Meet Penelope!

Age: 9 months

Penelope’s primary cardiac diagnosis is ASD/VSD.

Read Penelope’s story:
Penelope was diagnosed with ASD/VSD at one week old, and her surgery was performed when she was 6 months old! We spent a total of 3 days in the hospital, and those 3 days were the most challenging and rewarding 3 days of our life. We have nothing but great things to say about the staff in Atlanta and they truly were the shining light during such a dark time for us. We are forever thankful for how they treated us and our daughter.

Submitted by Penelope’s parent(s), Jessica Snider
Photo ID #35

Meet Thaddeus!

Age: 4

Thaddeus’s primary cardiac diagnosis is TGA.

Read Thaddeus’s story:
We found out about Thaddeus's heart defect at my 22 week anatomy scan. He was diagnosed with TGA. He had his arterial switch surgery at four days old. We spent about a month total in the hospital. He is now a four year old full of energy! He loves trains and Spiderman. We are so thankful for CHOA, Sibley Heart, and Dr. Alsoufi.

Something else to know about Thaddeus’s family:
We chose the name Thaddeus before we found out about his heart defect. Thaddeus means "of courageous heart."

From left to right: Lyla, Evie, Christa, Thaddeus, Jeremy

Submitted by Thaddeus’s parent(s), Jeremy King

Photo ID #36

Meet Landon!

Age: 11

Landon’s primary cardiac diagnosis is Transposition of the Great Arteries, Coarctation of the Aorta, ASD, VSD.

Read Landon’s story:
Our heart journey started in Wichita, Kansas on February 21, 2009. Landon was born the previous day without complications, but after 24 hours our world was turned upside down. Landon was rushed to the NICU to get stabilized after his pulse ox was 65. After what seemed like hours the cardiologist came out to tell us that Landon had 5 heart defects and was very sick. Later that night he was life-flighted to Children's Mercy Hospital in Kansas City where he underwent his first open heart surgery at 2 weeks old. We were in the hospital for a month and then sent home with monitors, feeding tube and machine, and oxygen.

As the weeks and months passed we settled into our new normal. After a few months he was able to come off the oxygen, but still had feeding issues until he was about 1 year old. Landon was stable until he was 7 years old when he underwent a stress test and MRI that indicated a need for another open heart surgery to complete his repair and address the narrowing in his right, left, and main pulmonary arteries. This surgery was done at CHOA, by Dr. Alsoufi. We were home a week later, and a month later we were at the beach. Overall, everything went well with his repair, but he does suffer from vocal cord paralysis from his last heart surgery.

Landon enjoys hunting, fishing, Camp Braveheart and baseball. To look at him you would never know he went through such a difficult start to life. Recently he was also able to undergo a procedure that has helped restore his voice as well. Our experiences at CHOA and Sibley have been wonderful,we are so very thankful for the entire staff, their compassion and commitment is amazing. As we look back on Landon's journey and think about his future we are so hopeful. Our main source of hope since we moved here 10 years ago has been the Parenting Your Heart Child Conference. There we were able to see adults living with their heart defects and hear their stories as well as listen to the various presenters providing information on support, science and sanity. We are so thankful for Kids at Heart and everyone that works tirelessly to make the program the success that it has become.

From left to right: Mark, Landon, Grace, Jamie

Submitted by Landon’s parent(s), Jamie Hoekstra
Photo ID #37

Meet Reese!

Age: 5

Reese's primary cardiac diagnosis is ASD.

Read Reese's story:
Reese got her diagnosis in 2016 when she was at the doctor's office with strep. They found a murmur and thought it could have been because she was sick and running a fever. She had open heart surgery March 13, 2019. We stayed in the hospital for a few days when she had her surgery but we got to come home 2 or 3 days after her surgery. The most challenging thing we have faced recently has been that she still does have a small murmur and if it doesn't close up by the end of this year they will have to do more testing to see what needs to be done. Knowing we are in great hands is very reassuring. Reese started pre-k this year and is doing a great job. She's the best big sister and so smart. She always talks about her scar and wants people to see it.

Something else to know about Reese's family:
We try to do a game night with the girls every Friday night.

From left to right: Blakely, Danielle (mommy), Reese, Kinsley, Mathew (da)

Submitted by Reese's parent(s), Danielle Harlin
Photo ID #38

Meet Paisley!

Age: 7

Paisley's primary cardiac diagnosis is Hypoplastic Left Heart Syndrome.

Read Paisley's story:
At 22 weeks gestation, following concerns during our anatomy scan, we received the shocking news that our baby girl would be born with a congenital heart defect (CHD). Paisley was born in September of 2013 with Hypoplastic Left Heart Syndrome. She was immediately rushed to the NICU and then transferred to CHOA one day later to make plans for her first open heart surgery.

On September 23, 2013, at just 6 days old, Dr. Kanter performed her Norwood procedure. She was in the hospital for one month due to numerous complications including a GI bleed, clotting of her shunt (which caused her to code), and feeding difficulties. Between her first and second surgery, Paisley was continuously in and out of the hospital due to feeding intolerance and a weak immune system.

At five months old, she began to show a different breathing pattern and was life-flighted to CHOA where it was revealed that her aorta had narrowed causing other difficulties for her already weakened heart. Dr. Kanter then performed her second open heart surgery (the Glenn) a couple weeks later on February 27, 2014. Following this surgery, her lungs collapsed and the doctors were very unsure of her future. For the next two weeks, she fought hard for her life! After again spending a month inpatient, we were able to take our baby girl home and stay there more often. Her body functioned better after this surgery but she still had difficulty with feeding resulting in an NG tube until she was 11 months old, reduced oxygen saturations causing respiratory concerns, and severely decreased muscle tone with subsequent physical delays.

Paisley has received physical therapy services and intermittent occupational therapy services her entire life. She wears ankle-foot orthotics to help compensate for her hypermobility and weak muscle tone. She also has a paralyzed vocal cord that was discovered during one of her pre-surgical heart caths. Paisley has seen her cardiologist Dr. Watson since the beginning of our battle and he has been a true lifesaver for her and our family. She visits him at Sibley Heart Center in Marietta for routine follow-ups, EKGs, and echocardiograms.

After her second surgery, Paisley progressed well until she reached age 5. That Christmas we began to notice a significant decline in her endurance and oxygen levels. Her lips and fingers would turn blue, her skin pale, and her breathing very labored with the slightest bit of activity. Finally on October 21, 2019 Dr Subi performed Paisley's third open heart surgery (the Fontan) and Paisley rocked it. With her previous recoveries having been so complicated, we were positively shocked when she was up walking four days after surgery and home after only nine days inpatient!

Paisley is now 7 years old and has been a totally different child since her Fontan! Her body is much stronger and she has so much more energy. While she continues to have difficulty with attention, executive functioning and some motor skills, she is living her best life. She is smart, sassy, and full of personality. She loves singing, dancing, caring for animals, and playing games with her daddy.

She is the true definition of a warrior and will always be our shining star! We are so thankful to her amazing team of doctors, surgeons, nurses, and therapists at CHOA and Sibley who have taken care of her and helped her to reach her full potential over the past 7 years!!!

Something else to know about Paisley's family:
Paisley is an avid dog lover and is always so happy when she gets to see UNO the cardiac therapy dog!

From left to right: CJ (dad), Paisley (heart warrior), Nikki (mom)

Submitted by Paisley's parent(s), Nikki Sumner
Photo ID #39

Meet Liam!

Age: 3

Liam’s primary cardiac diagnosis is VSD,BAV, IAA, Aoritc Stenosis.

Read Liam’s story:
Liam was diagnosed during pregnancy with a Interrupted Aorta Arch (IAA), VSD & Aortic Stenosis. At 7 days old he had his 1st open heart surgery to repair interrupted aorta and VSD and was in the hospital for 14 days. At 2 1/2 he had his 2nd open heart surgery to repair Aortic Stenosis, with a Valvuloplasty repair and was in the hospital only 4 days. At some point he will have his 3rd open heart surgery which will be the ROSS procedure. We are so grateful for everyone at CHOA and know he has the best care of doctors, surgeons and Nurses! Liam is a very active kid and you wouldn't even know he had any heart problems!!

Something else to know about Liam’s family:
We love to go to the lake in the summer on our boat!!

From left to right: Ethan, Kaleb, Adam, Kim, Kara & Liam in the front

Submitted by Liam’s parent(s), Adam Dutton
Photo ID #41

Meet Faith!

Age: 16

Faith’s primary cardiac diagnosis is Heart transplant restrictive cardio myopathy.

Read Faith’s story (in her own words):
Since birth, I have struggled with heart disease. At age 2, I underwent my first heart surgery. A PDA and co-arc was repaired. I began to thrive after this surgery. As I grew older, we began to notice subtle changes. I couldn't always keep up with my friends. I was tired more often and wanted to rest often. Around the age of 13, my mom started noticing more severe changes in my breathing and ability to exercise. She took me to my cardiologist for a check up to make sure everything was okay. Well, sure enough all the test came back great and we went home with no worries. For a year I continued to struggle with breathing, my energy was declining rapidly and I was gaining weight like crazy. Again, we headed back to the cardiologist, knowing something wasn't right. Once again, more tests and everything looked good. My mom continued to push because she knew something wasn't right with her daughter. A few months later we went back again, because I felt terrible! I was referred to the heart transplant/ heart failure clinic. A heart cath was performed, when the results came back the news wasn't good. The pressures in my heart were high and my heart was not relaxing. I was diagnosed with restrictive cardiomyopathy! This news came as a shock! Yet, finally an answer to the symptoms that had plagued me for years. I now was a patient of The Heart Transplant/Heart Failure Clinic at Egleston.

I continued to have checkups with the team of doctors, but they thought everything looked fine and put me on a low-dose of a few medicines. My symptoms continued to progress. I wasn't feeling well and my quality of life was declining. A repeat heart cath was preformed. On March 13, 2020, we heard heartbreaking news: I was in active heart failure and I had advanced restrictive cardiomyopathy. We were told that I would need a heart transplant in the distant future.

Well, I made it through the summer with my symptoms continuing to worsen. It was decided the time had arrived to start looking farther into the process of a heart transplant. My parents and I went to the evaluation, listening through a fog of disbelief. How could this be real? At this point, the team decided it was not the time for transplant. I was healthy enough to enjoy more life with my heart. But by September 26th, I did not feel well. As the day progressed, I began to decline rapidly. I was life-flighted to Egleston that evening. I spent several days in the hospital being treated for heart failure and fluid overload.

On October the 5th, I was listed with UNOS, to receive a heart at any moment. The distant future had become the present day! Life seemed to be spinning with change I could not control. My family, Jesus, and my heart transplant team held me and guided me through these uncertain days. I was able to return home on medication to help control the heart failure. We prepared my hospital bag, just as you would when awaiting a new baby. My mom said many times she felt like a new life was coming our way. It was true, I would be receiving a new chance at life!

On October 16, once again I awoke feeling horrible. We headed back to the hospital, our prepared bags in tow! My body wasn't reacting as needed to the medicines. I couldn't eat anything and was growing weaker. We knew at this point there was not much more that could be done until a new heart came. We waited day by day in the hospital, sometimes patiently, sometimes not, waiting for a heart. Thankfully and unbelievably, the wait was short!

On October 25th at 10:32 in the morning, we received the life changing call! The transplant team accepted a heart and I would go into surgery at 6:00pm. My entire family was allowed to come into the hospital and spend the day with me. We laughed, cried, snacked and played games my Grandma had sent. When the time came to go into surgery, we went together to the doors of the surgical suites. Together with my nurses we prayed for my surgery and the family of the donor. My surgery was a success! Three months out and my new heart is healthy and strong! I can walk stairs without becoming breathless!

We were cared for by what we consider the worlds best nurses and the worlds best children's cardiac team! Forever we will be thankful for the CHOA team! After 79 days, we returned home! We were greeted by friends and family lining our street waving signs of encouragement! As I live life with my new heart, daily will I praise Jesus for my life. I plan to grab every opportunity to encourage "Heart Warriors" as we embark on our journeys!

Something else to know about Faith's family:
We're a family full of love, fun and more memories than can be counted! Each member of our immediate and extended family support one another in ways that are heaven sent! We collectively and individually know that our Savior, Jesus, is the binding force of our beautiful family!!

From left to right: Asher, Faith, Grace, Chad (dad), Lathina (mom), Caleb, Shelby, Luke and Sophia (Niece)

Submitted by Faith's parent(s), Lathina Casey

Meet James!

Age: 2

James’s primary cardiac diagnosis is Shone's complex.

Read James’s story:
James Charles was born seemingly healthy. He was 30 hours old when he began to breathe hard and fast. The nurse took him down to the NICU and I didn't see him for several hours. Then they called us in a conference room and told us something was wrong with his heart. We met with Dr. Lindsey and he told us James had something called Coarctation of the Aorta. He was taken by ambulance to CHOA at Egleston that same night. He was there for 12 days before being strong enough to have his surgery at 13 days old. He had the Coarctation repaired but also has multiple other defects on the left side of his heart which labels him as Shone's complex. He stayed in the hopsital for 38 days that first time and has been back a few times over the last two years. He has had two heart caths done. James also has temporal lobe epilepsy and a gene mutation. He is in physical and occupational therapy, but is mostly a normal toddler!

Something else to know about James’s family:
We love to hike and have hiked in 7 states with James over the last year. He usually rides in a backpack carrier as he still tires very easily and has some left sided weakness.

From left to right: Kevin Davis (step dad) Iva (sister age 6) Gin (Mom) James (heart warrior)

Submitted by James’s parent(s), Gin Gipson
Photo ID #43

Meet Isaac!

Age: 9

Isaac’s primary cardiac diagnosis is Aortic stenosis/bicuspid valve.

Read Isaac’s story:
Isaac was diagnosed with aortic stenosis shortly after birth and had a cath procedure at 6 weeks to alleviate it. We were grateful that was enough intervention to keep him healthy until last fall when he began having fatigue with mild/moderate activity, and open heart surgery was scheduled. He had the Ross procedure April 2020 and recovered well and feels great! It's been such a blessing to have had exceptional care. Because of the great doctors and nurses and especially Dr. Phelps that we've seen since his birth, Isaac hasn't ever viewed his heart defect as something to be afraid of or something to inhibit his life, but more of something that makes him unique. Nobody really wants to have a child with medical challenges, and it's scary at times, but it's given us a greater desire to appreciate each day. The Lord has blessed us with understanding that He brings us joy and satisfaction in life, and that He is always near even in difficult circumstances.

Something else to know about Isaac’s family:
We like to ride bikes as a family.

From left to right: Mary Jo, Amos, Isaac, Silas (very front) Titus, Julia. Joanna and Nick in the back.

Submitted by Isaac’s parent(s), Joanna Nehring
Photo ID #44

Meet Addyson!

Age: 21 months

Addyson's primary cardiac diagnosis is ASD/ VSD.

Read Addyson's story:
We recieved Addyson's diagnosis of Down Syndrome at our 20 week scan. We declined the amnio because we would love her either way. Addyson was born on 4-29-19 and we spent 2 weeks in the NICU at Northside Hospital then we were able to go home. We saw cardiology for the first time 2 days later and were rushed straight to CHOA by life-flight; there was a terrible wreck on the highway so we had to be flown in! We spent a month at CHOA before surgery on 6-17-19 and a week later we got to come home. Addyson is doing great and her repair is doing wonderfully! She loves to play with her big sister and our cat, she loves to eat and is a great toddler!

Something else to know about Addyson's family:
We love to be outdoors and love going for walks. We love the beach. We love spending time together.

From left to right: Karlie, big sister-age 9. Addyson. Larissa and Alec

Submitted by Addyson's parent(s), Larissa Moran
Photo ID #45

Meet Keegan!

Age: 14

Keegan's primary cardiac diagnosis is Coarctation of Aorta; Bicuspid Valve.

Read Keegan's story:
Keegan was diagnosed on June 17, 2019. We went to her pediatrician for a well check on June 11th. She was extremely anxious and upset because she was going to receive some shots. They couldn't get her heart rate down and she was very emotional. While they were trying to calm her down, the nurse practitioner (Erin Ferguson- our hero) noticed that her heart had a "whoosh." I noticed Erin kept quiet and later pulled me aside so we wouldn't upset Keegan more. She said she wanted us to have EKG, Echocardiogram, and a couple of other tests. She was diagnosed with Coarctation of the Aorta and she has a bicuspid valve that we will monitor. The coarc needed to be taken care ASAP. Needless to say, we were terrified, confused, and shocked.

We went to Egleston and met with Dr.Petit who performed the procedure on August 12th. Keegan had a stent placed in her Aorta. Keegan was doing well for about 2 weeks, but we started to notice when she walked or ran her leg would start to hurt and would swell. Dr. Petit ordered an ultrasound, and found out that Keegan started to clot. So we went back to Egleston that night, September 5, 2019. They were considering another stent in her leg where the cath went in. That's where the clot was located. First for the following next 4 days, they were going to try to shrink the clot instead of another procedure. So Lovonox came into our life. Keegan started 2 shots a day for those days, in hopes Lovonox would work. The great news, it did! The bad news, Keegan is terrified of shots. They were to be given 8 hours apart at the same time. We did the shots for 8 weeks. 8 long weeks. Every week we would go get an ultrasound and to see the hematologist at Egleston. She would cry, scream, it was horrible. We kept saying so many kids have it much worse, but her anxiety was through the roof. I would have to go to school, her friends house, a vacation and give her shots. But it worked. Dr. Petit said for her quality of life, we had to stop the shots. It was too much for her. If it kept swelling we would do the procedure. The clot did not disappear, but was small enough that her leg stopped swelling. We could finally try to have a normal life. But as you know, CHD is not normal. Keegan will most likely have 1 or 2 more stents because she is not done growing around age 17. We know have Dr. Sallee as our cardiologist who specializes in aortas. We have to monitor her bicuspid valve, but nothing was done now because it's "doing its job!"

I think the most difficult part about all this was it was just such a surprise. One day she's playing tennis and the next you find out if they didn't catch this, her heart would have killed her playing tennis. The nose bleeds, occasional "I'm tired" at weird times, and definitely her anxiety, we never would we have guessed CHD.

Our hope for Keegan is knowing that she is in the best of hands at Children's. That one day there could be a cure for these kids. We have so many hopes! What I love the most is that Keegan is a shy, goofy, hysterical kid who likes to keep to herself, but after this entire journey, she's not afraid to say "I have CHD."

Something else to know about Keegan’s family:
We love to travel and anything with the water! We love University of Notre Dame because my dad went there. We are quite a sarcastic bunch. Keegan just said to me, "We quote the movie Eurovision way too much."

From left to right: Quinn, Keegan, Dean, and Megan Grzymala

Submitted by Keegan’s parent(s), Dean Grzymala Grzymala
Photo ID #46

Meet Marley!

Age: 7 months old

Marley’s primary cardiac diagnosis is TOF/PA/MAPCAS.

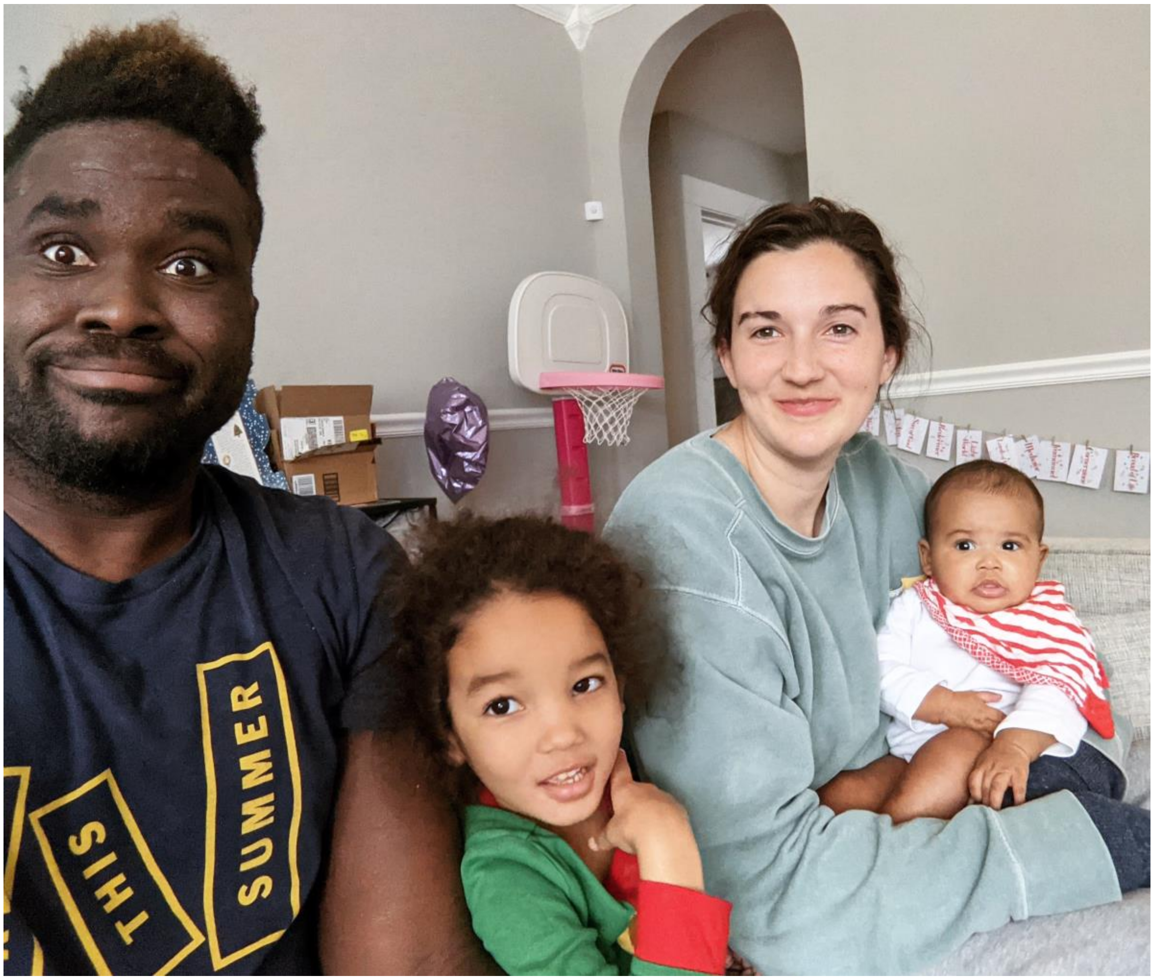
Read Marley’s story:
We found out about Marley's heart diagnosis when we were about 30 weeks pregnant, in May 2020. Many ultrasounds were done previously, but we were told that she was in a position that made it hard to see her heart, so Lexi went in for a specialist appointment and Kwam was on Facetime (due to Covid precautions) when we heard the news that something was not quite "normal." The doctors then confirmed at a fetal echo appointment at Egleston that Marley had TOF/PA/MAPCAS. We watched the Jimmy Kimmel monologue about his son who had the same diagnosis and started to get very worried.

We were initially told to expect 2-3 surgeries to get the full repair, but when Marley was born in July 2020, she had a Pulmonary Artery that reached her lungs. This was huge because the fetal echo could not determine if she had one or if it was big enough to supply blood to her lungs. She was able to hold off on getting surgery while undergoing one cath procedure, before we were allowed to bring her home. We couldn't have asked for better care while we were there. Many teary eyed bedside days were spent in the CICU, but we always felt supported and reassured by the nurses and doctors that saw us.

Surgery is fresh on our minds as she received her full repair in November 2020. It was 12 hours long with Dr. Subi who did an amazing job. I honestly don't even know what we did; it was such a long, scary day. I think I watched Doc McStuffins on the lobby TV. The most challenging part of it all was the fact that with the pandemic and a high risk baby, we limited a lot of interactions we have had around our family. We felt really isolated and alone at times.

With all the challenges faced during that time, we are so thankful for family, friends, nurses, child life specialists, doctors, all got really creative in making us feel supported sometimes virtually. We had friends drop off our favorite take-out at the hospital, send us giftcards for coffee, and social distance outside Egleston to give us a break from all the medical things. Thanks so much to Kids at Heart for sharing these stories to let others know we are not alone in our heart journey!

Something else to know about Marley’s family:
Our oldest daughter still talks about the Invisible String after reading her that book given to us by Kids at Heart. It helped so much as we stayed away from her at the hospital



From left to right: Kwam, Zara (4), Lexi, Marley (7 mo.)

Submitted by Marley’s parent(s), Lexi Awotwi

Photo ID #47

Meet Madden!

Age: 10

Madden’s primary cardiac diagnosis is Large VSD, PFO, Tetralogy of Fallot.

Read Madden’s story:
Madden was born in 2011 with a large VSD, PFO and Tetralogy of Fallot. We didn't know ahead of time so it was all quite a shock as you can imagine! Dr. Stevens, our cardiologist, let us know that Madden would need open heart surgery within the first few months of life. So May 2011 at just 3 months old Madden had his first open heart surgery.

Dr. Kirshbom performed the surgery at CHOA Egleston. He did a repair patch on the VSD and took out muscle fibers to widen his sub-pulmonary. Madden spent 6 days total in the hospital/CICU and then it was off to go home to recover.

In February 2016 at our yearly cardiology appointment Dr. Stevens told us Madden would need a 2nd open heart surgery to take out additional muscle fibers that had grown into a severe stenosis in his pulmonary. So after a quick trip to Disney, Madden had his 2nd open heart surgery May 2016. Dr. Kogon performed the surgery at CHOA Egleston and we left 4 days later for home to recover.

The one thing I can say about CHOA staff, doctors, nurses and just everyone in general is that they take just as much care of the parents as they do your child. There were many times they forced my husband and I to leave to go rest or go get a quick meal. They really take care of everyone in this stressful situation. They laugh with you in the funny moments, hug you in the happy times and cry with you when you feel hopeless. This journey hasn't always been easy for any of us but they always make you feel secure in the fact everything will be ok, and truly for us it has!

Madden is now 10 and in 4th grade. He lives a normal healthy life playing golf and swimming. He plays guitar and sports with his friends. Other than his zipper scar you would never know he had heart surgery(s). We have always looked at his heart defect as a strength and not a weakness. It's what you take away in trying times that adds strength to your character. Madden loves to tell his story and let others know you can live with a heart defect and you CAN be ok.

We truly are blessed and so is our heart hero Madden! I am not sure why I was picked to go on this journey, this journey that is a heart mom. I would like to think that it is because I was the best mom for the job, but I know that is not the case. Instead, I think that I was chosen because I am not the best mom. I am just a mom that fell in love with a little boy with a broken heart.

Something else to know about Madden’s family:
Our family really loves and is thankful to CHOA/Kids at Heart/Sibley Heart for all the events and gatherings for our heart heroes and families. We have been able to attend the Georgia Capitol event for CHD Awareness Week. Madden has attended Camp Braveheart which has been his favorite camp to date! We've done the Aquarium events and bowling. It's such a great program for our heart kiddos and families to connect with each other. Thank you CHOA!

From left to right: Kristi Cimino, Madden Cimino and Justen Cimino

Submitted by Madden’s parent(s), Kristi Cimino
Photo ID #48

Meet our Heart Center staff!

Name: Audrey Beckman

What's your job? Assistant Manager Cardiac Nursing at CACU

How long have you worked at the Heart Center? 22 years

Read Audrey's story:
I have "grown up" as a nurse in the Heart Center, on the Cardiac Stepdown Unit...now the Cardiac Acute Care Unit. I began right after I graduated from college on August 10th, 1998. And here I am still, 22+ years later. There is NO WHERE ELSE I could imagine being. The experiences I have had and the relationships formed have made me the nurse, wife, and mom I am today.

We are able to be with our patients and families at one of the most traumatic and also joyful times of their lives. We are privileged to walk alongside them in this journey and become part of their family. There are moments that take your breath away, when you witness miracles. Heart warriors who were at a point where you never knew what the next day, hour, or even minute would bring. Then you watch them leave the hospital and are filled with a joy that is unexplainable. And there are times when you are with your patient and their family when the unspeakable happens. And there is a grief you share that is unlike anything you have ever experienced.

Throughout my career I have learned to never take anything for granted, to revel in the smallest things. I have watched some amazing people, enduring what would break most, and yet still they remain strong. They love their children fiercely. The kind of love that rolls up its sleeves and isn't afraid to get its hands dirty. The kind of love that will go to battle for their child and not shrink away. I am honored to know these patients and their families.
There is a famous quote that says, "A hundred years from now it will not matter what my bank account was, the sort of house I lived in, or the kind of car I drove... but the world may be different because I was important in the life of a child." After my time here it feels more like, "A hundred years from now it will not matter what my bank account was, the sort of house I lived in, or the kind of car I drove... but my world will be different because I was privileged to be part of the life of a child."

Pictured: Ella Grae Bullard and Audrey

Meet our Heart Center staff!

Name: Chelsey Creel

What’s your job? Perfusion at CVOR

How long have you worked at the Heart Center? 5 years

Read Chelsey’s story:
Families are trusting us with their biggest treasure in the whole world. It's an honor to help heal them and send them back with their families. I try to treat every baby as if if they were my own during every case.

Pictured: Chelsey at work

Meet our Heart Center staff!

Name: Leslie Bishop

What's your job? NP at Sibley outpatient

How long have you worked at the Heart Center? 38 years

Read Leslie's story:
My first job out of nursing school was on the newly created Cardiac Floor at Egleston in 1981. I worked there until 2008, when I left to work as a NP in another CHOA department. The cardiac floor, now called CACU, moved many times and changed names a few times as well over the years. I returned to the Sibley outpatient world in 2010, first as a clinic nurse and then as a clinic NP. Obviously, I could not stay away from Sibley and our wonderful heart children and their families. I truly loved being a hospital nurse, but now I love working with outpatients and seeing them when they are healthy and happy and making connections throughout their childhood and teenaged years.

Pictured: Mary Nall, Josephine Gray, Leslie Bishop, Allison Smith

Meet our Heart Center staff!

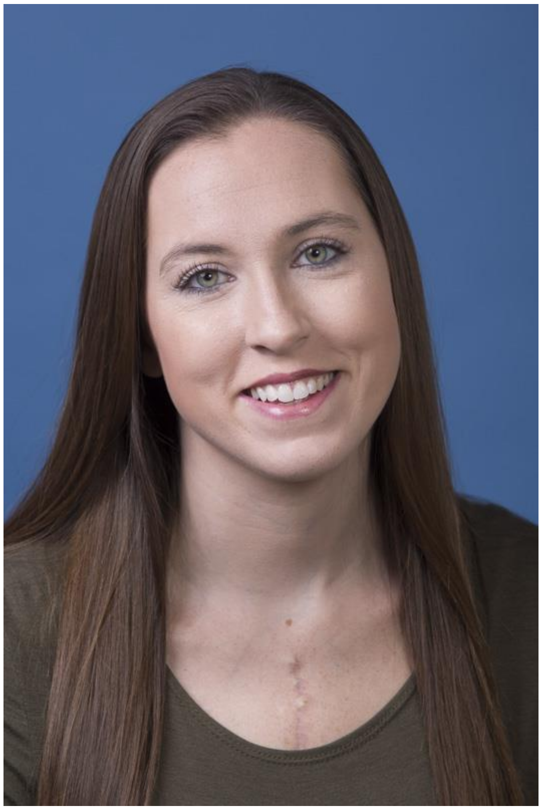
Children's
Healthcare of Atlanta

Name: Dana

What's your job? Sonographer at Echo

How long have you worked at the Heart Center? 6.5 years

Read Dana's story:
I feel so extremely blessed to be able to walk alongside such amazing kids and teens as they grow and change while living with CHD. Being a CHD survivor myself, I grew up in cardiology and remember very well what it was like to go to those visits: anxiety, nervousness, relief. We have so many phenomenal children and parents that make working here worth it all. I love watching everyone grow up and learn about who they are and what they can do with their lives!



Pictured: Dana

Meet our Heart Center staff!

Name: Laura Davis

What's your job? RN at CICU

How long have you worked at the Heart Center? almost 2 years!

Read Laura's story:
I LOVE getting to work with our heart kiddos! They, along with their families and caregivers are among some of the toughest fighters I've ever seen! I love getting to be a part of the Heart Center because I believe we try our hardest to provide the best care possible! Not only do we treat our kiddos medically, we treat our patients and family as a whole. We have so many different disciplines within the Heart Center to give our kiddos the best outcomes! I appreciate working with some of THE BEST doctors, surgeons, respiratory therapists, PT/OT, child life, speech, social work, chaplains, case workers, EVS and many many more! (I'm not biased at all... I swear!) We all come together to help our heart kiddos! Some days are incredibly stressful, long and draining, but it is all worth it at the end of the day to serve our heart warriors and their families! Over time, you become a part of these heart warriors family, you watch them grow and develop. I can't think of a more rewarding job. Not to mention, we have THE BEST NURSES! Their communication, advocacy for their patients and families and the pure love they show every day when they come to work.... It really makes a difference! We also like to have fun and make the hospital as happy a place as it could be! So happy, thankful and grateful to be a part of The Heart Center and the CICU!

Pictured: Laura (Left) & Madison (Right)

Meet our Heart Center staff!

Name: Nicole Coolidge

What's your job? NP at Single ventricle program

How long have you worked at the Heart Center? 13 years

Read Nicole's story:
I have had the pleasure of caring for CHD warriors in many different roles during my time in the Heart Center- from bedside nursing in CACU and CICU, to NP roles in cardiology and heart transplant, and now as the NP for the single ventricle program. Throughout all of these experiences in helping to care for your children, words like strength, courage, tenacity, endless love, and of course squishy cuddly cuteness fill my memory. I'm in awe of my patients and families every day. And since becoming a parent myself a few years ago, I have even more respect for what you all as parents endure- and with such grace. This past year has been filled with some of the heaviest challenges I've seen parents deal with to date- yet this past year I've heard about and encountered some of the most gracious, amazing displays of love, affection, and commitment to family that I've ever seen. I want to thank you all for letting me love on you and your kiddos over the years. My gratitude runs deep and I'm thankful every day for the opportunity to become a part of your CHOA family.

Pictured: Nicole, Brad (husband), Janie (daughter), Brooks (son)

Meet Hailey!

Age: 5

Hailey’s primary cardiac diagnosis is LTGA.

Read Hailey’s story:
Hailey was born in December 2015 around 10 AM. There were no indications at all that she would be born with a heart defect but by lunchtime that day her pediatrician was concerned and put in an urgent call for her to be evaluated by Dr. Toole with SHCC of Albany. We were very lucky that day because he was headed out of town and had not left yet. He sent Hailey to Atlanta to CHOA so that we could get an accurate diagnosis and form a treatment plan. Her first few days were very scary as we learned more about CHD and her condition. The doctors decided that she was stable enough to go home and grow. A few weeks before her first birthday we realized that her condition had deteriorated significantly and we raced her to Egleston from our home 3 hours away. A week after her first birthday Dr. Kanter performed a very rare and complex surgical repair called the "Senning-Rastelli/Double Switch." She was in surgery for almost 12 hours. Her recovery took a few weeks in the hospital and several more at home. She also was on a feeding tube for a few months while her lymphatic system healed. She started to grow quickly after that until her second surgery at almost 3 in October 2018. This was another long day in surgery with Dr. Kanter but it was very successful and has allowed her to lead a normal life since then. She attends pre-school and loves cheerleading, dancing, singing and shooting her bow! We feel so blessed to live in a state with an amazing heart center for children. We are also incredibly thankful for the Kids At Heart program. It gives us the opportunity to spend time with other families with similar challenges.

From left to right: Adam, Hailey, Erica

Submitted by Hailey’s parent(s), Erica Ferguson
Photo ID #4

Meet Emmie Lou!

Age: 18 months

Emmie Lou’s primary cardiac diagnosis is HLHS.

Read Emmie Lou’s story:
Emmie Lou is currently our only child. We had a bit of a tough time conceiving but with an awesome OB team and many, many prayers, I found out I was pregnant 5 days before Christmas. My pregnancy was fairly routine and easy until our 20 week anatomy scan. The sonographers were having trouble seeing all of the chambers in her heart. Everything else checked out normal so we were scheduled for another anatomy scan at 24 weeks. At that appointment, they still weren't seeing everything so I was referred to a specialist and then to our wonderful cardiologist, Dr. Toole. At 28 weeks we found out that Emmie Lou had hypoplastic left heart syndrome. We spent the next few months preparing for our new baby to have open heart surgery within days of her birth. The only way I know how to describe that time is: it was hard! There were so many terrifying unknowns. Emmie Lou's first surgery the Norwood procedure, was 9 days after she was born. 14 days after this surgery, she was moved to the step-down unit & 4 days later discharged from the hospital. We had to check oxygen saturations and her weight every night. The hardest part about the interstage period was giving her twice daily lovenox injections. We were extremely relieved when we no longer had to do those!   Before her second surgery, she had to be admitted at Egleston and have a cardiac catheterization. Because we live almost 4 hours away from CHOA & we were seeing signs of her needing her next surgery, we were advised to stay in Atlanta until the Glenn. This was a real challenge for us being so far away from our family, friends, & jobs. However, we knew that it was too risky to be too far away from the hospital and thankfully, we had amazing support at home! One night, we had to go to the ER at Egleston because her oxygen levels would not come up above 70%. After a long, restless night, we were admitted to the step down unit & stayed 24 hours. We discussed moving her Glenn date up, but then we actually ended up getting pushed back to our original scheduled date.   Her second surgery, the Glenn, was on December 20th and after 4 days we were able to go home, on Christmas Eve. By far, the best Christmas we have had thus far! We have had some minor challenges so far in our journey but we have had so much support from our friends and family. God has taken great care of our sweet girl and us through all of this. We are so thankful for the other heart parents we have met through our journey who truly understand what we deal with on a daily basis.   Emmie Lou has hit all of her milestones on time, gained weight well, and is such a joy and light in all of our lives. Seeing older kids and hearing how they are thriving with hypoplastic left heart syndrome gives us great hope for Emmie Lou's future! The constant research and advancements in pediatric cardiology also gives us great hope and we look forward to seeing how the care for these kids improves even more!

Something else to know about Emmie Lou’s family:
We all love to spend time together doing things outside.

From left to right: Dillon, Emmie Lou, Kimberly

Submitted by Emmie Lou’s parent(s), Dillon Ward
Photo ID #5

Meet Michael!

Age: 10

Michael’s primary cardiac diagnosis is Tetralogy of Fallot.

Read Michael’s story:
Michael was diagnosed at 3 days old. He has had 3 heart surgeries, 4 heart caths and several general surgeries.

Something else to know about Michael’s family:
We love to be outdoors hiking and camping!

From left to right: Baileigh, Chris, Ashley, James (front Michael, Madison)

Submitted by Michael’s parent(s), Ashley Henderson
Photo ID #6

Meet Emmaline!

Age: 20 months

Emmaline’s primary cardiac diagnosis is Hypoplastic Right Heart Syndrome.

Read Emmaline’s story:
Our journey began July 8th, 2019. We are foster parents, and our caseworker told us about a baby girl in Atlanta that was needing a placement. She had "some heart issues and would need extra doctor appointments " & would we be willing to meet her that week. The next morning I got the call from her saying the baby would be ready to go home in the next couple days & would we be willing to go to Atlanta, meet her and speak with her physician to see if we would be able to take the placement. So I left work at 10am and went home where my wife and I packed an overnight bag in preparation to stay at a hotel. We hopped in the car, stopped at the Carters store on our way because we were told that bringing some onsies would be a good idea, and 2.5 hours later we arrived at CHOA. We went to the information desk and stammered about a baby girl with heart issues that we knew nothing about, not even her name. Patient advocate Leslie heard us and took us under her wings. She brought us to our girl and then and there, we instantly became parents. We saw this tiny, 12 day old helpless soul hooked up to a million monitors with nobody to love her. Needless to say, we never made it to a hotel that night. 4 months of countless ER visits, inpatient admissions, 2 cardiac caths and open heart surgery in October 2019, we finally got to bring our girl home for good. Fast forward to April 7th, 2020...we officially adopted our daughter, complete with a name change. She will be 2 this year, and she is simply magnificent. She is truly the light of our lives, and even though our journey was filled with intense uncertainty, all the events led us to where we are today. And for that, we are truly humbled and thankful. We could not have made it without each and every person we met and helped us. It truly does take a village!

Something else to know about Emmaline’s family:
We are currently working with DFCS to adopt again! It's an exciting time here!

From left to right: Amy, Emmaline & Doni Queen

Submitted by Emmaline’s parent(s), Amy Queen
Photo ID #7

Meet Marliee!

Age: 1

Marliee’s primary cardiac diagnosis is Dilated Cardiomyopathy.

Read Marliee’s story:

We received our daughters diagnosis of DCM on Apr.30, 2020. She was born a healthy baby girl with seemingly no issues, however the week of Apr.30th my family and I noticed Marliee was acting different. First it started as her not taking her bottle, to increased respiration's and clamminess. We took her to Scottish ER where within an hour we had a diagnosis. Since then, she has been inpatient (as of Nov 2020, 7 months) and now has a Berlin heart until her heart transplant. The biggest challenge is our family being separated and watching our daughter go through so much. We pray constantly and have faith that the Lord will see her through, but it is also the love, support and excellent care Marliee receives from her medical team. Her nurses and physicians and everyone involved truly have Marliee's best interest and it shows. She is the epitome of a warrior! At only 10 months old she keeps pushing and keeps smiling, even on the tough days.

Something else to know about Marliee’s family:

We love going to the beach and eating at Fellini's pizza in midtown!

From left to right: Mom (Tiauna) Dad (Christopher) Brother (Rory) Sister (Randi) Heart Warrior (Marliee)

Submitted by Marliee’s parent(s), Tiauna Paul

Photo ID #8

Meet Greyson!

Age: 6

Greyson’s primary cardiac diagnosis is Hypoplastic Left Heart Syndrome.

Read Greyson’s story:
Greyson is most commonly known around Atlanta and social media as Duckie. He got this cute little nickname the very first time I heard him cry....or should we say quack? His breathing tube had been placed from day one, and he had it in for over 2 weeks, so when it was removed he sounded more like a little duck than a baby! Diagnosed with Hypoplastic Left Heart Syndrome inutero the promise of a new exciting chapter was rocked a bit. He was cared for and birthed in Jacksonville, FL. We lived in the hospital for 2 months, came home for 3, and headed back in for another few weeks. We have been in and out multiple times since for everything as simple as ear tubes all the way to ambulance rides due to RSV. After completion of the Norwood and Glenn, we moved to Atlanta specifically for Children's Healthcare of Atlanta. This single mama sold everything, packed up our vehicle, and came to a city with so much promise, hope, support, and ambition. The Kids at Heart group, the hospital itself, Sibley, the labs that the surrounding top Universities work with to increase longevity in our single ventricle kids, it all give us so much hope. Packing up your life and moving to a brand new city with no friends or family sounds like the biggest risk, but it gave the best payout imaginable. We love our CHOA/Sibley/Kids at Heart family. I love participating in the advisory board. Duckie loves Uno on a serious level. We both love the care at CHOA. Just all around a lot of love and happiness!

Something else to know about Greyson’s family:
We are all runners, Duckie included. We run Spartan obstacle course races, and train together year-round. We run, bike, and swim as training for our bi-annual races. We also are huge Georgia Tech fans. Daddy (Richard) is a Tech student and works for a Tech engineering company. Duckie has had the honor of having Ramblin Wreck come to our home this summer, he sleeps with a plus Buzz, he has been given a ride in Ramblin Wreck, he is the youngest judge ever for Georgia Tech's homecoming parade, and many other honorary positions gifted to our family. We are and love Yellow Jackets!

From left to right: Greyson (6 yrs), Parker (8 mos)

Submitted by Greyson’s parent(s), Nicole Cannata
Photo ID #9

Meet Aiden!

Age: 7

Aiden’s primary cardiac diagnosis is Double Inlet Left Ventricle, TGA.

Read Aiden’s story:
We received the Diagnosis when I was 36 weeks pregnant through a normal growth ultrasound. Aiden has had 3 surgeries, 4 days old, 3 months old and the most recent at 6 years old to complete the Fontan repair. Aiden has pretty much had the textbook case so not really any surprises other than the staged surgeries which we are so grateful for. The biggest challenge we face as a family is all the unknowns about how long will his heart last? His quality of life as an adult? But with all the unknowns as everybody is not guaranteed tomorrow we try to live in the moment and enjoy every minute and not take anything for granted. We are so thankful for the surgeons and nurses at CHOA and we could not thank them enough for saving our boys life! Our heart warrior is full of life, loves playing soccer, drawing and playing with his brother and sister. He is in 1st grade and is doing amazing!

From left to right: Top- Ella, Dad, Mom / Bottom- Lukas, Aiden

Submitted by Aiden’s parent(s), Lindsey Patino
Photo ID #10

Meet Laila!

Age: 17

Laila’s primary cardiac diagnosis is Tetralogy of Falloy.

Read Laila’s story:
When Laila was born, I immediately knew that something was not right. Her head just did not look normal to me . Being that I was born with Craniosynostosis, I pressed the doctor to give me a referral to have it checked out. They were reluctant to do so and assured me that everything was fine. She was diagnosed with craniosynostosis as well at 2 months. Craniosynostosis is a condition that is the result of skull sturea being fused together. Most times it requires an extensive surgery to fix. We were within a week of her head surgery and she came down with a cold. I knew they would not do her surgery if she had a fever so I took her to a new pediatrician and they found her heart murmur. The doctor told me I needed to have that checked out before her head surgery and was referred to Dr. Jones. Seems like we were in the cardiologist for hours before we were told she had TOF (4 defects of the heart). Dr. Jones said thank gosh that was caught before her head surgery or we would have had a big mess. She had her first open heart surgery at 4months and had her head surgery at 6 months. She had a second open heart surgery when she was 9. She is doing fabulous now with no restrictions. I am so proud of the young lady she is becoming and glad God chose us to be her parents.

From left to right: Nikki, Laila, Drake, and Corwin

Submitted by Laila’s parent(s), Nikki Watkins
Photo ID #11

Meet Evelyn!

Age: 2

Evelyn’s primary cardiac diagnosis is Tricuspid Atresia.

Read Evelyn’s story:
We received Evelyn's diagnosis post partum in the mother infant recovery, the pulse ox was off so they took her to NICU for more testing at the time we weren't informed of anything until after a diagnosis from Childrens in Dallas, Tx. At 4 days old she had a PDA Stent placed, at 3 months old she had the stent expanded and at 5 months she had the Glenn. We have faced so many challenges from being opposite side of the country from family and having no support to relocated after the Glenn to be closer to family. We have been so blessed for a smooth transition with Children's Healthcare of Atlanta, from Children's in Dallas thanks to Devine intervention that our Dallas Dr. Kane was a resident under Dr. Mahle many years prior. Evelyn has had so many set backs along the way from feeding issues to developmental delays but has thrived thanks to all the special care teams and individuals that have helped along the way.

From left to right: Evelyn, Kimberly, Michael, Dominic

Submitted by Evelyn’s parent(s), Kimberly Tarantino
Photo ID #12

Meet Laura Kate!

Age: 3

Laura Kate’s primary cardiac diagnosis is TGA, Tricuspid Atresia, Hypoplastic Aorta, VSD.

Read Laura Kate’s story:

We learned there were likely issues with Laura Kate's heart at our 19-week anatomy scan. A follow-up two days later with a high-risk doctor provided more clarity but our appointment with Sibley gave us a complete diagnosis. I do not think words can accurately describe how gut-wrenching hearing that diagnosis was. I sent out texts to friends and family- "horrible news, can't talk". We hadn't told our son that we were expecting and did not know what to do. On the Sunday evening following our Friday Sibley appointment, he announced out of nowhere in the back seat of our car, "well I'm just going to say it, we need a baby." My husband and I took that as our sign to tell him that he was going to be a big brother. We found joy through his excitement. While we did not know what the future would exactly hold, he was going to be a big brother and we celebrated. God also gave us many signs during our journey that he was there with us each step of the way. Laura Kate was born 4 weeks early and was transferred to Egleston from Athens on the morning after her birth. At 6 days old, Laura Kate was operated on with her first open heart surgery. We stayed in the hospital for almost a month total. We left Egleston with Laura Kate on a feeding tube, a medicine regimen, and many doctors' appointments ahead. Rotating between seeing our cardiologist and pediatrician, we spent every week with a different doctor for about a month. Feeding therapy allowed LK to wean from the feeding tube to a bottle within a few months. Laura Kate's second operation, the Glenn procedure, occurred when she was four months old. We stayed in the hospital for 10 days. She was put back on the feeding tube after surgery but worked hard and was taking a bottle again before we left the hospital. I can remember after our second surgery walking into the CICU and the doctor jokingly telling me that Laura Kate can give some of the meanest looks ever. (She got that from her mother.) Yet, she would also give the biggest smile that would make your heart melt. She was hooked up to tubes and wires and she was smiling. You learn how resilient these amazing babies truly are when you watch them battle. She is a warrior, just like so many fighting every day. No one is promised tomorrow. I spent many nights after LK was born staring at her in her crib with so many "what if" questions. I finally told myself, she is here, she is happy, enjoy every moment with her. We have spent the last three years celebrating milestones with Laura Kate. No one loves a birthday celebration more than our girl and we celebrate her big. Laura Kate is the most determined toddler I have ever met. She is a dare devil and you never know what she is going to say. Our preacher told me before she was born that she was a child of promise. I believe him and we are thankful for every day. We cannot even begin to thank the doctors and nurses and staff at Egleston and Sibley Heart Center that we met along our way and continue to see today. So many wonderful people that not only took care of our daughter but cared for us as her parents. Nurses that would cry with you and give you a hug when the day had not been the best. Physician Assistants that would sit down beside you in a rocking chair and talk after you burst into tears for no apparent reasons. Doctors, who would call nurses on their day off just to check-in on their patient. Dr. V, our cardiologist, hung the moon in our eyes and we look forward to our appointments with him. The quality of care at Sibley Heart Center and Egleston is beyond exceptional. Laura Kate is our daily reminder to live life to the fullest because she certainly does.

Something else to know about Laura Kate's family:
When Charlie was born we started something silly putting him in 13 Halloween costumes on the days leading up to Halloween and sharing with friends on Facebook. We call it the "13 days of Halloween". We have continued that tradition to date. Laura Kate jumped right in even participating while in the hospital after her second surgery. She played a patient and Charlie was Patch Adams from the Robin William's film.

From left to right: Charlie and Laura Kate

Submitted by Laura Kate's parent(s), Saralyn Stewart Fulcher
Photo ID #13

Meet Evie!

Age: 22 months

Evie’s primary cardiac diagnosis is Right ventricle to aorta.

Read Evie’s story:
Evie was diagnosed with pulmonary atresia, Right ventricle to aorta and a large VSD the day after she was born. She had a PDA stent placed when she was 4 days old. Her first open heart surgery was performed when she was 4 months old and then revised at 7 months old after showing signs of heart failure. After a 3 month hospital stay, heart failure and many other heart failure related complications we were discharged New year's Eve 2019. She's been growing and doing well since we've been home. We are grateful for CHOA and all the staff that helped us get through Evie's first year.

Something else to know about Evie’s family:
Evie and her older sister Maddie Jo hope to celebrate Evie's surgeries with their first trip to Disney (after the pandemic) !!!

From left to right: Evie

Submitted by Evie’s parent(s), Emily Green
Photo ID #14

Meet Bethel!

Age: 5

Bethel’s primary cardiac diagnosis is Complete Heart Block.

Read Bethel’s story:
We received Bethel's diagnosis of Complete Heart Block at 23 weeks weeks pregnant. We lived in Atlanta for two weeks prior to her arrival in the event she needed surgery at birth. Bethel celebrated her 5th birthday on Feb. 1, and to date has not had surgery. We see the cardiologist every 3 months to assess when pacemaker placement is needed. The "watching and waiting" for surgery and constant appointments have been challenging. Watching Bethel grow up and begin having anxiety and fear about appointments has been hard as well. We have great hope in our faith in Jesus. We trust that all that has happened and all that will happen in the future is in His hands. We're super thankful for the care we've received through Sibley for over 5 years! We feel like the staff at our clinic is family.

Something else to know about Bethel’s family:
Bethel loves to dance and sing and has quite the dramatic flair. She loves to take birthday brownies to the Sibley team each year in her birthday. If you asked her about her heart she would tell you she has a " 'pecial (special) heart!"

Submitted by Bethel’s parent(s), Holly Price

Meet Maddux!

Age: 3

Maddux’s primary cardiac diagnosis is Congestive Heart Failure, ASD, VSD, Holt Oram Syndrome.

Read Maddux’s story:

I was 36 weeks pregnant when we were referred to a specialist in Albany to have a level two ultrasound, what started out as any ordinary day ended up being the day that changed our lives forever from that point on. We found out that Maddux had many holes in her heart, which was referred to as looking like Swiss cheese. We were devastated that we had went the entire pregnancy and hadn't known anything was wrong. After many phone calls and tears we were then referred to Sibley Heart Center Cardiology in Albany and we saw them the same day. They were incredible. I was too far along in my pregnancy for them to get a perfectly clear diagnoses, so we were told about the multiple ASD's and VSD's and we worked out a few different plans for the day she would be born because there was no answer as to what kind of condition she would be in when she was born. We prepared for emergency surgery where she would go to the nearby children's hospital, NICU, or her being well enough for us to be able to go home. I stayed in Atlanta for the remainder of my pregnancy and began seeing specialists there and preparing for her arrival. Maddux was born March 28th and she was examined in the NICU, and we got to go home only five days after she was born. She was diagnosed with Holt Oram Syndrome, she does have multiple holes and has congenital heart failure as the blood rushing through all of the holes in her heart makes her breathing extremely labored. After that we were closely monitored by our amazing cardiologist Dr. Toole and we began counting down the days to her surgery which she had at 9 months old. She had a pulmonary artery band placed to give her the time to be stronger for a full repair of her ASD's and VSD's at Children's Healthcare of Atlanta. Maddux began declining after her surgery and we feared the worst, because it seemed each day presented a new challenge, but after many complications Maddux was finally starting to get better. She was taken off of intubation for the third time and was finally on the upward hill to recovering. Maddux will need another surgery to remove her PA band and to repair some of the bigger holes in her heart, so we continue to pray for strength when that day comes, and we are so thankful for our heart warrior. She is a light in all of our lives.

From left to right: Brittney Smith, Maddux Smith, Jordon Smith

Submitted by Maddux’s parent(s), Brittney Smith
Photo ID #16

Meet Zeke!

Age: 3 years

Zeke’s primary cardiac diagnosis is HLHS.

Read Zeke’s story:
We received Zeke's diagnosis in utero, at his 20 week anatomy scan. Zeke had his Norwood at two days old (inpatient for 36 days), his Glenn at four and a half months old (inpatient for five days), and a general surgery for his gtube placement, bronchoscopy, TEE, and a circumcision at 10 months old (inpatient for seven days). While we were inpatient for his general surgery, we found out Zeke was in heart failure. Fortunately we were able to correct this with medication. These three prior surgeries were performed at Primary Children's Hospital in Salt Lake City, Utah. He is projected to have his Fontan in April of 2021. Overall, Zeke has responded well to his treatment plan. He is growing and thriving. His development is delayed, as expected, so he receives weekly Speech and OT. He gives us hope. If he can come through all that he has been through, and still be joyful, who are we to not have hope for his future? While his journey is not always easy, he still has a fun loving personality that touches everyone in his life. He is an affectionate little boy, who loves to laugh and be silly.

Something else to know about Zeke’s family:
We are an Air Force family who love to camp and go on adventures.

From left to right: Gregg, Mikka, Zeke, and Layla

Submitted by Zeke’s parent(s), Mikka Rosado
Photo ID #17

Meet Sarah!

Age: 15

Sarah’s primary cardiac diagnosis is Dilated cardiomyopathy.

Read Sarah’s story:

Our heart journey began on February 5, 2018. Sarah, who was 13 years old at the time, had generally not been feeling well for several weeks. She developed a cough and was very tired and weak. We had taken her to her pediatrician and was told that she had bronchitis and should be better soon. On February 5, 2018, her cough worsened a lot and I suddenly realized that her legs were swelling tremendously. I immediately took her to her pediatrician who sent us to Scottish Rite who then sent us to Egleston. For hours while we were at Egleston, I still thought she had bronchitis, maybe pneumonia, until the doctors performed an echocardiogram and we were told she had cardiomyopathy and that her heart could stop that night. There are no words to describe the shock we felt. I remember screaming, "What are you talking about?" In the middle of the night at the doctor who gave us the horrible news. That is the night that our fight began. Sarah stayed in cardiac ICU for about a week and then was in step down for another week or so. We were told initially that she would probably need a heart transplant fairly soon. Thankfully, her ejection fraction , which was initially extremely low started moving up. After discharge from the hospital, Sarah entered an experimental study program with Dr. Mao with the drug Entresto. Her ejection fraction since entering the program has gone all the way to 51% which feels like a miracle to us. Although Sarah felt generally unwell for many months, she is now feeling much better and is really living a very normal teenage life with school, friends and just having a lot of fun. I think the biggest challenge our family faces is just having so much fear that something was going to happen to our sweet girl. I honestly think I have some PTSD from the whole experience. For months her dad and I would get up in the middle of the night to check on her. Looking back, I wish I would have listened to my instincts because I knew she wasn't well but I had no idea what the problem was. We don't know what will happen in the future, but we're so thankful that she is where she is at this point. It feels like she has been give her life back. We're so thankful for Dr. Mao and all the wonderful doctors and nurses at Egleston. They took a girl who had been so worn down physically and mentally because of her unknown heart disease and put her back together so that she is really living her best life ever right now. I have always admired the fact that the doctors and nurses at Egleston care about the whole child, physically, mentally, emotionally, and not just her heart. Sarah genuinely loves Dr. Mao, his nurses Suzie and Melissa, and all the staff at The Transplant Clinic.

Something else to know about Sarah’s family:

A fun fact is that our family has had over 250 foster children in the 16 years! Some stayed for just a few days, some months, years and we even adopted a few of them. Another fun fact is that our son Luke was drafted last year as a pitcher for the Texas Rangers so we are huge Rangers fans.

From left to right: Lindsay, Hunter, Craig, Luke, Philip, Bryant, McKenzie, Jennifer, Sarah, Hannah

Submitted by Sarah’s parent(s), Jennifer Schiltz
Photo ID #18

Meet Briley!

Age: 10

Briley’s primary cardiac diagnosis is Tetralogy of Fallot.

Read Briley’s story:

Briley was born with Tetralogy of Fallot and showed symptoms the day after. At the time our family was stationed in Okinawa Japan, requiring a in person apointment in Hawaii two weeks after birth. When Briley was four months we returned to the states for her 1st open heart repair. Where the plan was to narrow her pulmonary valve and graph a chamber wall to separate her top two chambers. Unfortunately the valve had to be removed, her esophagus was damaged, and she ended up with fluid on her lungs. After eight days inpatient after surgery, she is as released to return to Japan. Due to surgery and her inpatient stay Briley was diagnosed with torticollis and suffered from most of her muscles being extremely tight. She endured a year a phycial therapy due to inability to sit up, roll over, crawl or stand. Finally being able to achieve these unsupported at 18 months old. Around the age of two life was settling down to find out at three that Brileys heart was starting to enlarge and would require a 2nd repair at some point. As the years have gone by Briley has not let anything stand in her way of excelling academically and in the sport of gymnastics. Or through other medical related issues she has faced. Currently Briley is ten years old and thankfully has not had to recieve her 2nd open heart repair as of yet. She is being monitored very closely but remaining symptom free even with a heart enlargement of three times the normal size of a child her age. Currently Briley is enjoying learning to play golf, acting in community theater, and winning awards in 4th grade.

Something else to know about Briley’s family:

Our family enjoys spontaneous road trips, and putt putt hole in one competitions. After many hard medical events and learning to take one day at a time, sometimes moment by moment our family motto is- This is a moment, a very hard moment, but a moment just the same.

From left to right: Brigitte, Brian, Cooper, Briley

Submitted by Briley’s parent(s), Brian Lamon
Photo ID #20

Meet Anna!

Age: 3

Anna’s primary cardiac diagnosis is Tetralogy of Fallot.

Read Anna’s story:
Anna was born on June 17th, 2017, a seemingly healthy (big) 10lb 6 oz baby girl!! As we were being discharged from the hospital a nurse mentioned to us that Anna had a heart murmur and that we should tell her pediatrician to listen for it. From what we were told heart murmurs are common and typically go away on their own, so they weren't very concerned. The pediatrician listened and didn't hear anything, (she was crying so it was probably hard to hear!!), He listened again once she stopped crying and heard the murmur. He decided it'd be best to see a pediatric cardiologist just to verify it's only a murmur. When Anna was 11 days old we received the news that she had Congenital Heart Disease. She has Tetralogy of Fallot. After that diagnosis we started our journey with biweekly visits with the cardiologist until Anna's first surgery at 2 months old, where she got the BT shunt. It clotted the day after her surgery so she immediately went into the Cath Lab to have a stent put into the shunt. We had a rough experience, she ended up getting several infections which lengthened our stay. Once she recovered we were able to go home for about a week, then she took a helicopter ride back to the hospital for monitoring. We had several hospital stays over the next several months while we waited for Anna's TOF repair. Even with all of these trials and setbacks Anna always had a smile on her face. When Anna was 7 months old she had her TOF repair. The surgery and recovery went much smoother! After that she spent some time with a speech therapist to help her eat and an physical therapist to help her crawl! She has shown us what resilience looks like. She is such a smart and joyful girl! We are grateful to have her in our family!

Something else to know about Anna’s family:
We love to go camping as a family and we enjoy visiting the beach as much as we can!

From left to right: Alex, Anna, Wesley, Gwyn

Submitted by Anna’s parent(s), Bill Hammond
Photo ID #21

Meet Nathan!

Age: 10

Nathan’s primary cardiac diagnosis is Absent Left Pulmonary Artery.

Read Nathan’s story:

We found out about Nathan's heart defect when he was 6 years old. It was very shocking because he was very healthy with no symptoms. Since that diagnosis, he has had 3 heart caths and 1 open heart surgery. The only time we have spent at the hospital is following the procedures. Thankfully we have not experienced an extended stay. One of the biggest challenges we faced was dealing with the shock of the diagnosis. Kids at Heart was HUGE in helping us accept the diagnosis and needed procedures. Connecting with other heart families was the best thing for us in realizing there are families and children who go through this and thrive despite it. Another challenge that doesn't get talked about much is the impact CHD has on the heart healthy sibling. Although we didn't spend a ton of time in the hospital, we did have to leave our heart healthy child every time we did have to stay. The fear and uncertainty takes a toll on the heart healthy sibling. Although Kids at Heart does offer a few sibling activities, I would love to see more offered for younger siblings and more support for them. My heart warrior has been very open in sharing his story. We started an instagram account to document his journey and it has been an incredible experience. Through his instagram account, we have connected with heart families around the world. His courage in speaking about the hard parts of CHD has been very inspiring to so many going through the same thing. We are so proud of Nathan and everything he has been through. What gives us hope is seeing how much our doctors care for Nathan and how hard they are working to give him a chance at a better future. His diagnosis is extremely rare and what they have accomplished for him was thought impossible because it had never been successfuly done for a child his age. We are forever grateful for brave doctors who advocate so much for Nathan. I would also say to other heart families to make sure to connect in the heart community. Nobody else can really understand what it's like to sign those papers for heart surgery nor what it's like to watch your child experience that other than fellow heart warrior parents. There is something so powerful on this heart journey to realize you are not alone!

Something else to know about Nathan’s family:

We brought home a new puppy, Kona, in May of 2020. She has been such a joy and keeps us busy during the pandemic. We love her so much!

From left to right: Anna, Jonathan, Jennifer, Nathan with puppy Kona

Submitted by Nathan’s parent(s), Jennifer Bywaters
Photo ID #22

Meet Ian!

Age: 10 months

Ian’s primary cardiac diagnosis is Tetralogy of Fallot.

Read Ian’s story:
Ian is adopted, but we received his diagnosis before he was born. Then the pandemic began - we certainly weren't expecting that! And then Ian surprised us by arriving 5 weeks early! Despite the stay at home order, we rushed to John's Hopkins Children's hospital in Florida where he was born. His heart was doing well at birth, and he only needed to stay in the NICU for 5 days. We returned home to Cumming, where he was seen by the wonderful Dr. Iannucci. At about 3 weeks old, he spent a week in the CACU at Egleston and then it was determined he needed a shunt, which was performed by Dr. Shaw. He did great after that surgery, eating and developing well. He was able to wait until he was six months old for his repair surgery. He has done great since that surgery as well - it's amazing how quickly babies can recover from such a big surgery. We know he will need more interventions in the future - he doesn't have a pulmonary valve, among other things - but we have such confidence in Dr. Iannucci and Dr. Shaw, and the whole team at Sibley and CHOA. We know his future is bright!

Something else to know about Ian’s family:
We love camping and it has been something that feels safe and gives the kids a sense of "normal" during this pandemic. Ian is a great camper!

From left to right: Abbey, Steve, Nathan, Jen, Ian, Owen

Submitted by Ian’s parent(s), Jennifer Howe
Photo ID #23

Meet Leila!

Age: 9 months

Leila’s primary cardiac diagnosis is VSD, PFO.

Read Leila’s story:

Our heart journey began at birth. We were unaware of our daughters diagnosis during pregnancy. After Leila was born she was diagnosed with a heart murmur by the pediatric hospitalist. She was given an ekg to confirm her diagnosis was in fact a VSD and PFO. We were told most close within 48 hours so we were kept an extra day to monitor. Nothing had changed, so we were discharged and told to follow up in 2 weeks with the cardiologist. She has been seeing Dr Harden at Sibley heart center since. Two weeks after discharge Leila began having symptoms. She cried non stop, she wouldn't eat much, kept dropping weight. I won't go into too much detail because it was a pretty terrible time for us all. She was admitted to CHOA at Scottish Rite in August for failure to thrive. We had no idea what to expect. We were assigned an angel, a pediatrician by the name of Dr Aragon. He took time to explain everything to us along the way. We let loose and told him everything. Leila had multiple tests to confirm she had intestinal malrotation. She was taken to surgery in the following days and they also diagnosed her with meckles when they were in surgery. So that was fixed. Next finding was that her heart was enlarged in an X-ray, so they took the time to dig deeper into that. Her hole was bigger than suspected and we were told to mentally prepare for surgery in the future. She wouldn't eat still, always out of breath. She was discharged with an NG tube and got most of her feedings through the tube via a pump. We held onto hope in the next couple of months hoping her hole would close and she wouldn't have to have open heart surgery. We drug our feet and fell deep in prayer those months, however, came to decide that she would need the surgery after all. Fast forward to December 10th. At her preop appointment a young boy at CHOA at Egleston approached us and told her it was going to be okay. He then showed us his scar with a smile and told us this was his third surgery. He was an angel and in that moment I realized that Jesus shows up in mysterious ways just when we need it. On Friday, December 11th we walked our baby to the preop room and handed her off to a complete stranger. A stranger that stopped my baby's heart from beating. A stranger that hooked my sweet angel up to a machine that controlled her heart and lungs while the doctor patched 2 holes in her heart. I will never forget that feeling. And I will never forget the support we had from the wonderful people of CHOA. Our daughter is truly a miracle, a heart warrior! We want to thank the wonderful people of CHOA and especially Dr Kanter for repairing our girls heart! This was our journey and each year on her heartiversary we plan to give back to CHOA! Nothing will ever compare to what they gave us, but it's the least we can do for other families living the same experience, going through the same frightening worries, and for the true hero's who all work at CHOA saving lives everyday. Thank you for all that you do each and every day!

Something else to know about Leila’s family:

Our heart warrior, Leila Mae was also born with 13 pairs of ribs! Our special girl!

From left to right: Brock, Adaleigh, Christy, Leila

Submitted by Leila’s parent(s), Christy Breedlove
Photo ID #24

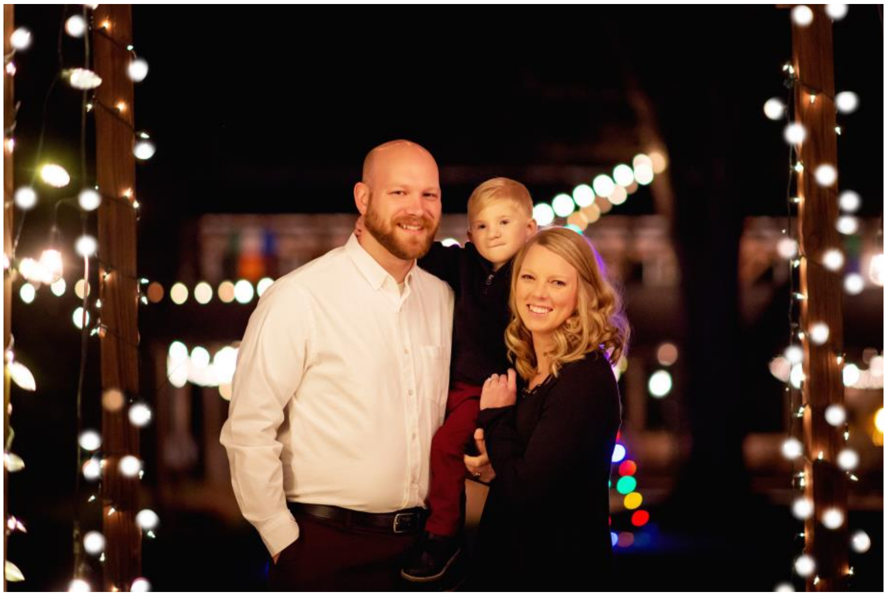
Meet Evan!

Age: 3

Evan’s primary cardiac diagnosis is Tetralogy of Fallot.

Read Evan’s story:
I was 23 weeks gestation when Evan was diagnosed with Tetralogy. This diagnosis came two weeks after his cleft lip and palate diagnosis. To say we were overwhelmed is an understatement. There were so many appointments prior to his birth. But CHOA has an amazing system set up to try and prepare parents for the birth of a heart baby. Evan was born premature and had a brief stay in the NNICU before being transferred to Egleston for a PDA stent placement at 3 weeks. We went home a week later. He had his initial Tetralogy repair on February 7, 2018. He was 4 months old. He needed a revision done in May, 2018, both performed by Dr. Subi. Evan also had a gbutton placement, a couple bronchoscopies and ear tubes placed in 2018 at Egleston. In January 2019, he had his cleft lip and palate repaired. Today, Evan is 3. He has some obstacles to overcome regarding his speech, but we are feeding tube free and we see Sibley only twice a year. He is a rambunctious and happy toddler and is the light of our lives. He touches everyone that knows him by his joy and hi strength.

Something else to know about Evan’s family:
Evan loves anything to do with cars and trucks and Blaze is his favorite cartoon. He is also a HUGE fan of chocolate.



From left to right: Dan, Evan & Lauren

Submitted by Evan’s parent(s), Lauren Gochenaur
Photo ID #26

Meet Grayson!

Age: 6

Grayson’s primary cardiac diagnosis is Subarotic Stenosis-membrane.

Read Grayson’s story:
Grayson was referred to Sibley at the age of 3 to check out a heart murmur. He was then diagnosed with a subarotic membrane. He underwent open heart surgery May 27,2020 to respect the membrane during the Covid pandemic! We are so proud of our heart warrior and how far he has come!

Something else to know about Grayson’s family:
Our family loves salt water fishing!

From left to right: Jill, Grayson, Jason, Trenton

Submitted by Grayson’s parent(s), Jill Ford
Photo ID #27

Meet McKinley!

Age: 3 (on 2/19)

McKinley’s primary cardiac diagnosis is Single ventricle.

Read McKinley’s story:
McKinley was prenatally diagnosed with CHD. When she was born she was specifically diagnosed with 5 heart defects: DILV, DOLV, TGA, ASD, and Pulmonary Stenosis. She had an Atrial Septostomy at 3 weeks old and had the Glenn open heart surgery at 6 months old. Our family has walked through many uncertain days. Trusting God throughout this journey and believing that He works all things together for our good is what gives us hope. Watching McKinley's joy for life and perseverance despite all the things stacked against her is incredibly inspiring! We are so proud of her!

From left to right: Jason, Ethan, Aidan, McKinley, Kaden, Zane, Kayla

Submitted by McKinley’s parent(s), Kayla Majors
Photo ID #28

Meet Liam!

Age: 13

Liam’s primary cardiac diagnosis is TOF.

Read Liam’s story:
We adopted Liam December 2009 from China. We knew he had a heart condition. He also has hearing loss as well. His first surgery was in April 2010. He just had a second surgery 12-21-2020. The surgeon repaired his tricuspid valve and placed a pulmonary valve.

Something else to know about Liam’s family:
We have 9 children! Six are adopted from China, five with medical needs. We are a CHOA family!

From left to right: Liam

Submitted by Liam’s parent(s), Cindy Adams
Photo ID #29

Meet Bethel!

Age: 5

Bethel’s primary cardiac diagnosis is Complete heart block.

Read Bethel’s story:
We received Bethel's diagnosis of Complete Heart Block at 23 weeks pregnant. We lived in Atlanta for two weeks prior to her arrival in the event she needed surgery at birth. Bethel celebrated her 5th birthday on Feb. 1, and to date has not had surgery. We see the cardiologist every 3 months to assess when pacemaker placement is needed. The "watching and waiting" for surgery and constant appointments have been challenging. Watching Bethel grow up and begin having anxiety and fear about appointments has been hard as well. We have great hope in our faith in Jesus. We trust that all that has happened and all that will happen in the future is in His hands. We're super thankful for the care we've received through Sibley for over 5 years! We feel like the staff at our clinic is family. Bethel loves to dance and sing and has quite the dramatic flair. She loves to take birthday brownies to the Sibley team each year in her birthday. If you asked her about her heart she would tell you she has a " 'pecial (special) heart!"

From left to right: Holly Gill Abigail , Bethel, Anna Elizabeth

Submitted by Bethel’s parent(s), Holly Price
Photo ID #30

Meet Gavin!

Age: 5

Gavin’s primary cardiac diagnosis is Restrictive Cardiomyopathy.

Read Gavin’s story:
Long Version Response: Our heart warrior, Gavin, was born one minute after his warrior twin sister, Sierra, on the morning of October 3, 2015. After a comfortable pregnancy to full twin term, we had no idea what the next few months would entail. It was not until 24 hours after their birth that we first heard of Gavin's heart murmur and the CHD terms which would follow. Gavin was initially diagnosed with PSD, ASD, and an open PDA. When the PDA did in fact close, this revealed a more emergent issue of Coarctation of the Aorta and Gavin went into early heart failure. We were life-flighted to Egleston, where he would undergo his first open heart surgery at 2.5 weeks old. This initial surgery successfully repaired his Coarc, VSD and ASD, but also caused irreparable heart block. He therefore underwent surgery number two one week later to implant his permanent pacemaker into his abdomen. With a pacemaker at just 3.5 weeks old, he received the nickname of IronG from loved ones around the globe, and lives up to the superhero title to this day. :-) We went home and were remarkably able to reunite Gavin with twin sister Sierra on their one-month birthday. A couple of beautiful yet trying months at home, weaning from his feeding tube and beginning to get into a home-living routine, we found ourselves in another emergency situation at the end of December as we saw some changes begin again in his behavior and eating. A visit to Sibley would reveal a new condition - A subaortic valve stenosis which had grown to severe levels, and would land Gavin in his third heart surgery on New Year's Eve. Many months pass in the New Year, though we begin to see that stubborn stenosis regrowing. With the help and grace of Gavin's Sibley cardiologist, Dr Iannucci, we receive opinions from Boston Children's Hospital and are sent there for Gavin's 4th open heart surgery, as the surgeon specialized in this type of repair. Thankfully, to this day, this stenosis repair has remained effective, and we are forever grateful for the teams in Atlanta and Boston working so thoughtfully together. At the beginning of 2019, Gavin was diagnosed with Restrictive Cardiomyopathy. The years between his 4 surgeries and now, we watched closely to see if his heart function would improve following the strain of those procedures, though while his squeeze is good, his little heart never fully relaxes. And so, we are fortunate now to have access to the amazing heart transplant team with Sibley and Egleston, and we continue on with a maintenance plan of medications and care, all of which has kept our IronG stable and well. There is so much anxiety for heart families, and we are given the gift of truly knowing and seeing that every day is a gift. We are hopeful for continued stability and growth for Gavin, as he develops into the kind, goofy, and smart little guy that he is today. ***PS - I'm so wordy, this is impossible to share on social media! ;-) Condensed version is likely better: Our heart warrior Gavin underwent 4 open heart surgeries in his first year of life, repairing an ASD, PSD and Coarctation of the Aorta, as well as implanting a permanent pacemaker and twice-removing a sub aortic valve stenosis. He was then most recently diagnosed with Restrictive Cardiomyopathy at the beginning of 2019, and is so far successfully responding to maintenance medications to lengthen any time prior to the need for a heart transplant. Gavin has a twin sister named Sierra, who remains his right-hand human every day, and very best friend for life. We did not know about Gavin's heart conditions prior to their birth, so there has been quite a lot of learning and growing in these five years since. Through our experiences and the strength of Gavin (aka, our IronG), we have been

given the gift of presence and clear understanding that every day is a gift. We know that heart families undergo such anxiety and uncertainties through each day and chapter of their journeys, and we are so thankful to have support in an organization like Kids at Heart.

Something else to know about Gavin's family:
We love travel and adventure, and are so looking forward to being able to get back out into the world again! ;-)

From left to right: Sierra, Ingrid, Stan & Gavin Smith

Submitted by Gavin's parent(s), Ingrid Smith
Photo ID #31

Meet Camdyn!

Age: 1

Camdyn’s primary cardiac diagnosis is AVSD and ToF.

Read Camdyn’s story:
At 14 weeks, Camdyn's genetic testing came back positive for Trisomy 21. One of my biggest fears of her diagnosis was a heart defect. Sure enough, we learned about Camdyn having an AVSD in utero during our 19 week anatomy scan. We were sent to Dr. Lindsay for a fetal echo where he confirmed her AVSD. Around 24 weeks, during an echo at CHOA, it was discovered that Camdyn also had ToF and pulmonary stenosis. We did not know what to expect when Camdyn was born, but she far exceeded expectations!! Camdyn had a full repair of her AVSD and ToF in February 2020 by Dr. Shaw. We were inpatient for 6 days and she made recovery look so easy! She is our our personal hero that we get to watch grow daily. Honestly, our experience with having a heart baby has been seamlessly easy with Camdyn. We are excited about her future and have learned so much from previous families who share their stories!

From left to right: Derrick (Dad), Camdyn, Amanda (Mom)

Submitted by Camdyn’s parent(s), Amanda Thompson
Photo ID #32

Meet James!

Age: 14

James’s primary cardiac diagnosis is Coarctation of Aorta.

Read James’s story:
When James was born, we didn't know about his heart defect. Our family excitedly filled our hospital room, eager to hold him. He was only 8 hours old, when he didn't come back from the NICU, and a Sibley doctor came to our room to tell us about his defects. In a blur we can barely remember, he was driven by ambulance to Egleston. At 1 day old, he underwent a balloon valvuloplasty to hopefully help his aortic stenosis. At 3 days old, he had surgery to correct his coarctation. His hospital stay was not without trial. For three weeks we sat by his bedside and listened to repeated bad news. Somehow, he came home and miraculously thrived. We were told to expect surgery before age 2. But our miracles kept coming. He grew without concerns, without medications, without much worry. At age 7, we had an emergency visit for chest pain. His valve leakage had become significant enough that we were referred to the aortopathy clinic. It was there we met Dr. Iannucci, who has the perfect personality to ease a growing boy's mind. We kept our eye on him, and ended up on some physical restrictions as things continued to change. In the spring of 2020, in the midst of a pandemic, Dr. Iannucci suggested we have another cardiac stress test. When it was compared to the one he had had several years before, the changes in James' heart were obvious. Our case was sent to be discussed. We were given the call that it was recommended he have the Ross procedure. On July 28th, James had open heart surgery to replace his aortic valve with his pulmonary valve. He was old enough to ask questions, to discuss the science behind it, and to even ask if he could keep his old valve

Something else to know about James’s family:
We love to explore local parks and hike with our 3 dogs. We attend a hybrid homeschool, so we spend a lot of time together, as a family. Fun fact, James' grandmother has the same heart defect as him!

From left to right: Matt, Oliver, Isobel, James, Lauren

Submitted by James’s parent(s), Lauren Cadle

Photo ID #33

Meet Caleigh!

Age: 2

Caleigh's primary cardiac diagnosis is Atrial Septal Defect.

Read Caleigh's story:
Caleigh was diagnosed with Atrial Septal Defect on May 22, 2018, when she was just 1 day old. She stayed in NICU for a week until we were all released from the hospital together. Our family never truly faced any challenges after her diagnosis, because in all honesty we tried not to think about it. We focused mostly on the fact we had an amazing, smart, beautiful, loving, happy, and thriving child. Our challenges arrived when time came for her actual ASD repair surgery. Emotionally, I, her mom, was not prepared for the fluctuation of emotions that came with seeing my child hooked up to so many monitors and incapacitated. Our hope came from our trust in the power of God and our grateful attitude that our child had a successful operation. Caleigh has conquered every step of recovery, from walking her unit, the day after surgery with chest tube still in place, to continuing to be the vibrant and joyful child we know she is.

Something else to know about Caleigh's family:
Caleigh is our 1st and only child so far. She has a furry brother, named Cooper, they love chasing each other and sharing food.

From left to right: Chiandria, Caleigh, Khorey

Submitted by Caleigh's parent(s), Chiandria Beauford
Photo ID #34