

To: You  
From: Us

"A gift of stories  
from parents &  
patients with  
HLHS."



## Welcome!

If you are reading this, then you, like all of the contributors to this booklet, love someone with Hypoplastic Left Heart Syndrome. You may be feeling uncertain. You are not alone. We share our journeys with you to give you hope and to offer encouragement.



HLHS affects approximately 1 in 10,000 live births in the United States every year. Here are 20 of those journeys. As you'll see, individuals with HLHS can and do live full and active lives. A diagnosis of HLHS is not the end. It is just the beginning.

### Welcome to the journey.

This book is a joint project of the National Pediatric Cardiology Quality Improvement Collaborative and Sisters by Heart.

To find out more, please go to

<https://jcchdqi.org/parents>

**National Pediatric Cardiology  
Quality Improvement Collaborative**



When I think of the progress that's been made in the past 30 years for children with Hypoplastic Left Heart Syndrome, it's extraordinary! There is no other congenital problem or even pediatric disease in which so much progress has been made in such a short time as HLHS. In the 1970's, this problem was universally fatal, with no survivors. Now, many surgical centers report over 90% survival from the first stage operation, and with the efforts of care teams working together in the National Pediatric Cardiology Quality Improvement Collaborative learning network, we have been able to reduce mortality between the first and second surgeries from historically 15% to more recently 6%. It's so gratifying and telling that the national conversation about kids with HLHS has shifted from better survival, to better quality of life – we now get to focus our attention on improving prenatal diagnosis, optimizing growth and nutrition, reducing time in the hospital, and getting early services in the home to help improve neurodevelopment. We now have the privilege of thinking about adolescence, young adulthood, and beyond! As a pediatric cardiologist, I've been so lucky to know and care for many of these children. I think of 12-year-old Ryan, who throws a 60-mile an hour pitch on his school's baseball team. I think of 6-year old Parker, who is learning to play the organ and whose story helped pass Parker's Law in New Hampshire, which mandates universal oxygen saturation screening for newborns. I think of 8-year old Sammy, who is rocking 3rd grade and likes to ski. I think of Brian who is 18 and a die-hard snowboarder. I think of Lily, who is approaching 30 years old, has finished pediatric residency and recently applied to be a pediatric cardiologist! There are so many others and I'm past my word limit, but they have all touched my life, made me a better doctor and person, and made me proud of what our field has done and will continue to do!

**David W. Brown, MD**

Boston Children's Hospital

**Resilience.** I am regularly overwhelmed and inspired by the resilience of my HLHS children and their parents.

It starts with the parents. From the very beginning they are strong and focused, no matter the pain and fear. They dig deep and become the most impressive and capable parents, almost overnight, achieving personal growth that typically takes decades.

From the start of the journey, our bond is close. They are more partners than patients. We face obstacles and celebrate milestones together; we shed tears and review the cath data, they text videos of their baby breathing and pictures from the trip to the beach. We even share the stress and worry. I am not sure that they realize that, but it is true. This is not a 9-5 job, this is an 'all in' commitment for the duration and it is worth every bit of work.

Through the months and years, the children, in the footsteps of their parents, develop the same profound resilience. It is impressive to watch and a constant reminder that if they can be that resilient, so can I.

Bambi Alexander-Banys, MSN, CPNP

Single Ventricle Monitoring Program Coordinator

Cardiology Nurse Practitioner

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In the days after my son, John, was born with HLHS, I allowed myself to cry every morning in the shower. The days were dreadfully long and lonely in the Pediatric Cardiac Intensive Care Unit. In my pursuit for normalcy, I tried to make small talk with the nurses. But in reality, my entire body ACHED to hold, cuddle, and feed him! With empty arms and a broken heart, I frantically pumped breast milk, so I could at least do SOMETHING for him. I wondered if he would ever receive this nutrition.

With utmost tenacity and dedication, the surgeons performed the open heart surgeries needed to keep our son alive. After the operations, John's recoveries were met with challenges and complications. I worried about his quality of life.

Today, this little boy eats pizza, fights with his brother and sister, and gives slobbery kisses! He meets all the developmental milestones for a three-year-old and is enrolled in a "normal" preschool.

I wish I could go back in time and offer wisdom to that scared mom crying in the shower. I would tell her that in some ways, this is a warm and wonderful experience. I would tell her that someday, she will reflect back and be humbled by God's daily love and provision throughout this whole scary mess. I would tell her she's starting a better life where she cherishes every detail, loves more deeply, and overflows with a thankful, mended heart.

Gina (Mother to John, 3 years)



My son, Landon, was diagnosed with HLHS one day before he was born. This journey changed my perspective on the world and truly opened up my eyes to every small miracle that he does. I experienced the pure joys of him taking his first bottle, laughing, smiling into my eyes, sitting up on his own, as only a heart parent can truly appreciate.

This is a life-long journey, full of many ups and some downs. The best part is, you will love your baby in a way that you could have never imagined before.

You will learn to appreciate the small details and be thankful for small everyday blessings. This experience will open your eyes and give you a brand new perspective unique to heart parents. Nobody wishes for their child to have a CHD, but once you are blessed with one of these very special babies, you will be forever changed and in awe of your child. You will NOT take the small things for granted. Our babies are simply amazing and SO strong. Their resilience is astounding.

You can get through this. Take it one day at a time, one moment at a time if necessary. There is a lot of support out there for you. us heart parents have to stick together!! May God bless you and your precious little one.

Autumn (Mother to Landon, 7 mos)



Halfway through my 2nd pregnancy, the day before Christmas Eve, at a routine sonogram, our unborn baby girl was diagnosed with HLHS. We were stunned, devastated, and heartbroken. News like that is life changing. You wonder how you will ever get through it, how your family will get through it, most of all how your new baby will get through it. For almost 5 months we feared the unknown. We worried. We submitted ourselves to God and held onto our faith. We educated ourselves on what to expect, knowing all the time that there were so many different possibilities and outcomes - negative and positive, we chose to focus on the positive. We prayed and prayed, along with family and friends, that our story would be one of triumph and success. We prayed through the unknown, through the anxiety and worry, through 2 surgeries, and extensive hospital stays...and we never lost hope.

We felt overwhelming gratitude and joy in every outcome, more love than we have ever known, and saw proof that this journey is not hopeless by any means! One year after being diagnosed with HLHS, we are loving on a beautiful, bouncing, baby girl! Hallie Grace is 8 months old now and by looking at her, you would never know what she has been through. She has defied the odds and amazed us all, including her doctors, over and over again. Hallie is our miracle, our constant reminder that we have been abundantly blessed!

Christie (Mother to Hallie, 8 mos)



To watch Jaden play with his toys and wrestle with us, you would never suspect he has HLHS. He is so full of life and love; the happiest, sweetest, and most opinionated one year old you will meet. He loves books, playing peek-a-boo and snuggling. He also loves to eat- birthday cake and blueberries are his current favorites.

We went in for our routine 20 week ultrasound filled with anticipation of seeing our child. We never expected to hear the news that he would be born with HLHS. We had never heard of HLHS, so how could our son possibly have it?

This journey can be hard, exhausting, and overwhelming. Hospital life can be grueling. But once you get past those hard days, the "boring" days come. Boring days filled with hanging out in your jammies all day at home, going on walks to the park. Living in a hospital, you meet the most amazing people who truly care for your child. They will cheer with you at your little warrior's small victories, cry with you on hard days, and hold your hand every single step of the way.

Remember that it is okay to cry, and it's okay to be scared. When things start to get overwhelming, remember that you are not alone. There are so many people who truly care for you and your little heart warrior, and it will get better.

Watching Jaden LIVE LIFE full of LOVE and HAPPINESS has made every hard day worth it.

Karla (Mother to Jaden, 1 year)



I never asked "Why Toby." I know that may sound strange when faced with an HLHS diagnosis but it never occurred to me to cry out to God and ask "why?" Now don't get me wrong, the news was devastating, literally heart breaking, but these things happen. Toby and his broken heart were going to be born to someone, why not us? I don't know if Toby needed us or we needed Toby in our family but either way, God sent him to us and we are honored to have him.

Toby was born on June 20, 2013 and other than a broken heart, he was (and still is) perfect. Five days later he had his first open heart surgery. There is nothing quite like handing over your baby not knowing if you will ever hold him again. But Toby was ready for a fight and by the grace of God he came through both his Norwood and Glenn with a zipper down his chest and a mended heart.

His fight isn't over; his heart will never be fixed. He's had struggles and setbacks and we have found strength we didn't know we had. But there is hope, there is joy, and there is life with HLHS. His smile is infectious; the twinkle in his eye is magnetic. In his chest beats the heart of a warrior. He is the strongest, toughest, bravest person I know. This boy with half a heart has all of mine.

Jen (Mother to Toby, 18 months) ~ Team Toby



I know how you're feeling right now. Like the rug has been pulled out from under you. Like you planned for the beach trip of a lifetime, only to end up in the Arctic. I know you're afraid and confused and the only question you have is "Why?" It's ok to be afraid, it's ok to be upset, it's ok to be overwhelmed. This is the moment where your life changes and things will never be the same, but I can assure you that you will find a strength and a sense of purpose that you never thought existed inside of you.



The last two years have been a challenging journey for my family, including surgeries, hospitalizations, and days upon days of therapies. In spite of these struggles, my son greets each day with a joy that I've never seen in anyone else. In the beginning, though, it was tough to learn all the terminology, deal with the sleepless nights, and try your best to stay upbeat while telling loved ones over and over about your child's situation. As I began to understand what I was doing, and as my son began to improve, things became a little easier every day. Is it fair? Not at all. Can you still make this an amazing life? Absolutely! Your child will show you what strength really means.

My son now walks, talks, and even attends preschool. He's a daily encouragement to me. Some people never get to meet their hero; I get to raise mine.

Chris (Father to Nolan, 2 years)



Bennet was not diagnosed with HLHS until he was 24 hours old. He was beautiful and stable one moment and then fighting for his life the next. We had never heard of HLHS, we didn't know anyone who had it, and we were sure it was the end of our world. Those first few days and even weeks after he was born were filled with so many hopeless emotions. I wish I could go back and tell myself what I know now. That

Bennet was going to be a feisty, thriving 2 year old. That he was going to hit milestones in his own time but that he WOULD hit them. That he was going to love life. I would tell myself that I shouldn't fret about Bennet's future because there was more hope that I could ever imagine for kids with his heart condition. And I would tell myself to reach out to other moms early on because they would be the ones to help me heal. I know you are scared and I know you are unsure of what the future holds for your family. But what I want you to know is that there is love, friendship, strength and HOPE to be found on this journey. You and your family will be better for it. Your child is going to teach you amazing, wonderful things. You are NOT alone. Welcome to our Hypoplastic Left heart family!

Christie, (Mother to Bennet, 2 1/2 years)





It seems such a distant, yet vivid memory—that day we learned our son's diagnosis. I'm not sure how we survived that pregnancy. I remember being afraid of everything. Afraid to talk to him. Afraid to set up the nursery. Afraid of every morning I woke up to the realization that it wasn't a dream.

I spent so much time in fear, I didn't see the possibilities. Luckily, my son defied my fears. In fact, he defied most of the timelines they placed on him. We left the hospital three weeks sooner they anticipated. We battled RSV, sepsis, and made it through the second surgery, never missing a beat. There was no doubt that this little boy was set to conquer this thing called life.

Watching him grow has been nothing short of a miracle. He's a little boy that loves cookies, drumming with his dad, and hanging out with his sisters. He plays, sleeps, and likely dreams about trains and planes. He's a spunky two year old who captures the heart of everyone he meets. But most importantly, he fills me with hope every day.

Sometimes I wish I could relive those months and believe that everything was going to be ok. I would dare to dream about a little boy that would inspire me to live and love with no boundaries.

So while it seems impossible now—believe. Hope. And know that the road ahead is not an easy one, but one with more amazing sights than you can imagine.

Melissa & Hugue (Parents to Yoshi, 2 years & 2 months)



The light at the end of the tunnel remained distant for a long time and, at times, appeared to be getting further away. Regardless of how dark life appeared the light never disappeared and now that Avery is post Fontan we have made it through the tunnel. Initially, the completion of three planned surgeries would be what I marked as the end of a difficult journey. While there was a sigh of relief to complete her surgical plan, it wasn't what brought the light. Reflecting on the time since diagnosis, the biggest surprise came from the change that has transpired in my family. The stress and anxiety that consumed us diminished over time. The change occurred slowly, almost unnoticeable, and what occurred was a shift in reality. Reality varies from person to person and changes over time. At diagnosis my reality was altered to include raising a daughter with a complex heart defect. With the help of medical staff, family, friends, and others in the CHD community I was able to adapt and adjust to a new reality to meet the demands of each day. This reality slowly became my new normal. The surgeries may be complete, but the unknown still remains. The worry will always be present, but the adaptation has reduced the stress. What may seem insurmountable to others is now routine, regardless of how difficult it is. The darkness has been replaced with light and the future now appears brighter than ever.



(Trent, Father to Avery, 2 years)

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Pregnant with my first baby that I had hoped, prayed and dreamed of for so long. I would tell myself "This moment is going to change your life forever, but it will not destroy you or your dreams."

You will go home and research things you've never heard of. You'll read stories that will scare you to death and make you think your life is over. You will be angry and feel cheated out of the bliss that you thought you'd feel during your pregnancy. You will cry a lot, and that's ok because for every fallen tear something inside is getting stronger and it's not just the little fighter in your womb.

You will hear the term "heart mom," a label I rejected for so long, and then one day you will find the strength to not only embrace being a heart mom but to be proud of that title. You will learn what it means to be an advocate for your baby. You will learn to stand on your own two feet and you will like it. You will undoubtedly find strength that you never knew you had.

You will earn an honorary nursing degree, becoming so familiar with the anatomy of your baby's heart that your family and friends will ask you to explain to them in layman's terms what you are talking about. You will learn how to change your baby's feeding tubes, monitor oxygen saturations, and administer lifesaving meds around the clock.

You'll become so familiar with the PICU and all of its sounds that you'll be silencing alarms and changing dressings on that little scar that runs down your warrior's chest that used to make you cry - that same scar that made you shudder with the thought of all that your precious baby has endured, the scar that your friends' babies don't have. Then one day that scar will take on an entirely new and different meaning. Underneath that scar lies some of the darkest, bravest, and victorious moments of your baby's life - moments that no one in the world will ever understand but you. That scar will always bring tears to your eyes, but they will change. Eventually, they will be tears of pride and strength.

As I sit here watching my brave three year old Isabella dance around in her tutu, singing and playing, I can tell you that she is my hero, but she's not the only hero I have. Isabella has a little sister, Ava, who also bears that same scar, that same diagnosis of Hypoplastic Left Heart Syndrome. Ava is also my hero. If I can walk through the fire twice, I am here to tell you that YOU will get through this and you will be better because of it. Be brave.

Nicole Delia (Mother to Isabella, 3 & Ava, 1 year)



We walked in to our 20 week ultrasound excited to see our baby's growth and walked out with a million questions and complete uncertainty. Hope? Would there be hope for this little one? We were told the left side of our baby's heart was very small, and she also had an intestinal complication. Needless to say, the following weeks were filled with more ultrasounds and tests. The doctors concluded that our baby had a variation of Shone's complex and HLHS. So, the next 20 weeks were a whirlwind of appointments, research, and questions. Molly was finally born in mid November and was immediately transferred to Lurie Children's Hospital. The doctors carefully collected data and debated the best option for Molly. They weren't sure if she would need the HLHS series of surgeries, which wasn't a good option because of bad valve issues, or if they should try to make the left side of her heart work because it might be "just big enough." The network of family members and friends who sent messages of prayers, good wishes, and hope was essential. At two weeks old (after having abdominal surgery at one week), Molly had open-heart surgery to fix a handful of issues (VSD, coarctation, leaky valves), and it worked! The left side started functioning correctly. About two weeks later, we took our baby home. Molly celebrated her first birthday this past November and is thriving. Yes, there is hope! She is our miracle.

Sarah (Mother to Molly, 1 year)  
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"You never know how strong you are until being strong is the only choice you have." This quote spoke to our hearts after we found out our unborn son was going to be born with a multitude of cardiac anomalies, that he was going to have 3 surgeries at minimum to have a good quality of life, and that he would forever function as a single ventricle child. The fear was beyond comprehension and the ignorance we felt was overwhelming. We felt guilty and lived with fear until the day our sweet baby boy, Kylan, entered this world. Being strong for him was the only way we could face his first open heart surgery, watch him come out with his chest open and literally see his heart beating inside his chest. At that point the fear and the pain started to turn to miracles, joy and blessings. Every milestone since that day has made us realize the bravery, strength and resiliency of these kids, who fight for every breath and live everyday with half of a heart. Kylan lives his life with ambition, positivity and hope, and has a continuous smile. He is a thriving five year old who goes to Kindergarten, loves karate, and pushes himself to his limit to keep up and have fun with his friends. The journey is not easy but is such a blessing. Never forget there is a rainbow after the storm and hope if you believe.



Raina & Nick (Parents to Kylan, 5 years)

I'm writing this to parents that just found out that their child has Hypoplastic Left Heart Syndrome (HLHS). I'm sharing my story with you because I want you to know that although I had a rough start, I have lived a pretty normal life.

My parents brought me home from the hospital thinking I was a healthy baby. When I was five days old, I didn't want to eat and started acting funny. My parents took me to the ER and I was transported to our children's hospital. There, they told my parents I was very sick, and I had a congenital heart defect called HLHS. I needed my other organs to heal before I could have surgery. At ten days old, I had the Norwood. My surgery went great, but I had to stay in the hospital for about 30 days because I didn't want to eat. I ended up getting a G-tube and went home when I was a little over a month old. I was one of the first children in the interstage home monitoring program, and that may have saved my life. Because of low O2 saturations, I was cathed at two months. I didn't tolerate my cath and had the Glenn the next day. I went home five days later and my G-tube was removed shortly after. I needed physical therapy because I was in the hospital so long, but by the time I was three and ready for the Fontan, I was all caught up.

After the Fontan I lived a very normal life. As a toddler I took tumbling and swimming lessons. I started school with kids my age. During grade school, I continued to swim and also played T-ball, soccer, flag football and tennis.

Right before I started my sixth grade year, I went into heart failure. I had to be admitted to the CICU, and was listed for a heart transplant. My heart continued to fail quickly and after three months, my doctor told me I needed more support. I was the first HLHS child in the USA to have a Heartware Ventricular Assist Device placed. I slowly began to feel better and get stronger. Eventually, they decided to let me wait for my transplant at home, and I was the first HLHS child in the world to go home on a HVAD. I eventually went back to school and even joined the archery team. Finally, after 208 days, 15 hours, 39 minutes and 55 seconds I received my new perfect heart. I have been doing great since transplant.

There are many ups and downs on this HLHS journey, but never give up!  
God's blessings to you!

Jackson, 13 years



Lucas was diagnosed with HLHS when he was seven days old. Etched in our minds are the stunning life-changing words, "Lucas has HLHS – let's finish talking in intensive care." He had the Norwood surgery four days later. Now at age nine, Lucas has gone through the Glenn and Fontan surgeries and a few catheterizations and all that goes with them.



We kept him isolated during the interstage period, between the Norwood and the Glenn. He was exclusively breast fed, every 1-1/2 hours, the first year and his cardiologist called him a "tank." His activity-level gradually slowed before his Fontan surgery, but he didn't know life any other way and steadily moved through each day. After the surgery everyone celebrated the way he could run around and enjoy more energy. With lots of love and patience, a level of normalcy has finally reached our lives.

We faced each challenge with good spirit, hard work, love and hope, and we have sought and found blessings in the experience. Parenting, surgery and nursing care intersected and we worked together for the sake of Lucas. Today Lucas is a very happy, active little boy. Our family is closer than ever and Lucas' health and happiness has been well worth all of the trials.

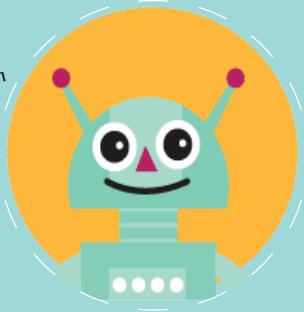
Kathy (Mother to Lucas, 9 years)



I am 9 and I have HLHS. I got to play soccer and it was really fun and I got to do a lot of other things too. I don't really remember my surgeries. Whenever people see the huge scar on my chest they say, "Wow, what happened?" I tell them it was from the surgeries I had when I was a baby and people are amazed when I tell them that doctors cut it open and did surgery inside my chest. I'm glad that I'm alive and I thought that the Doctors would do a good job and I would be fine at the end of my surgeries.



Hi, my name is Refael. I'm 10 years old. When I was born, the doctors realized that something was wrong with my heart. To help me feel better, I had to get 4 heart surgeries. My first one was when I was a month old. The doctors didn't want to do the surgery because they said the surgery wouldn't work, but my father told them they have to try the surgery. It actually went great.



Going through heart surgery is hard, but totally worth it for so many reasons. Obviously, the surgery will make your child feel better. I am able to have a really great life. Because of my heart surgery, I have everything-- great friends, family, toys. If you are ever scared, think about something you like to distract yourself. When the scary part is done, you will realize it was all worth it.

I am so thankful for the doctors who saved my life, and for my mother and father for always being there for me. Don't give up because things will be good. Think about how worth it the surgery is, and how great you will feel when it's all behind you.

Refael, 10 years

I don't let Hypoplastic Left Heart Syndrome define me. This is the message that I have kept in my mind for the 24 years I have been alive. Thanks to this message, I am now a 24 year old, 3rd year medical student going into Pediatric medicine. I can't imagine how difficult it must be as a parent hearing the words, "your child is missing the left side of their heart and needs open heart surgery." There is nothing you did or could have done to prevent this from happening. The only thing you CAN do is let your child live their life to the fullest. I was lucky enough to have parents that encouraged me along the way at every obstacle and challenge I faced. Having HLHS has even given me that extra motivation to prove my doctors wrong and do things I never imagined possible. I am an Eagle scout, I've hiked the Grand Canyon – twice; I graduated from a 4 year university, I am graduating from medical school next year, and I've got so many more things I want to achieve in my life. A diagnosis of HLHS does not mean your child won't be normal. It only means they'll have that extra determination in everything they put their heart and mind towards. Sure, there are going to be challenges along the way and nothing is going to be easy. But at the end of the day, I can say that having HLHS has made me a better person, has made me appreciate every aspect of my life more, has introduced me to some amazing people, and has driven me to accomplish everything I set out to do.



Tom, 24 years



When I was born with Hypoplastic Left Heart Syndrome (HLHS) in 1985, my doctors knew of no known survivors of this heart defect. My parents did not know what would come of my life, but they did trust that God would see us through it. Nearly 30 years later, by God's grace my heart is still going strong.

It's easy for people to think that HLHS brings nothing but hardship and pain. Instead, I'm reminded of James 1:2-3 in the Bible: "Consider it all joy, my brethren, when you encounter various trials, knowing that the testing of your faith produces endurance." I'm confident that no matter what I face in my life, the trials are never outside of God's will for me. What my parents knew back then, and what I've carried with me always, is that since my life is centered on Christ and He is my Rock, He gets me through all the hardships that come along this beautiful journey.

I'm thankful that I've gone through all that I have in my life since it has given opportunities to give hope to others when that hope seems so far away. It came down to a choice: I could either sulk in self-pity because of all the challenges and pain I face with my heart condition, or I could accept the blessings and the trials God has allowed in my life, having full trust in Him who has a greater plan than I could ever imagine.

Jeni, 30 years



30 years ago, my parents were told, "Your daughter has a congenital heart defect called Hypoplastic Left Heart Syndrome. Her left ventricle did not develop, and there is not anything we can do to fix it. She will die in about a week; you can either take her home or leave her here." My parents' worst nightmare quickly turned into reality.

My parents were introduced to Dr. Norwood and his amazing team at Children's Hospital of Philadelphia a few days after I was diagnosed. Though the success rate was about 20%, my parents knew there was not another option. After two open heart surgeries before the age of two, I went on to live a very "normal" life. I went through the public school system. I played recreational sports until high school, graduated at the top half of my class, and went off to college. After four great years, I graduated with my degree and have been teaching ever since!

Parents, I know you're scared. You've just been told that your child has a life threatening disease and you aren't sure of the outcome. Please don't panic; there are options available! You are your child's voice! FIGHT FOR THEM! Once your child conquers their surgeries, you've got to do everything you can to allow them to live their life as "normally" as possible. Yes, follow the limits set by your doctor, but you also need to allow your child to learn their own limits over time.

Maribeth, 30 years





Your world is upside down. You're facing challenges you never thought you would. Life as you know changed forever. This is temporary! You WILL find your 'new normal'. You will discover you are stronger than you ever knew. One day you will understand all of the words the doctors say and will learn to talk their talk. You will not only be a heart parent, but a wise advocate, a nurse, and an inspiration.

My baby (Kennedy Mae) was not given much hope to survive. She was on life support twice, she coded 3 times, she failed to thrive, and she was 100% tube fed. Doctors said she'd never have a good quality of life. Sometimes I wondered if they were right, but my heart would whisper 'they are wrong.'

Through Kennedy's first year of life in the hospital, and doctors appointments several times a week, I struggled just to function.

Through it all, I remembered everyday, "Seasons always change." Kennedy is now 4, thriving, brilliant, 100% orally fed, beautiful, advanced in some areas, and the absolute light and joy of my life! The doctors were wrong. She beat all the odds!

She lives a FULL life with her half heart. You would never know she is sick, other than her blue lips.

She's worth every bit of this fight and I am beyond blessed. Our babies are natural born fighters!

Big heart hugs from one Hlhs mommy to another,  
Becky (Mother to Kennedy, 4)

### **My best heart mommy advice:**

1. Trust your gut above anything anyone ever tells you.
2. Do not be afraid to get a second opinion if you feel the need.
3. The more educated you become on your baby's CHD, the better advocate you will be.

If you are reading this it probably means that you have just had a family member or child diagnosed with HLHS (Hypoplastic Left Heart Syndrome) which can be (duh) super-scary.

I'm Cassidy, a survivor of HLHS. At age 12, after four surgeries, a pacemaker, six catheterizations, and like, a gazillion other kinds of procedures I can still do most of the other things my peers do. Pretty much the only things my doctors restrict me from doing are gymnastics, going to altitudes of over 5,000 feet, soccer, sparring in Tae Kwon Do, and swimming after surgeries or procedures. At times, all of them kind of suck.

So far I'm doing really well. I'm currently on 1st quarter honor roll, got to a really high level in my school's spelling bee, swam for a few months, learned to spin on ice skates, starred in an AWESOME school play, played basketball, am learning multiple languages including French, and absolutely LOVE texting/hanging out with my friends, and watching TV on Netflix.

Although I'm a pretty good student, sometimes PE is hard for me because we have to run a lot and I always get tired and out of breath before everyone else does which can kind of suck.

I also want to say a HUGE thank you to all the doctors and nurses who have helped saved my life because you guys are like, far, far, far beyond amazing. And I'm going to thank one of my very good friends for changing her birthday from a pool party because I had just had a surgery and wasn't able to swim. She is awesomesauce.



There are few moments my wife and I remember with specificity - statements made and emotions felt - from our HLHS experience. One of the moments forever etched in our minds is the day we were told of our son's HLHS diagnosis. The doctor was very calm and looked at us saying, "He will never be captain of the football team, but he still might be valedictorian." No words can describe how you feel as a parent hearing of your child's half a heart and how overwhelming the time is shortly afterwards, while trying to come to the realization that things are not going to be "normal" for your child.

After three open-heart surgeries, our now 4-year-old son is waiting on a donor heart for transplantation. He loves life and lives enthusiastically - going to preschool, playing with his trucks, and reading books. He amazes us every day with his endless energy.

The resilience of infants and children with HLHS, and what they teach us as adults, is incredible. I've had the opportunity to meet many in our same situation and each parent states the same, "My child inspires me to live better and with passion, on a daily basis."

Always remember that you do not have to go through this alone. There are hundreds of parents who've been in your shoes and are willing to share their stories and provide endless support. The road ahead is not going to be easy; however, we can tell you the end results are great.

Chris (Dad to Will, 4 years)

What did I do wrong was the question I asked over & over again. I was always told it was nothing that I did; it was something that just happened. Here I was supposed to be her mother and protect her, but I couldn't even do that. I couldn't protect her before birth, how was I going to protect her once she was born?

But we now have a bubbly, stubborn, loving, funny, little 16-month old girl who is the love of our lives. The first 8 months were a roller coaster ride; I can't lie. Molly has had NEC, blood clots from PICC lines, she has crashed on us, and she has had to be put on ECMO. When she crashed, the doctors performed CPR for 45 minutes. She suffered a slight stroke, and has had a few small seizures due to lack of oxygen during CPR. But today, you couldn't tell anything has ever happened to her! She is climbing on laundry baskets, chasing after her big brother, and talking up a storm thinking you know exactly what she is talking about! Our doctor appointments have slowed down a lot, since Molly has had her Glenn procedure. Right now, we go every 3 months to see our Cardiologist in Kansas City. We are just waiting for the next step - the Fontan procedure.

Marsha (Mother to Molly, 16 months)



Our heart journey did not start at birth like a lot of other CHD families. Our journey started when we were matched through foster care/adoption with our beautiful heart warrior Destiny. Destiny was 17 months old and lived in foster care from birth. She had many failed matches before us due to her heart condition and people being put off by the fear of caring for a little one with a CHD. She'd already had her Norwood and Glenn but was waiting to gain weight before having her Fontan. Destiny was born with a true single ventricle heart. She also has left side deafness and her left eye is smaller than her right but when we see her we see our daughter not her labels.



The moment we met her we fell in love with this beautiful little girl. We were so scared of so many things but we set out to learn as much as we could about her single ventricle heart from her doctors, from heart groups, and by talking to other CHD parents. Seven months after being in our home and hearts, it was time for her to have her Fontan. We were terrified to say the least but she came through the surgery with flying colors! Just 5 days post Fontan she was sent home! She was so pink and had so much energy. It was an amazing transformation. She is now 4 1/2 years old and is doing fantastic. She is still behind developmentally but she is on her own timeline. Destiny has cardiology follow ups every 6 months. She is the love our lives and we would not change a thing about choosing to adopt a little one with a CHD.

Lori and Steve (Parents to Destiny, 4 1/2 years)

When you first meet Will, you would likely be struck by his vibrancy. His smile, his laugh, his jokes, and also his intelligence draw people to him. What might not be so obvious is the heart defect; unless you catch him with his shirt off and see his battle scars! Will was born in May of 2012 with Hypoplastic left heart syndrome. He has had his Norwood and Glenn procedure, and three caths. Every day he makes us proud. Every day is more than worth it. Every day is a chance for him to shine, and shine he does.



Allison (Mother to Will, 3 years)



When I found out my baby sister was going to be born with half of a heart, I was so sad. I didn't know how a child could live with only half of a heart. My mom and dad soon found a place of hope through the heart community and I soon had friends who also had half of a heart. They showed me that my sister Charlie would be just like me. However, she might turn a little blue at times or have to take things like running and playing a little slower. I also realized that as her older sister I could be there to sing to her and hold her

hand and give her love and support when she needs it the most. If I could switch places with her or give her my heart, I would in a heartbeat. Charlie is why I work so hard in life and strive to live every day to the fullest! I am my little sister's number one fan!!

Makayla age 11, (Sister to Charlie)



Always remember that  
you do not have to  
go through this alone.

Meghan, age 23, HLHS



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