fontan operation to complete the series of surgeries. Our miracle is now a regular 17-month-old little boy who makes a mess of our living room like any other heart healthy kiddo. He's happy, spunky and laid-back. Our journey hasn't been easy, but it's been worth every second to get to where we are now!

Stark's story

Our story started at our four-month ultrasound when we were going to find out the gender of baby Novak. Shortly after finding out we were having a boy, we discovered there was something wrong with his heart, and we began the process of diagnosing him with a major heart defect – hypoplastic left heart syndrome (HLHS).

We met our pediatric cardiologist, and she explained the anatomy and our treatment options. Not wanting to overwhelm us, she said, "I want y'all to go home and process this. It's a lot to take in. I need y'all to be ready to fight when you come back." I'll never forget that sentence. We have not stopped fighting since.

Stark was born June 8, 2012. Any doubts we had about fighting for him to live quickly vanished. He was perfect. We wanted to do everything possible to save his life. The Norwood was performed at 5 days old – his first open heart surgery. A little over a month after he was born, we took our heart baby home! At around four months, we went back for his second surgery, the Glenn. Again, about a month later, we returned home.

The first five months were a bit of a blur. We took Stark for check-ups in Dallas, but for the most part, the next year progressed pretty normally. He was a normal baby meeting his milestones. Because of his heart defect, his oxygen saturations ran lower than someone with a normal heart. This left him a little "bluer" than other kids, especially when he was cold. He took medications for his heart every day. This was our normal.

The goal was to do the third surgery, The Fontan, around 3 or 4 years old. Stark began to have trouble with his tricuspid valve, which was causing his heart to overtax itself. In May of 2014, he underwent his next surgery to replace his failing valve with a mechanical one. He recovered from this surgery much like the others. His follow-up echocardiogram looked great.

In October of 2014, we noticed his face was puffy. He had a stuffy nose but no fever. His pediatrician sent us back to Children's Medical Center Dallas. I remained optimistic that this had nothing to do with his heart. Unfortunately, he was in complete heart failure. I was in denial. I thought, "This can't be happening." He showed no signs of heart failure up until this point. I asked the doctor, "Isn't there some medicine we can try to help his function?" The doctor on call that day said, "I think if we found a heart this weekend, we would take it." I couldn't believe it. While we knew that transplant was in the future, we thought it was a distant future. Now it was right in front of our faces, and we didn't know how to react.

We spent a week in the hospital trying to adjust to this next chapter. It was hard. We were so bonded to our regular cardiac team, we didn't want to meet the transplant team. They didn't know us, and we would have to build a new relationship. We wanted our child to live, but it was hard to know what he needed in order for that to happen. I asked the transplant chaplain, "How am I supposed to pray? I don't think I can." She took my hand and said, "We know that things happen every day. We don't pray for them to happen, but we pray that in the event something does, they make the choice to donate. Pray for the choice."

We went home after deciding to list for a heart transplant. Stark had a PICC line placed and had IV medication infusing 24/7 to help his heart function. Stark's big brother went back to school, and my husband went back to work. We pulled Stark out of daycare and made arrangements for family to watch him when we worked. We lived each day and waited for the call.

On November 23, my husband's 32nd birthday, we got a call at 1:02 in the morning from our transplant coordinator, Kelly. She told us they had found a heart for Stark. I made her repeat the sentence. I woke up the house, packed, and headed to Dallas. He went back for surgery around 2:30 p.m. Although it was his fourth open heart surgery, I have never been so scared. I'll never forget Kelly calling me from outside the OR to tell me the new heart was in and beating. There really aren't words to describe that moment. I was very grateful. We finally got to see him around 10 p.m. that evening. For the first time in his life, our son was rosy and pink.

Our life has completely changed since the transplant. Stark can finally do the things his old heart wouldn't let him do. He has more energy than we know what to do with! It's such a change. Prior to transplant, he would tire so easily and become drenched with sweat at the smallest amount of exertion. It has been the biggest blessing.

I look back at our journey, and I know there are chapters still unwritten. There is more to come for Stark and his story. He has a good life, and it's worth it. To all my heart moms and heart families out there, please don't give up your fight. It's worth it. These kids are amazing and resilient.

Stark's life wouldn't be possible without the choice a family made in spite of a terrific loss. To all my donor families out there, thank you.

"Without the organ donor, there is no story, no hope, no transplant. But when there is an organ donor, life springs from death, sorry turns to hope and a terrible loss becomes a gift." – UNOS

London's story

In January 2013 when I went to find out if our baby was a boy or girl, we found out she was a girl with half a heart. Her diagnosis was tricuspid atresia, severe coarctation of the aorta and double outlet right ventricle. We were completely devastated at how grim the diagnosis sounded coming from the doctors. We were referred to Children's Health for a fetal echo and meeting with all the teams. They told us how they would attempt to fix what she has and about the program they will use interstage. We moved from Oklahoma City to a small condo close to Children's to entrust them with her only chance at life.

London Claire was born on June 5. She was pink and as perfect as an APGAR score could get. It was so shocking and hard to understand that she was very, very sick. She had her Norwood on day seven and had an extremely difficult recovery. We stayed in the ICU for eight weeks as she struggled to gain weight and learn to feed.

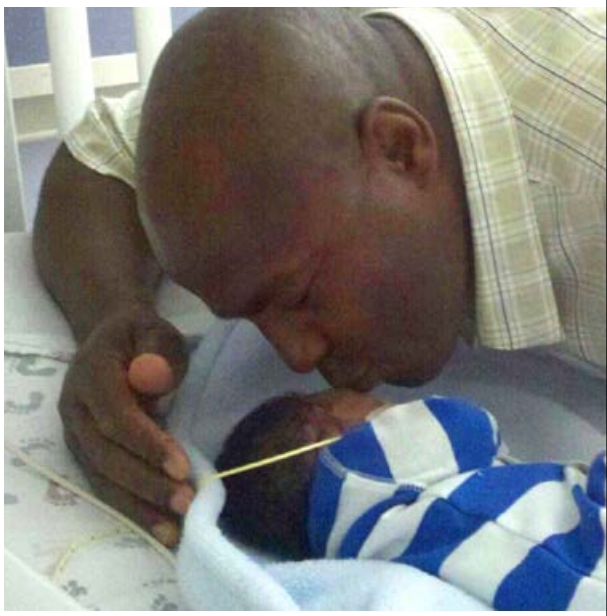
Interstage was extremely difficult for us, but our nurses and doctors completely carried us through. They will be there for all questions; they will stop at nothing to intercede for you. Do not fear you are in this alone or you have this child that totally relies on you. I know you're feeling not sufficient for this kind of job. We were given the "close to death" conversations five times throughout our interstage. We had days that all seemed hopeless.

London had her miracle Glenn procedure on Dec. 31. She excelled through that recovery and has been doing nothing short of excellent after that surgery.

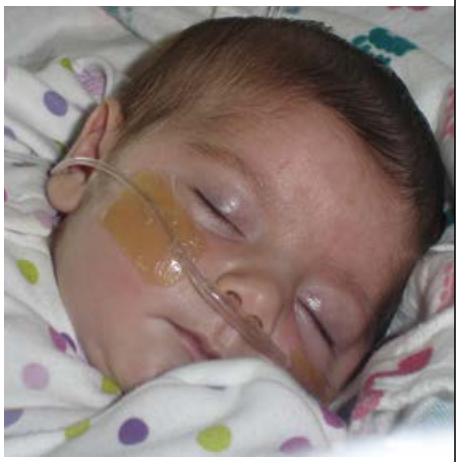
She eventually started eating and drinking after many hours of hard work. She now acts like any other toddler and eats like any other toddler with no residual impairments. Every cardiology appointment has been fabulous. I hope she can give you hope through your hard days. Keep pushing through; there were days I didn't know how I was breathing...but now it all was worth it.

Braidon's story

Braidon story began on May 26, 2014. I had a routine checkup at my OB/GYN. While having the sonogram, the nurse noticed only three chambers of Braidon's heart. The nurse checked a second time to see if she was missing the fourth chamber. She couldn't explain anything to us, so she went and notified the doctor of her findings. After the doctor checked the sonogram photos, she came in and spoke to my husband and I explaining what they were seeing. We were shocked of the news we had just received; we both cried. The doctor tried calming us, but the tears continued. Immediately the OB/GYN made phone calls to set us up with an appointment to visit with a doctor in Dallas at the Fetal Care Center. At that point, we were scheduled to have a visit within the next day or two. Life had changed suddenly for us. At that moment my husband and I began praying to God to guide us and give us strength. Abortion was no option for us. This baby deserved life. We continued on with scheduled appointments. In June we learned our baby was diagnosed with pulmonary atresia and double inlet left ventricle. Wow! That was a mouthful. We were educated about our son's heart defect while still in the womb. Braidon was doing well. There were many, many echos performed and just as much monitoring. We took numerous trips to Dallas for appointments. On Aug. 4 I had to reside in Dallas until after Braidon's heart surgery. Braidon was born Aug. 15, 2014. He underwent two stent procedures, a heart cath and open heart surgery. Between those procedures and surgery we had a lot of appointments monitoring his heart. We never realized so many things could be wrong with such a small heart. We have learned so much about the heart. We are blessed to have had the doctors and nurses through this entire journey. Children's Medical Center is a blessing. The Safe at Home program is wonderful. We absolutely love our family at Children's Medical Center. They are the best! Braidon is home now doing very well. Braidon is 6 months old and is moving around as if he never had one stitch! God is good! We give God all of the praise!



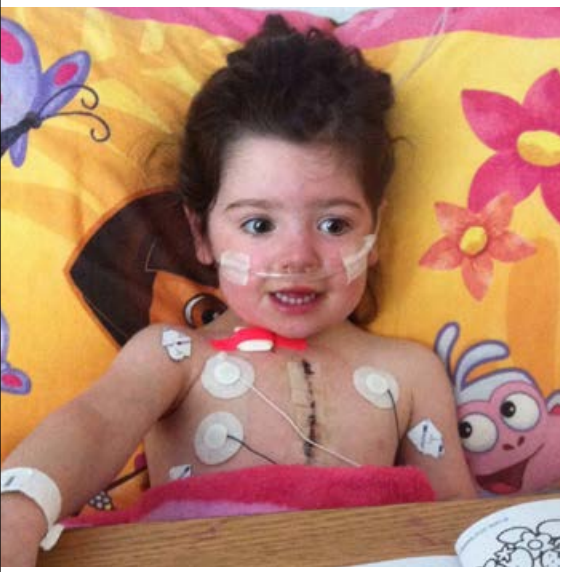
Natalie's story



On April 1, 2009, my father passed away. I never thought I could survive my father's death. I was a "Daddy's Girl" to say the least. I was also 24 weeks pregnant with my daughter, Natalie. I did not know how I could get through this, but I knew God had a plan.

I remember on the night of April 23, I was lying in bed and I thought to myself, "life cannot get any worse than it is right now." Words I will never say again. The next morning, I went in for what I thought was a routine sonogram. See, my kids have always been difficult during sonograms, so I really did not think anything about it. However, we came out of the sonogram 2 1/2 hours later with our world shattered. I was terrified. I do not even remember what all the doctor told me that day except she thought my daughter had hypoplastic right heart syndrome. We were going to have to give birth in Dallas, Houston, Boston or LA, and my daughter would not live a normal life span. What is a normal life span, I kept thinking?

But wait it gets better; we would have to set up an appointment with the pediatric cardiologist to confirm her condition in a few days. A few days…really? You are sending me home with this? I was scared, terrified and confused. What was God's plan anyway? This could not be happening to me. Had I not been through enough already?



The next few days went really fast. We had our meeting with the pediatric cardiologist in Amarillo who confirmed Natalie's condition; tricuspid atresia. Basically, Natalie had very under-developed lower right heart chamber, almost non-existent.

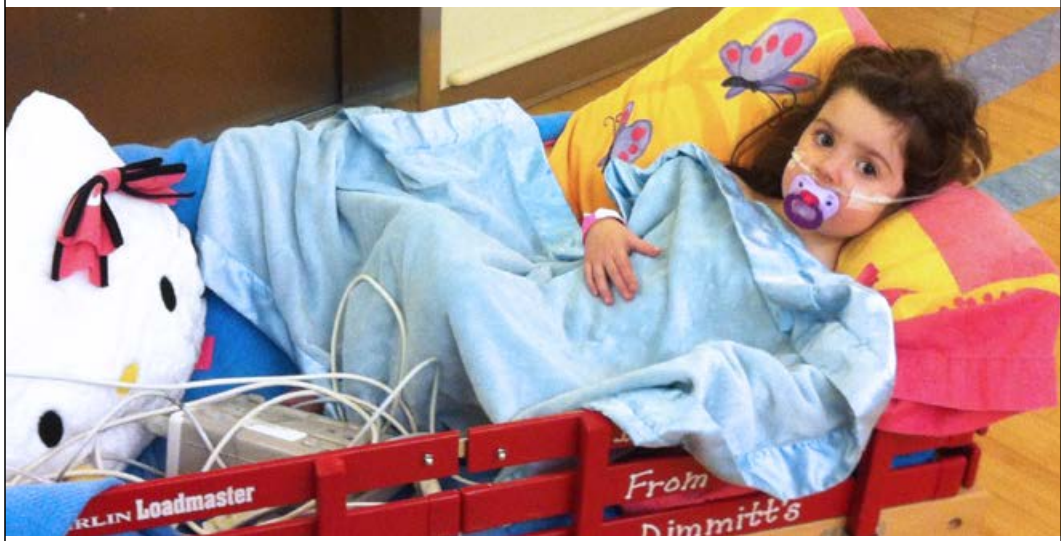
On the morning of July 16, I woke up to my water breaking. I was scheduled for a C-section the following week, so Larry was in Amarillo. Thankfully, my mom was still in town, because she was scheduled on a noon flight back to Amarillo that day. I remember thinking as I gathered my stuff, "Here we go, God please watch over us both."

Natalie was born, and by a miracle, she did not have to have surgery the first week. In fact, she was among the small percentage that was able to hold off. The surgeon told me this never happens, but it happened to Natalie.

On Aug. 24th, 2009, Natalie had her first open heart surgery. I had looked at a few blogs, but a blog cannot prepare you for your child going through open heart surgery. She was so young; she did not even cry when they took her.

The surgery lasted six to eight hours, they updated us every hour, and so far things were looking great. Then, our cardiologist came out and told us Natalie was not tolerating the shunt they were trying to put in. He said if we leave it in she will not make it through the night, but if they take it out, then we will have to look at other options. I just stood there with this look like, "Why are you telling me this, take the damn thing out." The doctor just stood there starring at Larry and I for what felt like forever; finally I asked if there was more. He said, "No, I am just waiting for some emotional response of sorts." I again just stood there motionless, but inside I was screaming, "You did not come out here and tell me my daughter was dead; you came out and told me we needed to look at other options, so why are you looking at me like that? Go in there and take the shunt out." God shielded us for the first time on our journey. He protected our hearts from what, I cannot imagine.

I know I will not be able to give this feeling the experience it deserves, but I will try. After the doctors sewed Natalie up, they brought her down a long hallway into the CVICU (cardiovascular intensive care unit). Larry and I got to stand there and see her before the doctors and nurses took her all the way into CVICU. This is the case after all heart surgeries.



As I stood in the hallway waiting for my daughter to come around the corner, I had all these emotions. I was relieved she was alive; I did not know God's plan, but I was so happy, yet fearful for the unknown future.

Natalie, however, was in a stressful situation to say the least. Things were changing day by day, minute by minute and sometimes even second by second. One minute, she was going to have an MRI, then the next minute not. Then she was going to have a heart cath, then not. Then, she was going to have surgery, and then at 1:30 a.m., they decided she didn't need it. One day we had three options and the next, we only had one...a heart transplant.

Once again, I was scared to death; the word transplant was beyond anything I wanted to hear. A heart transplant had positives, but it had a lot of negatives too. It is basically trading one group of problems for another set of problems. Sure transplant would give Natalie a chance to live a pretty normal life, but a heart in a child this young would not last forever. I went through what felt like the most important and intense interview of my life. When you need a transplant, you do not just get on the list. There were tests Natalie had to go through, such as brain function, liver and kidney function, etc. I had to meet with two child life specialists, two therapists and the entire transplant team. They gave me a binder of all the medications Natalie would need following transplant and their side effects, such as leukemia. It was an endless few days. Then, the day came when Natalie was officially placed on the list.

I remember blogging that night...

"I am not going to lie, I am terrified. I have to keep telling myself at least we have an option, and we are blessed with the amount of support we have. I know God has a plan for her, and we will get through this part. We still have a long road with transplant that will continue the rest of her life. It is so hard for me to ask you all to pray for a heart, because for a heart to become available, someone has to lose a loved one...a baby. I feel selfish asking God for that. I pray that by a miracle everything works out somehow, and she does not have to have a transplant..."

I posted that on September 19 and on September 21, we got a call at 5 a.m. that Natalie's oxygen had dropped in the 20s and they were having a horrible time raising it. Natalie would have these periods, but she always recovered. I asked the nurse if they had stopped her feeding, and she said yes. I knew what that meant... surgery. I got up and started getting dressed only to get a call a few minutes later saying Natalie would be going into surgery at 7:30 a.m.

No, they did not have a heart for her, but they had to do something, and they were going to re-attempt the first surgery again. The surgery that did not work the first time!

Larry and I got to the hospital around 6:30 a.m. As we were walking into Natalie's room, all the staff just kind of looked at us with this solemn expression, I did not even notice until later. The nurse asked me if I wanted to hold her. I remember thinking this is weird because I am pretty sure a few weeks ago they told me you cannot hold your child after they are intubated, but I had not gotten to hold her in about three weeks so I was all for it.

The next 30 minutes went by like five, but there was this peace during that time. There was so much commotion going on, it was shift change for the staff and many people were coming in to see us.

Natalie's surgery only lasted four hours, compared to the previous surgery of eight hours. Larry actually answered the call when they called back and said she was doing better than they could have ever hoped for. "Hoped for" – I thought, that is a strange comment.

It was not until later that afternoon that the light came on in my head. I ran back to Natalie's room, looked at Larry, and said, "I do not think anyone thought Natalie would survive." We started to thinking back on the morning, the people's faces, their actions and words, event the nurse who called Larry to let him know Natalie was doing better than they could have "hoped." The surgeon's face when he came to talk to us after the surgery. People comments of how much a fighter Natalie was as I walked down the hall said it all. I dropped to my knees right then. God blessed us more than we could have ever imagined right then and there that day. He answered my prayers!

Heath's story

There are thousands and thousands of books, websites and references on CHDs. None of which came close to making me feel prepared, or as prepared as I could feel, than the face-to-face meetings and conversations I had with the medical team members that would soon be involved in Heath's care, as well as the first-hand experiences that the other parents had with heart defects. Upon learning our baby was going to be a boy, (our third!), we also learned there was "something not quite right with his heart." That day began a whole new chapter in our family's life. If there is one thing I absolutely regret, it was the first thing I did upon hearing the term hypoplastic left heart syndrome. I Googled the term! Of course, there are numerous CHDs, and most children have multiple defects in some form or another. But one common thread when you learn you are facing some sort of major medical issue is that we all turn to technology. I can't stress enough how much I wish I hadn't Googled HLHS, especially during my most fragile state. There are so many statistics that are outdated, as well as studies that are still being conducted. I wish there had been someone, back then, telling me to stay open-minded and to initially provide me with connections to others with first-hand experiences.

By Sept. 14, 2012, we were far beyond the meet and greet of getting to know the ins and outs of hypoplastic left heart syndrome. We had been there, done that in terms of sonograms, meetings with the surgical team and mountains of paperwork. We could probably re-draw the diagram of an HLHS heart and what each surgery meant regarding how it would change the heart. But today we entered the world of CHDs, and there was no turning back. Our son would experience the first stage of three surgeries at only 5 days old. From there, he began earning his nickname, "Rock Star." Heath seemed to be healing so well and sooner than seemed typical. I remember stepping out to grab something to eat, for what seemed like the first time in days, and coming back to a big sign on his door stating that Heath had just taken his very first bottle! This is a huge deal. Feeding for these babies can be quite the hurdle. By taking the first bottle attempt completely, he was making it known that the feeding tube would not last much longer. At only 9 days old, four days post Norwood, Heath graduated to the "Step Down" floor. Through sleepless nights, blaring monitor alarms, one medication after another and training to become Heath's "nurse" we checked off one success after another. Just over a month later, Heath was discharged to go to the Ronald McDonald House down the street, where he and I would ultimately live for seven months. This was one of my proudest moments as Heath's mom. My baby had gone through the unthinkable and fought harder than anyone I had known. His eagerness to thrive meant we went home without the feeding tube, without requiring oxygen support and on fewer medications than we originally planned. I continued to beam the brightest smile I have ever seen. Heath deserved the name Rock Star, for sure. His second surgery, the Glenn, was much more difficult than the first, and it did a number on Heath. Managing his pain became one of the top issues. Eventually, we got through it, and we were able to check another major milestone off our CHD list.

By no means was everything easy-going. It wasn't exactly a walk in the park, but I continued to be amazed at how determined Heath seemed to be to get over the hurdles. It seemed like he had a natural instinct to keep going. He wasn't a quitter, and still, he remained so pleasant during all the challenges placed in front of him. I think it is important to understand that we absolutely had hard times. We went through times that were so difficult to get through, that it's only by the grace of God that we did. In addition, I could write chapters upon chapters on Heath's actual story. My hope is that you will see success during the times that you fear will get the best of you. I want you to know that it is possible to get beyond the big things and come out happy in the end. Your timeline will be different, but happy endings come in so many forms! Like most of the heart patients I have grown to know, Heath's need for a new heart came into play. The conversation was always an expectation, but it still hit me like a ton of bricks when we actually went through the process to get him qualified for listing. Heath had what was labeled as 'failure to thrive' because he was so low on the growth chart. His heart function seemed ok, but his oxygen was staying around the low 70s when it should have been in the low to mid 80s. There were enough variables in place that we knew something needed to be done. A few months before Heath turned 2 years old, he was placed on the heart transplant list as a status 1B. We welcomed yet another new chapter in our life as a heart family and played the waiting game. It became harder and harder for me to see him seem to decline and not be able to do anything for him. The days seemed to rush by. By the time he turned 2, we found ourselves in the hospital getting ready for surgery. We never received the call that a donor heart was waiting for him, but the time had come for us to do something. Heath received a new mechanical valve, and within a month of that replacement, our son gained a pound! It may only be one pound, but Heath went months and months without gaining an ounce. Our Rock Star was shining again! You will be surprised how strong you can be, and you should feel proud that you are chosen to care for such a gift! Heath has grown our family in ways only having him could have done. Remember the moments, the easy and the hard times, are not what define us. It is how you handle those moments that shows who you are and who you can be. I would never trade our trials for anything, even if it meant Heath would have been born "healthy." That may sound silly or even harsh, but it's true. Your heart baby is such a gift, and you will be so very blessed as their parent! Now, that's encouragement!

Mason's story

He is a 5-month-old baby boy with CHD. He has a big sister who is 3 years old, two dogs, one cat and a whole lot of people who love him! His favorite food is milk, he likes long walks around the house and his favorite toy is a singing turtle.

We found out during a routine ultrasound that Mason was going to be born with the rare heart condition of hypoplastic left heart syndrome, or HLHS. To say we were shocked is an understatement! We immediately started doing all the research we could to find out more about the diagnosis and to find the best place to take care of him once he was born. After much consideration we decided that Children's Health was the place for our baby.

Mason was born in September of 2014, 6 pounds 2 ounces, and he looked like a perfectly healthy baby boy. Because of his prenatal diagnosis, he was immediately taken to the NICU at the hospital where he was delivered and was soon transferred to Children's Medical Center. We knew we had a long road ahead of us. At 5 days old, Mason underwent his first open heart surgery. He was in the hospital for one month and one day total. There were plenty of ups and downs…heart babies take things at their own pace! That's one of the biggest things I would tell parents new to the CHD diagnosis – no two children are alike, and no two journeys will be the same. Mason's stay was longer because he had trouble gaining weight after his surgery. He was on an NG tube due to a paralyzed vocal cord that caused him to aspirate when trying to feed by mouth. We knew before surgery that many heart babies have trouble eating by mouth, so it was something we were prepared for.

When Mason finally started to gain a little bit of weight, we were excited but also a little bit nervous to finally be able to go home! Thanks to the Safe At Home program we were able to go home with the knowledge of what to look out for with Mason. We knew to contact them if he turned blue, if he had a fever and if he didn't gain weight, and they gave us a few other things to be on the lookout for. We were able to contact them at any time with questions we had, and they made contact with us once a week to make sure Mason was doing OK.

I am a HUGE believer that kids thrive in their home environment. I think Mason is a testament to that! A month after leaving Children's Medical Center Mason was able to start feeding by mouth and ended up doubling his weight by 4 months old! He was not only doing well, he was thriving! He got to be a normal baby! As I am typing this, Mason is 12 days post Glenn surgery (the second open heart surgery out of the three-part series). This means that we made it through the interstage (the period of time between the first and second surgery)! Safe At Home gave us a scale and a pulse ox machine to take home so that we could do daily checks with both to stay on top of any issues that could possibly arise. I am proud to say that Mason never had to go back to the hospital for any unscheduled visits during this time. Mason has now "graduated" the Safe At Home program, and their team threw Mason a little graduation party after his second surgery. We are so thankful that we were able to take our baby home for those few months in between!

Adeline's story

Double-inlet left ventricle, hypoplastic right ventricle, transposition of the great arteries and coarctation of the aorta. It sounds like a whole lot, and it was, but it isn't the end of the story. Actually, it is just the beginning of an admittedly long, admittedly trying, but thankfully continuing and happy journey.

Her name is Adeline Camille. She was born May 16, 2012. She loves her big sister and has a completely infectious laugh with a wee bit of orneriness mixed in. In her young life, she has faced two complicated open heart surgeries and numerous long nights in the hospital and come out on the other side with an enthusiasm that lights up a room. You may think, "How can one really think a baby 'fights' these things or 'overcomes' so much?" We know because we have seen it firsthand. And not only in Adeline, but also in other children that have heart defects. There is a fight and a drive in these kids. It comes from their loved ones and their caregivers. It comes from them.

Now, life is pretty normal for us and, most importantly, for Adeline. She has follow-ups with her cardiologist every six months to check her heart function and takes a couple of low-dose aspirin every day. I wish we kept count of the number of people who, when finding out about her heart history, remark, "I never would have known."

Logan's story

In 2014, my wife and I started a journey that would change our lives completely, but in a way we could never have imagined. We knew the arrival of our son that spring was going to be a big change for the two of us since Logan would be our first child and neither of us had much experience caring for young children.

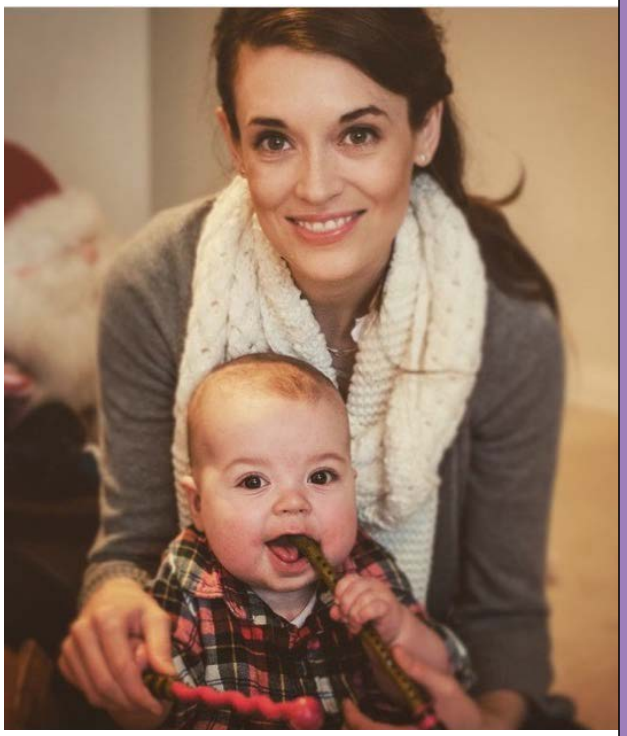
Our Journey started unexpectedly just one day after Logan was born. Our scheduled delivery had gone exceptionally well, and Logan was born into the world at 11:03 a.m. on April 10 as our healthy 8 pound little boy. Our pre-natal appointments had all gone very well and without any hint of problems. We began to pack our bags on the second day of our hospital stay while we waited for Logan to have his standard tests and procedures completed. It was one of these tests for congenital heart defects that probably saved our son's life.

The pediatric doctor from our local hospital consulted with a specialist in the Dallas area and confirmed that Logan's heart needed the immediate attention of a skilled cardiology team. Having heard positive stories from friends about their experience with treatment at Children's Medical Center, our decision to choose them for Logan's care was easy. Within a few short hours our newborn son went from being in our arms to being put on a plane headed for Children's Medical Center Dallas. Since my wife, Amanda, had just given birth, she would not be allowed to accompany our son on the plane, so I would be the one to sit with Logan as we prayed for answers once we arrived at Children's Medical Center. It's fair to say that up until this point neither of us had ever felt this helpless. Once at Children's Medical Center, the diagnosis began to emerge. It was difficult to hear and comprehend a complex heart condition, but at least we now had a name for our son's heart defect. We were taught (not just told) about a series of operations that would give our son a chance at a beautiful and productive life; reassuring words for any parent.

Our little boy has hypoplastic right heart syndrome, and you may hear it referred to as HRHS. The Norwood Procedure (BT Shunt) was performed when he was 7 days old to begin the process of reconstructing a workable cardiovascular system for Logan. The days leading up to surgery were tough and character building; it is humbling to be taught how to love someone in a brand new way. The concierges, social workers, case managers, ministers, nursing staff, therapists, doctors and surgeons gladly provided the information on each step of our son's journey. No question was insignificant to this aspect of the process. Because Children's is a teaching hospital, questions were and are still encouraged. A month's stay in a children's hospital is difficult, there is no way of getting around it, but there is hope. We saw small flickers each day. One day it may be that your child's oxygen saturation numbers are two points better, or that your child smiled or laughed at something in a book you're reading to them. Believe us when we say that it does get better, and one day you will stop hearing the monitors go off in your sleep. We also became pros at reading our child without the assistance of computers, trusting our parental instincts, but also freely sharing concerns when we didn't have answers.

We also found humor to be the key to sanity. Although difficult, we like to use the example of our son's vocal chord paralysis. After surgery, our son's vocal chord was paralyzed due to a vein that runs along the side of the vocal chord and the heart, which is not uncommon but isn't always permanent and can be corrected with speech therapy or simple procedures years down the line. We teased that our son might start kindergarten and introduce himself with the raspy voice of Batman, and how that might work to his advantage when making friends. Humor helps.

If you and your family chose to go through the Safe at Home program you have made a wonderful choice. Before you are discharged from Children's Medical Center, you will receive the proper training on how to care for your child, and you will have a number you can call or text at all hours if you have a concern. We made many calls leading up to our son's second surgery, and it gave us the confidence to care for Logan in the comfort of a home. Like many that may come to Children's, our home was not a safe driving distance from the hospital. We were extremely fortunate to have relatives in the Dallas-Fort Worth area and had jobs that allowed us to work remotely. While everyone's situation is unique, know that the Ronald McDonald House is available if you need a place to stay, and the social workers at Children's Medical Center can help you find the most comfortable arrangement possible. It is now January, and Logan is four months past his second of three scheduled surgeries. What may surprise parents of children that may need multiple surgeries like ours is that while it is beyond challenging to watch your baby or child go back to an OR, we had a better idea of what to expect with his second operation. We also were more confident in what his care would look like, along with what questions we needed to present before discharge. The day we walked into clinic and were told by Nurse Myers that we were released for travel was almost as heart wrenching as seeing our boy recover from two open heart surgeries in just five short months. We could finally take our son home! Life since the Glenn has been more like we thought it would be before our son's diagnosis. We have a few more doctor and therapy appointments, and we do have to be a little more careful with his exposure to crowds, but for a lot of new parents, these are precautionary measures that many choose to take even with the healthiest child. Each day is such a gift, our son brings us so much joy and purpose. He's a chubby, happy little guy that is always ready to play and laugh. Laughter fills our days more than the worry or the sound of monitors.



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