CHD MAGAZINE™

HEALTHCARE HEROES

SEPTEMBER 2022

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RECIPES

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THE HEART COMMUNITY COLLECTION
HEALTHCARE HEROES 2022

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CHD Magazine & The Heart Community Collection

CHD Magazine is approaching its one-year anniversary and we could not be more excited.

Because of your willingness to share some of the most intimate and vulnerable parts of your lives - your CHD journeys - you have been able to bring hope, inspiration, and a great sense of community to our thousands of readers worldwide.

This month, we pause from our regular magazine arrangement to celebrate the year together by showing our deep gratitude for healthcare teams in this special edition of CHD Magazine: "Healthcare Heroes."

Check out our cover stories with Thomas Dahlborg, CEO of the Dahlborg HealthCARING Leadership Group, and Pantea Vahidi, the founder of Compassion Clinic.

We are honored to be able to carry forth the outline used on Talk Time with Pantea Vahidi's Compassion Clinic. We have asked our contributors to tell us about a difficult time in their medical journey and how that time was made easier by the kindness of a healthcare provider.

To our healthcare teams, we hope that as you read these stories you will know that you are seen, you are loved, and you are appreciated. Thank you for “fanning the flames of good” (Thomas Dhalborg), and gifting us moments we will never forget. Sometimes the best gifts come wrapped in our biggest struggles.

To read previous issues of CHD Magazine, or to submit your article for consideration for publication, you can visit us at: www.theheartcommunitycollection.com

Our next traditional release will be coming your way this February just in time for Heart Month! The lineup is amazing and we can't wait to share!

Remember to stay tuned in December as we release our holiday catalog.

As always, CHD Magazine is available electronically, in flip book format, as well as pdf download. This allows us to keep this incredible resource free and accessible to everyone as well as environmentally friendly.

Thank you for all you do,

Jenny Muscatell

CREATOR | EDITOR IN CHIEF

Jenny Muscatell

AUTHOR OF THE JOURNEY OF FAITH AND AN OPEN HEART.
RADIO HOST FOR CHRISTIAN MIX 106,
CO-FOUNDER OF MUSCATELL MINISTRIES,
CO-FOUNDER OF THE HEART COMMUNITY COLLECTION.
VALIANT WORKS PUBLISHING

JENNYMUSCATELL.COM
MUSCATELLMINISTRIES.COM

BEHIND THE MOVEMENT

TOGETHER

OUR MISSION

As members of the heart community, we understand the importance of connection. It is our mission to provide quality resources to those impacted by congenital heart disease. In our store, you will find a wide variety of reading materials, from children's books to memoirs and educational books to cookbooks on healthy living. Head on over to our social media and event pages where you can stay up to date on the latest news from The Heart Community Collection.

Maybe you or someone you love was born with a CHD. We understand that can be scary and want you to know that you are not alone.

Our community is filled with an incredible group of givers who are passionate about joining forces to raise voices and spread awareness for those impacted by CHD. We are always looking to grow our community. If you would like to partner with us, please visit our website today and submit the membership request form at: theheartcommunitycollection.com

Perhaps you've written a book on the topic of CHD or manage a non-profit organization that supports the heart community. We want to hear from you! Maybe you are a jeweler, musician, motivational speaker, artist, or medical expert who'd like to share your work with the CHD community. We'd love to explore a partnership with you.

OUR WHY

THE CHD VOICE

Each of our founders faced their CHD journey during an era where little was known about congenital heart disease. Social media did not exist, and access to the World Wide Web was only beginning. Needless to say, support was limited. The idea of the strength and presence of a united community of voices and experiences being shared for the common purpose of helping others through their CHD battle is breathtakingly beautiful. It is our joy to connect with others on a shared mission - we truly believe we are stronger together.

TEAMWORK

MEET THE FOUNDERS

Anna Jaworski is an Oma, Heart Mom, podcaster, producer, author, and blogger. Anna is the Host of "Heart to Heart with Anna" - a podcast for the congenital heart defect (CHD) community. The podcast is an interview-style podcast where Anna talks with doctors, nurses, Heart Warriors, Heart Parents, Heart Siblings, and other members of the CHD community. Anna is also the Producer of "Bereaved But Still Me" - a podcast for the bereaved community, "Guerreros Del Corazon" -- a podcast for the Spanish-speaking CHD community, and "Heart to Heart with Nicole and David" -- a podcast for Adults in the CHD community by Adults in the CHD community. Anna is the visionary behind The Heart Community Collection. It has been her dream to form a networking community who works hard to support one another for the shared goal of CHD awareness and Support. Anna serves as the host for THCC team meetings. You can learn more about Anna by visiting www.heartsunitetheglobe.org.

Jenny Muscatell is a licensed social worker, author, and radio host at Christian Mix 106. With over two decades of experience in the social services field, Jenny has established an extensive reservoir of expertise specializing in crisis intervention, health systems, and end of life care. She has been regarded as a fierce advocate. Jenny is the author of the Amazon Best Selling book, "The Journey of Faith and an Open Heart," and a mom to an HLHS thriver. Jenny's mission is to give voice to the vulnerable, hope to the hurting, and a platform for the unspoken to be told. Jenny is the Creator and Editor in Chief of CHD Magazine. She is a fierce advocate for CHD at both home and work. She is often behind the scenes working out graphic designs, website management, and social media outreach.
To learn more visit www.jennymuscatell.com.

Amy M. Le was born in Vietnam and immigrated to the United States in 1980. The fall of Saigon propelled her family to embark on a treacherous journey to America. She lived in Seattle most of her life and worked for large corporations like Microsoft and T-Mobile. In 2017 when Amy's mother passed, Amy quit her corporate career to write her mother's story. "Snow in Vietnam" was her debut novel published in 2019. Amy is a Vietnam War survivor and a Congenital Heart Defect (CHD) warrior. Today Amy is a full-time author. She resides in Oklahoma with her husband and son. When she is not writing, Amy volunteers for a child advocacy center. Amy is the networking and marketing guru who works to create opportunity and connections within The Heart Community Collection. You will often find her behind the scenes working on social media outreach and CHD Magazine editing. Learn more about Amy by visiting quillhawkpublishing.com

THE TIME TO COMFORT

- Kat Hansen-

> It was the concern in his voice, the sympathy in his eyes as he made eye contact...

Our son Harding was born in 2014 with Congenital Heart Disease, and with it came plenty of challenging moments. However, one of the most challenging moments of our CHD journey that I remember was when I experienced caregiver burnout during the Interstage Period between Harding's Norwood and Glenn surgeries.

Harding's birth forced my husband and I to quickly master the skills of an intensive care cardiology nurse in order to bring him home during the Interstage Period. My husband had to go to work every day, so I had to do the bulk of the caretaking in our household. In addition to "normal" daily tasks *any* mother would need to attend to, I was also weighing Harding's body and diapers, tracking his fluid input and output, recording his oxygen saturations, changing his nasogastric tube, administering his multiple medications, noting the color of his skin, and watching his breathing movements day in and day out. Caring for my medically-complex son and his older sister who had her own medical needs at the time, attending several doctor appointments, and occasionally making trips to the ER or calling 911 services to our home, filled my weeks.

THE TIME TO COMFORT

- Kat Hansen-

Caring for my own needs became a distant memory. After one particularly scary trip to the ER, Harding was admitted to the cardiac intensive care unit (CICU) at Cincinnati Children's Hospital. I hadn't showered in days, my anxiety was at an all-time high, and coffee had been my only meal that day. I was both mentally and physically exhausted and had been pushed way beyond my limit.

I was holding a sleepy Harding in my arms when the attending cardiologist quietly entered our hospital room. It was Dr. Byrnes - he'd always been one of my favorite CICU cardiologists.

I think he saw my exhaustion through our hospital room window because the first thing he asked was, "How are you doing Mrs. Hansen?" It was the concern in his voice, the sympathy in his eyes as he made eye contact - he truly cared to know the answer, and his gentle smile immediately made this interaction different from all the other times a doctor had entered our hospital room.

He couldn't have known that no one had asked me how I was doing in a long time, and that question, and his demeanor, broke me. I ducked my head while tears started running down my face. Dr. Byrnes was at my side in an instant and asked, "Can I hold him for you?" Silently nodding my answer, I passed Harding into his arms and buried my face in my hands to try to stop the onslaught of sobs. Dr. Byrnes held Harding for a few moments while saying hello to him, and then gently laid him down in his crib. Then he looked at me and gently commented, "I'm so sorry Mrs. Hansen, Is there anything I can do for you?"

I looked up at him through my tears and replied, "I don't know. Everything is just so hard right now, and I'm so tired. I don't know what to do."

Dr. Byrnes nodded and said, "I understand, the Interstage can be a really hard time for families. You are not alone in feeling overwhelmed by it. But Harding is so lucky to have you as his mom. You are working so hard to keep him as healthy as he can be, and it's working." His kind words only made me cry harder, which didn't seem to bother him at all. After a moment he asked, "Have you eaten lunch yet today?"

"No," I replied softly.

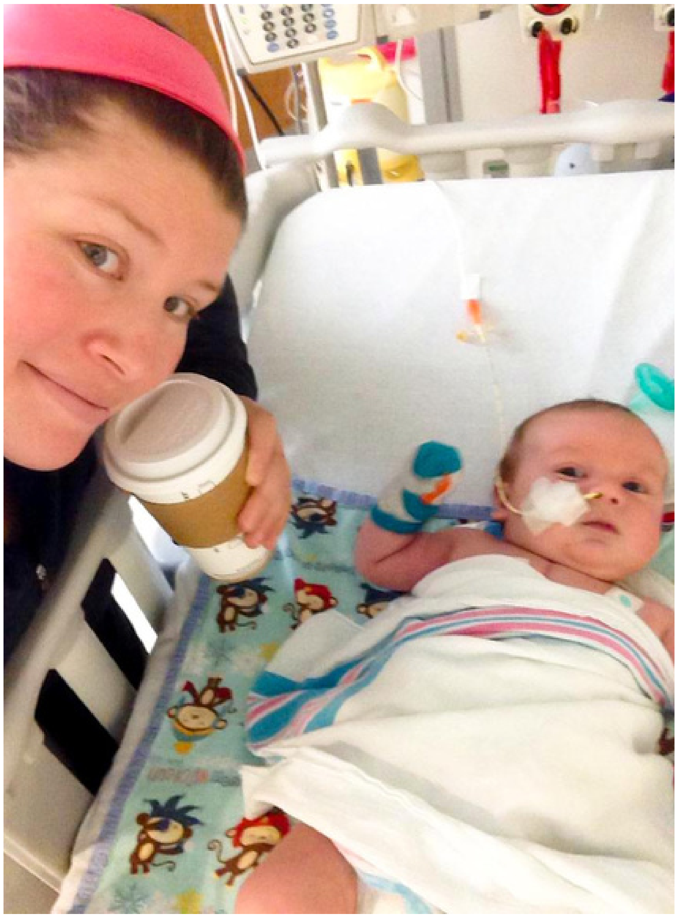
THE TIME TO COMFORT

- Kat Hansen-

"I will have one of the nurses bring you something to eat, Does that sound okay?" I nodded my head in agreement.

"Okay then. Before we dig into details about Harding's health, I just want you to know that everything is going to be okay. We're going to do everything we can to get him feeling better and back home soon. If you need anything at all, even just a break, let us know, and we'd be happy to keep an eye on him for you while you take a walk or get a bite to eat. Alright?"

It was in that moment that my tears paused, and I was able to take a deep breath. Here was a busy doctor with countless patients to see that day taking time to comfort me and offer me a helping hand. He was compassionate and cared not only for Harding's health but my own as well. Realizing I hadn't answered yet I said, "Thank you Dr. Byrnes."



"From that day with Dr. Byrnes in the CICU after one of the nurses brought me Starbucks and some snacks per his request." - Kat Hansen

Kat Hansen

AUTHOR OF HOPE AND COURAGE - SIX LIFE LESSONS FROM THE PARENTS OF A CHILD WITH CONGENITAL HEART DISEASE & CO-HOST OF THE HOPE AND COURAGE PODCAST

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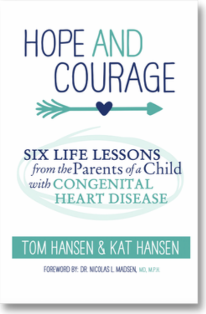


On Mercy

By Michael Liben | Bereaved But Still Me

Mercy doesn't always come on angel's wings. It isn't always gifted on a soft white pillow, and it isn't always in the form of a court order. Sometimes it comes in the form of a middle aged man in a white lab coat. There are moments when you have to recognize the messenger and maybe strain a little bit to see him.

Friday morning, ten years ago. We make a mad two-hour dash to a hospital we've never seen and know nothing about. Our daughter is there following an epileptic seizure. She has a pace maker and a complicated heart condition that was corrected thirteen years before. She was there three weeks earlier with a previous seizure, so we thought we knew what we were looking at. We had learned years before that in the Heart World, nothing happens overnight and that whatever was ahead for us, we could handle it.

On our arrival, the head of ICU took us aside to put us into the picture. The seizure had prevented her lungs from getting oxygen to her blood, and there was already untold damage to her brain. "The doctors had begun (what they called) brain resuscitation", he explained but he didn't look comfortable.

> “
> I LEAPED OVER THE STAGES OF GRIEF AND DID MY BEST TO LAND IN THE LAP OF ACCEPTANCE.
> ”
> - Michael Liben

Basically he told us that we had two options, Bad and Very Bad. Very Bad was that she might wake up. If she did, she would never eat on her own, she would never be able to care for herself for anything. She would live a life in bed. She would never smile.

My wife, son and daughter went into prayer mode. My wife started reading Psalms over our daughter's bed. My children were having their own conversations with The God of Abraham. Like Aaron, Moses's brother, I became still, very still. I pondered the words of the man in the white lab coat. My family was once again praying to bring her back from over the abyss. I admired their faith that God would act and that she would once again scrape by. But I also understood what the doctor had given me.

He had given me the information we needed to go forward. I leaped over the stages of grief and did my best to land in the lap of acceptance.

I, too, prayed. But this time I prayed for her safe passage.

On Mercy

By Michael Liben | Bereaved But Still Me

In the next three days, I had spoken constantly with the same doctor as well as a Neurologist. I knew what was happening and understood the consequences. The doctor, in his opening had put me where I needed to be and I will never forget that mercy. He gave me the information I needed in order to prepare for what was to come. I was ready to catch the rest of my family as they were heading for a terrible fall. I would be there for them.

My son accused me of not having faith, and that he would help to bring her back. I told him that I had buckets of faith but that my faith was that things tend to work out as they should, whether or not we like the results. I suggested that he might be running, head first, towards a brick wall but I also knew he would have to hit it rather than take my word for it. But I was there for him because the man in the white lab coat had prepared me.

On Monday night when we got the final word, my older daughter began screaming uncontrollably. I was there for her.

My wife fell silent, as I had been three days before. I was there for her.

It is now nearly ten years on. I recently spoke to a class of medical students who were preparing to work in the ICU. We talked mostly about transplant issues, but I could not let go of the middle aged man in the white lab coat. As I told them the story of what he told me and how he presented it to me, I could see they were uneasy. One student asked if it wasn't cold to tell a family such bad news upon arrival. Something stirred deep inside as those days came flooding back. I raised my voice and told all of them, "Your job is to deal with information. Families need information to know how to proceed, and false hope was not going to do that. If you can't call it straight for the people who need to know, then go find someone who can." This cold, difficult moment was going to be hard on the messenger as well as the family, but that is the strength of Mercy. I will forever remain thankful to the man in the white lab coat who knew just what to say and how to say it.

> "
> THIS COLD, DIFFICULT MOMENT WAS GOING TO BE HARD ON THE MESSENGER AS WELL AS THE FAMILY, BUT THAT IS THE STRENGTH OF MERCY.
> - Michael Liben
> "

Mercy is often delivered quietly, almost secretly. We have to keep a look out and find it where we can. In some sense, we define our own Mercy, by teasing it out of our own experience. It may be all around us, if we are willing to see it.

Michael Liben

Michael Liben | Host
Bereaved but Still Me Podcast

3 AM WILL ALWAYS BE THE WORST

By Natalie Griffin

There's something about three in the morning that makes whatever situation you are in a million times worse. Perhaps it's because of the exhaustion, or maybe it's because the world is so quiet that your mind is free to run wild.

In late September 2021, my month-old baby was admitted into the hospital for failure to thrive. I was positive it was due to a severe tongue-tie. Instead, my happy fantasyland disintegrated around me early one morning when the doctor explained that my daughter had a large VSD. He told me that she would require open heart surgery sometime within the next three to five months. Trust me, those were the longest months of my life.

It was in the middle of yet another Covid spike, so she was only allowed two visitors— my husband and me. As if that wasn't isolating enough, my husband didn't have any more time off work. So, I sat up in that tiny hospital room with my rapidly declining newborn to digest all of this news.

Alone.
I didn't call my husband to tell him until much later in the day.
I ignored all of my mother's calls.
I didn't know how to think.
I didn't know how to speak.
I didn't eat.
I didn't drink.
I was even afraid of holding my baby.
I flat-out was not okay.
I had an irrational fear that they'd see my weakness, report me to CPS, and take my baby away.

> "SO, I SAT UP IN THAT TINY HOSPITAL ROOM WITH MY RAPIDLY DECLINING NEWBORN TO DIGEST ALL OF THIS NEWS."

As each day passed, both her condition and my mental state declined a little more. Very quickly, I determined that 3AM would *always* be the worst part of any day.

And for every hospital stay from then on, that rang true.

While changing her diaper around that horrific hour one morning, I finally broke down.

Suddenly, I could see exactly how frail she was, exactly how her breathing wasn't right, exactly how sick she really was.

3 AM WILL ALWAYS BE THE WORST

By Natalie Griffin

For the millionth time, I started to cry. But this time, I couldn't even stand—I couldn't even breathe.

I don't know how long I clung to the bassinet, begging God for a sliver of help, before my angels came in.

The night nurse hurried into our room. I remember thinking her timing was impeccable, but she probably either heard my gut-wrenching sobs, or a neighbor heard me and called up front.

The nurse was a sweet, motherly type of woman. Blond hair, soft features. Like a child, she wrapped me in her arms and let me sob into her chest. She didn't care that I likely got snot all over her. She didn't laugh or gaslight me when I begged her not to tell CPS I wasn't okay. She held me until I was able to speak again. She took the time I needed to care for me—and I wasn't even her patient.

This amazing nurse stayed with us until sunrise. In hindsight, this might be because my daughter's condition seemed to be worsening, but in the end we both needed her to be there. She explained everything on the monitors to me, showed me what she was watching for, helped me become a part of my baby's healthcare team.

> “
>
> I DON'T KNOW HOW LONG I CLUNG TO THE BASSINET, BEGGING GOD FOR A SLIVER OF HELP, BEFORE MY ANGELS CAME IN.
>
> ”

But most of all, she told me it was okay to feel the way I did. It was okay to feel confused, numb, and panicked all at once. It was okay to zero in on the breastfeeding and fight for it—it was the only thing I remotely had any control over.

I wish I could send a note to myself back then (because I *certainly* don't want to experience any of it again!) and tell myself to write down all of our nurses' names. Because this is only one story out of several where these medical professionals helped me step up to the plate to fight for my daughter's life.

3 AM WILL ALWAYS BE THE WORST

By Natalie Griffin

> IF THAT WOMAN HADN'T COME TO ME WHEN SHE DID, LET ME CRY, HELD ME LIKE A MOTHER, I DON'T KNOW HOW MUCH MY SOUL WOULD HAVE BROKEN.
>
> NATALIE GRIFFIN

If that woman hadn't come to me when she did, let me cry, held me like a mother, I don't know how much my soul would have broken. I don't know how long it would have taken me to get to a point where I could be there for my little one.

After our CHD journey, there are pieces of me that are still completely shattered that may never heal again. But I know that this amazing nurse held together a vital part of me— the scared, new mother part. The part that I couldn't lose. She helped stitch it together so I could grow into the powerful heart momma I am today.

Natalie Griffin

Heart Mom

NatalieGriffin.com

I THINK WE SHOULD DISCUSS A HEART TRANSPLANT

-Skylar Collins-

Skylar Collins - HRHS

Those were the words...

“I think we should discuss a heart transplant." The minute those words were said to me five years ago, it’s been nothing short of an adventure. My name is Skylar Collins. I am from Tri- Cities, WA. I am twenty-eight years old and I was born with Hypoplastic Right Heart Syndrome (HLRS). I wasn’t surprised it came down to this, but I was in awe of how fast it came. I had no idea what crazy ride I was in for.

Evaluations were scheduled, tests were being done, appointments were constantly being made. It all happened so fast. I felt like I didn’t have time to process it all.

Fear took over at one point and phone calls would get declined, and emails weren’t answered as quickly as they should’ve been. I knew what was coming and I was fearful of the outcome. It took a while for me to accept this adventure that was laid out for me. What made it easier was knowing I wasn’t alone. My family and friends rallied around my wife and me, showing us overwhelming support. But what really helped was when my wife, Alex, who told me she was with me no matter what. I knew I had to do it, if not for me, for her.

After evaluations and tests, I learned that not only did I need a heart transplant, but I needed a heart and liver transplant.

> “
>
> FEAR TOOK OVER AT ONE POINT
>
> ”
>
> -Skylar Collins

I THINK WE SHOULD DISCUSS A HEART TRANSPLANT

-Skylar Collins-

Only so many centers had the capability to do that, but thankfully we were accepted by the one who had the most experience, UCLA Ronald Reagan Medical Center. That was when I learned that the relationship you have with your nurses, doctors, social workers, and even non-medical hospital staff, can have an impact on your fight. It was the first time that I felt I was actually heard and seen as a person and not “another patient."

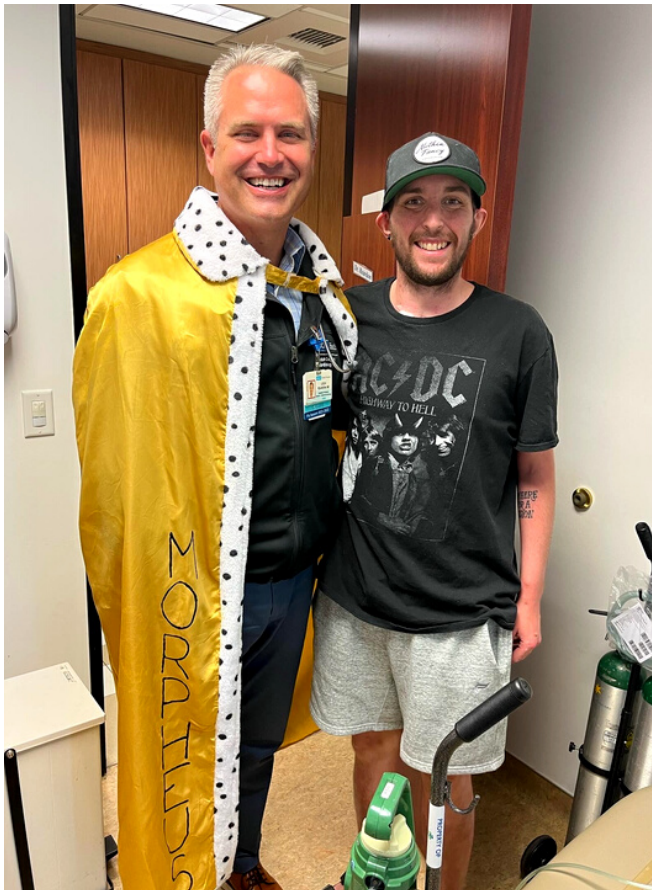
The day after a heart cath, an ACHD doctor, Dr. Reardon, came into my room, looked at my cath site, and asked if I wanted to take the bandage off. Of course I said yes but in the next second he ripped it off without warning. He then informed me that he was also a CHD patient and understood the discomfort and told me I had to just go for it. That was when I realized that relationships with medical professionals didn’t always have to be surface level. That realization helped because I was hospitalized at UCLA while my wife had to stay in Washington. The hospital wasn’t allowing visitors because of the pandemic.

Overtime, I had built relationships with the nurses in my unit, the doctors on my case, the cleaning ladies, and even the people who delivered my meals.

> “
> IT WAS THE FIRST TIME I ACTUALLY FELT HEARD
> ”

There have been countless nights where the nurses and I would play cards until two in the morning. One doctor taught me how to solve a Rubik's cube, another would talk college football with me, and some would just stay and let me talk about what was going on inside my head. These relationships kept me from severe anxiety and depression.

Later on when visitors were allowed, and Alex was able to be with me, the relationships I had built were carried over to her. So much so, that we were invited to one of the nurse’s wedding!



-Skylar Collins-

During my transplant journey, I was put on status "seven" twice. The first time was because the heart surgeon suddenly went on medical leave. I was discharged and placed on status "seven" for about ten months, which forced us to move back to Washington.

The second time was because of complications within the program. I was discharged for about two months, but in those two months, my health failed drastically. Fluid was building up around my lungs constantly, the edema in my legs was getting worse, and my Oxygen saturations wouldn't hold up.

During all this time being discharged, those relationships continued. They checked in on us, asked for updates, and genuinely cared about our adventure because they were invested in us. They wanted to see a positive outcome from this adventure.

When the program was having complications and I was getting worse, my doctors advocated for me to get back on the list. After being admitted to the hospital for my second status "seven," I received an offer a month later.

Every relationship I built in that hospital over the last two years stayed right by my side, praying and sending positive vibes throughout the journey.

Going into post-transplant, every doctor checked on me and stayed to visit; nurses from my old unit visited me while on their break. Even though I couldn't talk, the smile on my face when seeing them said it all. These relationships made an impact on my journey, my fight, and my hope. These people served as my family while I was away from mine.

When transplant was suggested to me five years ago, the fears that once delayed me from answering my emails, never came to surface. That's not to say this journey wasn't difficult, but it was a lot easier to go through because of these relationships.

Skylar Collins

WARRIOR SPOTLIGHT

- Brandon Lane Phillips -

BRANDON

"BORN AND RAISED IN RURAL LOUISIANA, DR. BRANDON LANE PHILLIPS WAS DIAGNOSED WITH A CONGENITAL HEART DEFECT SHORTLY AFTER HIS BIRTH. FROM AN EARLY AGE, HE DEVELOPED A DESIRE TO BECOME A PEDIATRIC CARDIOLOGIST BECAUSE HE SO GREATLY ADMIRED HIS CHILDHOOD PHYSICIAN."

BY BRANDON LANE PHILLIPS

A Lifetime of Lessons

By Brandon Lane Phillips

A Lifetime of Lessons

I had my first heart surgery at the age of two. Dr. Vargo was my pediatric cardiologist. I adored him. He always made me feel like I was *more* than a patient to him. He called me his “friend” during appointments. When I was away from my hospital room when he made rounds, he left me personal notes so I would know he came by.

Early on, I knew I wanted to be a physician and work with Dr. Vargo. I looked forward to my checkups. Those were the times I could ask him how to make my dream a reality. He gave me helpful advice, such as “a physician’s bedside manner is just as important as how smart they are.”

I often wrote to him between checkups to share news or request his help with a school project. He always replied.

A Lifetime of Lessons

By Brandon Lane Phillips

2000 brought some changes and I was excited for my cardiac checkup. It was the year I told Dr. Vargo I would be starting medical school in a few short weeks.

On the second day of school, I received an unsolicited opinion that I would require a second heart surgery.

I called Dr. Vargo to ask *his* advice. He had just told me everything was fine a few weeks before. He said, “Medicine is not an exact science. There are gray areas. Two doctors can look at the same set of data and come to two different opinions, and neither may be wrong.” Although his words were unsettling, they proved to be one of the most important lessons I learned in medical school.

Three years later, Dr. Vargo walked across the stage with me and hooded me at my medical school graduation. My dream had come to fruition.

> “ONE DAY, WHILE WORKING WITH HIM IN CLINIC, I LOOKED THROUGH MY MEDICAL RECORD. EVERY LETTER I SENT HIM AS A CHILD WAS THERE”
>
> - Brandon Lane Phillips

Soon, I would begin my pediatrics residency at the very hospital where I had been a patient, and Dr. Vargo would serve as my academic advisor.

One day, while working with him in clinic, I looked through my medical record. Every letter I sent him as a child was there - intertwined with ECG and x-ray reports. His lessons taught me how to emulate the care and compassion he had shown *me* as a patient.

Three years later, I decided to pursue my fellowship training in pediatric cardiology at the hospital where I had my second heart surgery. Dr. Vargo’s influence was still evident even though he would now be located a thousand miles away. It so happened, he had trained many of the physicians who taught me my craft. Each year Dr. Vargo made a special trip to attend a conference where I was in fellowship so he could check on my progress as a cardiologist.

A Lifetime of Lessons

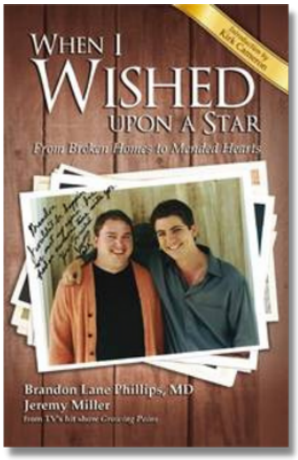
By Brandon Lane Phillips

Today, I still enjoy visiting with Dr. Vargo and consulting him on interesting patients.

Dr. Vargo is the inspiration for my life's work. He has played many roles - physician, mentor, advisor, teacher, and ultimately friend - during my lifetime. I have had many outstanding teachers during my twenty-eight years as a student, but none have touched my life as profoundly as Dr. Vargo.

Brandon Lane Phillips

Author of When I Wished Upon a Star



Born and raised in rural Louisiana, Dr. Brandon Lane Phillips was diagnosed with a congenital heart defect shortly after his birth. From an early age, he developed a desire to become a pediatric cardiologist because he so greatly admired his childhood physician.

Dr. Phillips received a bachelor's degree in chemistry from Louisiana Tech University in 2000 before pursuing his medical degree at Tulane Medical School. He completed his residency in general pediatrics at Texas Children's Hospital & Baylor College of Medicine in Houston and his fellowship in pediatric cardiology at Mayo Clinic in Rochester, Minnesota. A highlight of Dr. Phillips's medical education was receiving portions of his medical training from the very physicians who had cared for him.

As a second-year medical student, Dr. Phillips had an essay about his chronic illness and the experience of having open-heart surgery between his first and second years of medical school published in the Journal of the American Medical Association (JAMA).

Dr. Phillips considers it a great honor to have been invited back to Tulane Medical School several times to lecture to the medical students about pediatric cardiology and share his journey from patient to physician with them. He is currently a Clinical Assistant Professor in Tulane's Department of Medicine.

Among many of Dr. Phillips's awards and accomplishments, he is most proud of his Young Alumnus of the Year award from Louisiana Tech University in 2006 and the Robert C. Baird award from Tulane University School of Medicine in 2004, which recognizes a senior medical student each year who embodies Dr. Baird's ability to

A Lifetime of Lessons

By Brandon Lane Phillips

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overcome hardship and exemplify excellence and achievement. He was also recognized as a Distinguished Alumnus of Louisiana Tech University’s College of Engineering and Science in 2014.

He is a fellow of the American Academy of Pediatrics, the American College of Cardiology and American Society of Echocardiography, and is board certified by the American Board of Pediatrics in both general pediatrics and pediatric cardiology. In addition to his position on the Board of Trustees for Starlight Children's Foundation, Dr. Phillips has previously served on the Board of Directors for the Louisiana Chapter of the Make-A-Wish Foundation. He has served many summers as a camp counselor at special camps for children with heart defects, and he has also worked with Samaritan's Purse on the Children's Heart Project, even traveling to Mongolia in 2009 to help support the organization's mission.

Dr. Phillips has authored several medical journal articles and contributed to the book Common Cardiac Issues in Pediatrics.

Kirk Cameron, Brandon Lane Phillips, Jeremy Miller

AS SEEN ON

The Hour of Power

Herman and Sharron

Jesus Calling Podcast

His book, "When I Wished Upon a Star" co-authored with Jeremy Miller from TV's hit show "Growing Pains," highlights the many ways hope and faith can bring two friends together to overcome personal tribulation.

COMING SOON

Exciting News!!

Join us for an Instagram live
9/14/22 at 3pm CT
@theheartcommunitycollection

We will be interviewing Brandon Lane Phillips and Jeremy Miller. They have some very exciting news to share. You will not want to miss it!

The Legacy Continues

We here at CHD Magazine and The Heart Community Collection are beyond thankful for Dr. Phillips and the work he does. He pours kindness, compassion, and wisdom into his patients, the CHD community, and truly anyone he encounters. Read on to hear this touching story by Chris Donald.

A Lifetime of Lessons | The Legacy Continues

Brandon Lane Phillips | By Chris Donald, RN, BSN Hypoplastic Right Heart Survivor

I have worked with Dr. Phillips for a good part of my career as a nurse. We met when I was a NICU nurse. I was caring for one of his patients.

The baby's mom was devastated by the child's newly diagnosed heart defect and I wanted Dr. Phillips to talk with the mom in hopes to show her that children with congenital heart disease can live a full life and do very well.

The result was unique. As Dr. Phillips asked me about my background, we learned that we both had congenital heart disease. We also learned that we were both operated on by Dr. Francisco Puga at the Mayo Clinic.

Dr. Phillips was the first other adult I met who was born with congenital heart disease. It was amazing to connect to someone who understood what I had gone through!

That moment in the NICU started something special. Later on, Dr. Phillips asked me to apply for a clinic position in pediatric cardiology. I became a nurse for several cardiologists and loved being able to care for patients who were going through the same struggles I faced and continue to face.

As time passed, Dr. Phillips moved to Louisiana. I missed having him in the clinic. Little did I know, nine months later my husband would accept a faculty position at the pharmacy school in the same town that Dr. Phillips lived.

After almost a year apart, we were once again reunited as probably one of the few nurse and doctor pairs who have CHD.

Working with Dr. Phillips is a great honor. As I reflect upon that first conversation we had in the NICU almost ten years ago, I am still amazed how that moment brought forth a lifelong friendship.

Over the years, Dr. Phillips has shared many of my life's ups and downs. He is a great uncle to my son and makes our work together wonderful. It is so much easier going to work each day when you work with your best friend!

Chris Donald

RN, BSN
Hypoplastic Right Heart Survivor

The Perfect Match

CARLI VALENTINE

The Perfect Match

When trying to navigate the very difficult journey as a heart parent, it is essential to find the right doctors and team. This search is what ultimately led us to finally getting the help my medically fragile son needed so very badly.

Initially, we accepted the medical team we just happened to stumble upon. However, as time went on our child's health was not improving and we were desperate in our search to figure out how to help. We quickly realized how vital it was to do our research and seek out exceptional doctors, therapists, and medical professionals.

My son's first heart surgery took place locally at our children's hospital. Upon recovery, he was still having residual issues that were supposed to be remedied with this initial surgery. I needed answers.

I explored a variety of local Facebook groups and posted asking if anyone had a pediatrician that they absolutely adored. After numerous amazing recommendations, I found Dr. Isabel Cristina Lau.

From the start, she was extremely thorough and helpful. She gained my son's trust almost instantly. He spent his visits with her dressed in her lab coat and practiced using her stethoscope while they imagined his future as a doctor in her practice. She always made his visits with her fun, and took a special interest in getting to know my heart warrior.

> "
> SHE GAINED MY SON'S TRUST
> "
>
> - Carli Valentine -

The Perfect Match

CARLI VALENTINE

She had an unprecedented loving and kind demeanor that always put my son at ease. He enjoyed his visits with her, and our family always felt very comforted knowing that we had her on our side.

During one of our conversations at a routine medical appointment, she told me that she also had a son with a CHD. The amount of understanding and compassion my family receives from Dr. Lau is truly one of the most amazing gifts we could ever receive. She always listens to every concern that I have with my heart warrior and consistently helps me come up with new ideas to try to help him.

Even though we found an incredible pediatrician that we adored, we still needed to find a solution to the many health challenges my son continued to face. One evening, while I was sitting in a college course I was enrolled in, I was reading a medical journal article written by a cardio-thoracic surgeon named Dr. Carl Backer. He was, at the time, practicing at Ann Lurie Children's Hospital in Chicago.

Dr. Backer was the author of numerous medical journal articles written about my son's exact heart defect. He strongly recommended adding an additional procedure while performing cardiac surgery on kids with the same CHD.

At the bottom of the article I saw Dr. Backer's email address. Anxiously, I typed an email to this surgeon asking for help and pressed send. To my astonishment, I received a response from this cardiac surgeon before my class was even complete. I was completely shocked. Through correspondence, we arranged for my son to have further testing done so that the surgeon could analyze the results. After further review, Dr. Backer speculated that an additional surgery would be helpful for my son.

Both of these medical practitioners changed my son's life for the better and we are forever grateful for them. Dr. Lau was such a wealth of knowledge and was very encouraging when I sought out Dr. Backer across the country for my son's second cardiac surgery.

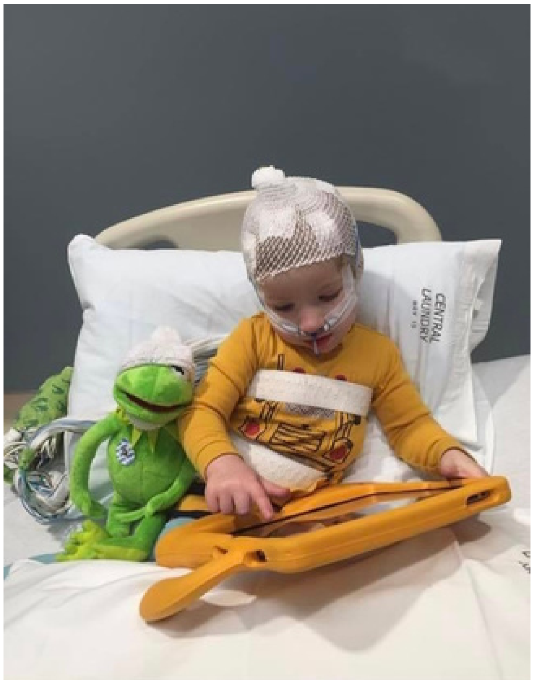
The Perfect Match

CARLI VALENTINE

Many of his in- state specialists hinted that they thought this surgery was unnecessary, and Dr. Lau supported and encouraged me to follow my instinct and helped guide me to make this very difficult and stressful decision.

Dr. Carl Backer is an amazing cardiac surgeon and the surgery he performed greatly changed my child's health and quality of life. Dr. Backer spent a lot of time on the phone with me and communicated through countless emails in a quick and caring manner. I am very grateful for the amazing research he has conducted with my son's particular heart defect and all the countless surgeries he has performed to change the lives of so many heart warriors.

These medical professionals truly are exceptional. They care so much about their patients and it resonates in the quality of care that they provide.



They devote a huge majority of their time and energy to bettering so many childrens' lives. My recommendation to other parents advocating for their medically compromised children would be to follow your instinct and always seek out amazing health care workers who you feel are the best fit to care for your child. We have received so much compassion from these amazing professionals and an overall incredible quality of care.

Carli Valentine

AUTHOR OF EXTRA SPECIAL HEART & MANY MORE

CARLIVALENTINE.COM

PANTEA VAHIDI

PANTEA VAHIDI

"MY VISION IS TO RAISE AWARENESS ACROSS THE WORLD INTO THE HUMAN SUFFERING THAT NO ONE IS EXEMPT FROM, AND ELEVATE EMPATHY AND CULTIVATE COMPASSION."

COVER STORY | COMPASSION CLINIC

COMPASSION CLINIC

- Pantea Vahidi -

She lay on the bed talking with her mom - her head tilted heavily towards the iPad sitting on the side table. Mandy was quadraplegic with Cerebral Palsy - in the hospital for severe abdominal pain. Morning report brought an onslaught of information. “She is such a difficult patient” I heard one staff member warn. “Beware, she even has her mom on video to supervise our every move” a night shift nurse advised me in our handoff.

At my first encounter I found her reactive and irritable but after spending some time with her, she let her guard down. I combed and braided her hair. The next time I walked into the room, her mom was no longer on video.

Early in the afternoon Mandy’s doctor stopped by the nursing station to tell me her medical imaging showed no explainable reason for her to be having the pain. My mind questioned, H*ow is the absence of an abnormality proof that she doesn’t have pain? We do not find a brain tumor in imaging each time we have a headache, but we still feel pain.*

The doctor stormed into the patient’s room and I followed her. She told the patient her imaging showed nothing and she would be discharged home. Her words cut through silence but her body language and tone increased the volume - so much so, that when the doctor left the room, the patient told me “Just because I’m laying here on the bed and can’t move, doesn’t mean I don’t understand - that I don’t pick up on what she is implying."

I felt cold inside and partly embarrassed. I knew what she felt. I felt it too. It wasn’t the first time I had seen someone’s pain discounted and it doesn’t only happen within the walls of a hospital, it happens in life. All of us have experienced feeling misunderstood and dismissed at some point in life. “Compassion transforms thorns into flowers, compassion transforms vinegar into wine, compassion transforms hurt into healing, compassion transforms a king to a servant” were excerpts from a poem I heard from my father growing up. He would recite it, especially when someone had done us wrong and we were tempted to react.

COMPASSION CLINIC

- *Pantea Vahidi* -

I believe my father’s foundation was built on the shoulders of his father; who in a rare and shocking move, forgave the boy that killed his eleven-year-old son with a knife in an argument at school and pardoned him from a life sentence in prison. While I never met my grandfather, I’ve been told, at the time of his son’s death and by the prosecution of his son’s killer, he said, “One family is grieving the loss of a son; there is no need for another family to lose their son."

Perhaps compassion and forgiveness are learned behaviors. I learned them as a young girl growing up in Iran in a way that spanned the length of my childhood. I learned that when death is imminent, uncertainty is the chronic theme, and fear is the only thing you can feel. Gathering with friends and family and taking in those who lost their homes in the bombings was the only way we got through the hard times. There was no other remedy for going to bed thinking you may not wake up alive, as the bombings were around the clock.

Decades later during my time at the bedside as a nurse, I started to notice how spending time with patients and showing compassion toward them miraculously improved their outcomes, whereas the deficit of compassion was detrimental.

This contrast between the presence and the absence of compassion intrigued me to look into this ancient virtue. With my STEM background I first took on the literature to search for scientific evidence on the effects of compassion. After studying all the content I could find on compassion, I found myself as a member of the Compassion and Empathy Scoping Review research team at the University of California San Diego (UCSD) reviewing the literature and learning the neuroscience behind how compassion affects the brain.

I quickly learned that the literature is abundant on listing all benefits of compassion including physiological and psychological. I also noticed that all great teachers such as the Dalai Lama have talked about it and inspired and invited millions to participate in compassion and forgiveness.

COMPASSION CLINIC

- Pantea Vahidi -

> WE TALK ABOUT COMPASSION AND WE EVEN HAVE SCIENTIFIC PROOF THAT IT IS THE ELIXIR THAT CARRIES MORE BENEFITS THAN ANY REMEDY I KNOW
>
> PANTEA VAHIDI

We all have invisible Pain

But one question arose - we talk about compassion and we even have scientific proof that it is the elixir that carries more benefits than any remedy I know, but how do we define, practice, and measure it in healthcare?

After creating a "Compassionate Care Initiative" at a major healthcare system in California, I was sad to learn that we do not even have a standard definition for compassion, and found that even leaders within the same room define it differently. That being said, integrating life experience with my nursing expertise and the literature, I set out to define compassion.

Compassion is understanding the pain, need, or situation and taking a thoughtful and meaningful action in response to provide relief, comfort, hope, joy, or strength. Think back to a time when someone was compassionate toward you and see how it fit into this definition. The outcome of compassion is that the recipient feels seen, heard, and understood while the giver feels a reward like no other which the literature names "compassion satisfaction." But it doesn't end there. As a nurse, I can say with conviction that compassion is the only remedy I know of that benefits three people - the giver, the receiver, and the observer. No other pain relief that we provide can benefit so many.

Imagine a viral video where you see two cute toddlers running and hugging each other. Merely observing that compassionate exchange brings a smile to your face while you did not even participate in the actual exchange.

With so many social, mental, and physical benefits, why aren't we compassionate more often? I believe there are several barriers to compassion with one of them being a lack of understanding. We don't know what we don't know. If I do not know what someone else is going through, I would not know when they could use some empathy and compassion.

I always remind my audience in my workshops or keynotes that while everyone in the hospital has pain, not everyone that has pain is in the hospital. Most, if not all people, are dealing with some invisible pain. The pain could be from a past trauma, or a current struggle, nonetheless, we all suffer.

Suffering is our shared human experience and one way to cultivate compassion is to raise awareness about the invisible pain that everyone is battling with behind closed doors.

COMPASSION CLINIC

- Pantea Vahidi -

COMPASSION CLINIC™ TALK TIME

NOW EVERY TUESDAY

AUGUST 2, 2022
12-1PM PST
1-2PM MST
2-3PM CST
3-4PM EST

VALUABLE INTEL ABOUT PATIENT EXPERIENCE

"We suffer silently even though we are experiencing it collectively"

Your Host:
Pantea Vahidi, RN
Founder of Compassion Clinic™

Special Guest:
Mona Powell
Founder of Dotstash

With the intention to raise awareness and cultivate compassion around the globe, I founded "Compassion Clinic" and launched a show called "Talk Time". During "Talk Time" ordinary people come together and share their personal struggles and how they have navigated it all. Facilitating such conversations leads to tapping into that shared humanity. The feedback I have received from the program has ranged from being inspired by the resilience of the guest speaker, to an enhanced awareness into what others are going through, to taking action to assure no one goes through such pain ever again.

My vision is to raise awareness across the world into the human suffering that no one is exempt from, and elevate empathy and cultivate compassion. My goal is to equip everyone, especially care teams, with practical tools to provide compassion even when being compassionate is hard. I have taught The Vahidi Compassion Model at UCSD to medical and PMH students as well as to nursing students at San Diego State University. I will do all I can to make sure Compassion Training becomes a required curriculum in all medical schooling and medical-related training.

While we enter healthcare with a heart to serve, we are not always equipped with the practical tools to remain compassionate over the years in a very high-stress environment.

Having trained thousands of healthcare professionals over the past three years with practical compassionate tools, I have witnessed how these tools empower healthcare professionals to reconnect to their inherent compassion, the very inner calling that drove them to healthcare to begin with.

> “
>
> I have witnessed how these tools empower healthcare professionals

Compassion has saved my own family and myself on more than one occasion and I have seen it transform the lives of many right in front of my eyes. Having cared for suicide survivors and hearing some of them say, "if I felt that one person cared about me I wouldn't take that final step," I dare say compassion saves lives. Also, having experienced code blue and resuscitating patients, sometimes successfully and sometimes not, I declare in any speaking opportunity that when all else fails, compassion prevails. You cannot always save a life, but you can always touch a life.

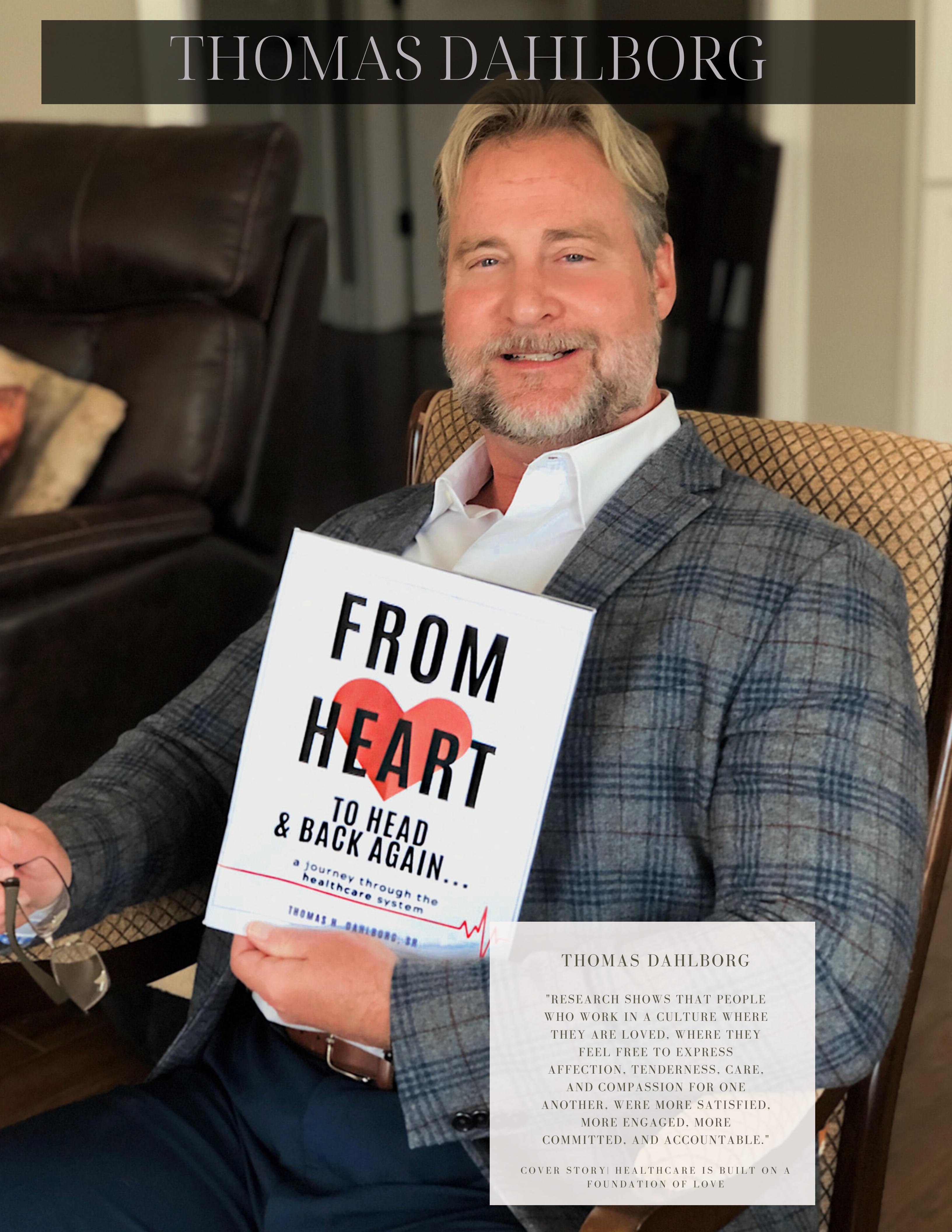
Mandy was discharged that day and as I was preparing her for discharge she said, "I have been hospitalized for three weeks and you were the first person to make me feel human and safe enough to hang up with my mom. All I did was sit and comb her hair and braid it, but for her, that meant the world.

"Compassion transforms thorns into flowers, Compassion transforms hurt into healing." It truly does.

Pantea Vahidi

Compassion Ambassador | Infusing every aspect of the care experience with compassion | Caring for our caregivers | Speaker | Educator | Researcher | Healthcare Consultant
panteavahidi.com

THOMAS DAHLBORG



THOMAS DAHLBORG

"RESEARCH SHOWS THAT PEOPLE WHO WORK IN A CULTURE WHERE THEY ARE LOVED, WHERE THEY FEEL FREE TO EXPRESS AFFECTION, TENDERNESS, CARE, AND COMPASSION FOR ONE ANOTHER, WERE MORE SATISFIED, MORE ENGAGED, MORE COMMITTED, AND ACCOUNTABLE."

COVER STORY| HEALTHCARE IS BUILT ON A FOUNDATION OF LOVE

HEALTHCARING IS BUILT ON A FOUNDATION OF LOVE

- Thomas Dahlborg -

Thomas Dahlborg

Thomas Dahlborg - "I had just been told I had had a heart attack. I was 35 years old. I was scared and alone. "

Complete Heart Block

“Is this Mr. Dahlborg?”

“Yes, Mike. This is Mr. Dahlborg. He is going up to the med/surg floor. The cardiac floor is full tonight and short staffed. I will be joining you for the stroll to pass along all the information they will need.”

“Sounds great. Tom? I see your name is Tom. Do you mind if I call you that?”

“That would be great, Mike.”

Mike spoke to me the entire way to my floor. I was not sure of all that he said as I was still floating in and out of the dark, but between him and my nurse, there was enough Power of Light for me to hold and embrace.

“Tom, they will take good care of you on this floor.” And then Mike whispered, “By the way, this is my favorite floor. You are in good hands. And if you need anything, ask for Linda. Or if you just want to take a joy ride, you just ask them to page Mike, and I will come up and getcha.”

I had just been told I had had a heart attack. I was thirty-five years old. I was scared and alone.

> “
>
> "MIKE SPOKE TO ME THE ENTIRE WAY TO MY FLOOR. I WAS NOT SURE OF ALL THAT HE SAID AS I WAS STILL FLOATING IN AND OUT OF THE DARK"
>
> ”

- Thomas Dahlborg-

HEALTHCARING IS BUILT ON A FOUNDATION OF LOVE

- Thomas Dahlborg -

My bride had just left after a grueling day with me in the hospital to be with our kids. I was afraid I was going to die. I was cold, and a feeling of doom was still creeping in all around me.

Mike from transport asked to call me by my first name, he talked with me about the Sea Dogs (the Red Sox minor league baseball team), and about taking a joy ride. He joked with me and not at me.

"Mike, thank you for caring for me, and about me. I feel a little less scared and some of the darkness of fear was pushed back behind your Light."

My ER nurse, who walked up to the floor with Mike and me, spoke with the floor nurses and ensured all my information was transferred accordingly. She then approached me, "Tom, Linda and the rest of the care team here will take great care of you. Feel better."

"Tom, my name is Linda. Mike told me to keep an extra special look out for you."

"He is a good guy."

"Yes, he is."

> Thank you for caring for me, and about me.

Now this was a true care team. Linda and Mike truly seemed to care for one another. Love one another. And now they were each caring for me. Loving me.

"I will be guiding you into your room in a moment, and then I will help you off of this stretcher and into your bed. Are you going to make it easy for me or will I need to ask for some additional help?" Linda asked with a wink.

Smiling and forgetting some more of my fear and loneliness for the moment, I responded, "I think I got this."

HEALTHCARING IS BUILT ON A FOUNDATION OF LOVE

- Thomas Dahlborg -

When it was time, Linda carefully guided me from the stretcher to the bed while ensuring I did not fall and my IV was not disturbed.

And once in the hospital bed, she reattached the pulse oximeter, the heart monitor feeds, and an automatic blood pressure cuff.

“I will be right back. You relax as best you can. Take natural breaths.”

After I watched Linda leave my room, I took a moment to scan my surroundings. The room was bare. There was nothing here except my bed, a small cabinet of some sort next to me, an array of technology, and … whiteness. “Perhaps to combat the darkness,” I said to myself.

The room felt empty. The room was bright. The room was cold. Ice cold.

“Tom, how is your head?”

Linda had returned.

“It is still pounding. I am not sure if it is from the nitro or me missing my Vioxx.”
“Why are you on Vioxx? I don’t see that in your chart.”

“For joint and head pain. I take it daily. Prior to Vioxx I was taking Naproxen.”

> “
>
> IF SHE ONLY KNEW I JUST WANTED TO GO HOME AND CRY
>
> ”

“Ok. I have the Naproxen listed but not the Vioxx. I will update our chart. In the meantime, I will see what I can do for your head. How is your chest pain?”

“I am okay.”

“Listen. Don’t try to be a tough guy for me.”

If she only knew. If she only knew I just wanted to go home and cry.

“Tom, I need you to be real with me. My job is to take care of you and keep you safe. You need to help me do so. You need to partner with me. Capiche?”

HEALTHCARING IS BUILT ON A FOUNDATION OF LOVE

- Thomas Dahlborg -

Linda was right. We were supposed to be a team.

“Linda, I have been trying to manage this chest pain and pressure for a couple of weeks. Sometimes it has been so painful that I am not able to stand up. And at other times, it has felt like someone was sitting on my chest and everything in between. Right now, I am not at the worst. And if that worst is a ten then I would say my pain is currently at a six and the weight on my chest is like an eight.”

“Very helpful, Tom. Now tell me about your breathing.”

“Since the initial spell, it has been challenging. I feel like my chest can’t expand to get a deep breath. I feel like my lungs are only partially filling up. Even just talking with you is challenging.”

“I am going to apply some more nitro paste on your chest to help alleviate some of your chest discomfort. This will go right over your coronary arteries to help open them up. Unfortunately, this may exacerbate your headache, but we will manage that.”

I replied, “Okay," but I really didn’t want the headache to worsen.

> “The darkness I had felt, and continue to feel, crept closer and closer as it battled the light

With great care, Linda loaded the paste onto what looked like parchment paper and then placed it on my chest over my heart.

“Your chest will feel better shortly. I am also going to give you oxygen to take some stress off of your lungs.”

And with that she placed a clear hose around my head and inserted two mini tubes from the hose into my nostrils.

“Just breathe normal. This will help."

The darkness I had felt, and continue to feel, crept closer and closer as it battled the light of Mike and Linda, and I must have looked stressed again.

“Tom,” Linda said as she sat on the edge of my bed, looked deeply into my eyes, and held my hand firmly, “I’ve got you.”

HEALTHCARING IS BUILT ON A FOUNDATION OF LOVE

- Thomas Dahlborg -

Research shows that people who work in a culture where they are LOVED, where they feel free to express affection, tenderness, care, and compassion for one another were more satisfied, more engaged, more committed, and accountable.

Love, trust, and leading people with a dedication to helping them honor their healthcare calling are keys to achieving the quintuple aim: health outcomes, experience, value, care team well-being, and equity and thus the greater good for all.

And ensuring love, compassion, and caring for one another are the number one priorities in healthcare also leads to a knowing that we will get through any challenge together — and that no one (e.g., doctors, nurses, housekeepers, patients, families, communities) will be left behind.

Mike and Linda clearly felt loved and cared for, and cared about, by their leaders. And they too, exuded their love and their light in how they shared their hearts with all of their patients.

And on that night so many years ago, their love let me know that I, too, would not be left behind.

HEALTHCARING IS BUILT ON A FOUNDATION OF LOVE

- Thomas Dahlborg -

I have learned much over the past forty years in healthcare, and I continue to learn.

From the frontlines of healthcare as a transport aid and a housekeeper, to a wide variety of leadership positions, and also as a patient who was told he would never work again and to get in line for a heart transplant, I have learned.

I have learned the importance of leading with love and compassion and caring, and how doing so positions each of us to find the certainty in the uncertainty and to reassure, to guide and to best support our patients and one another. (Linda showed me firsthand.)

I have learned the importance of relationship and understanding and how truly important it is to not only listen to understand, but to truly listen because we care.

I have learned the power of vulnerability and how when we love one another, we create trust and safety and empower one another to be our authentic glorious selves ever loving, ever learning, ever growing.

I have learned that leading with love, and truly caring and understanding the power of compassion, positions us to have the tough conversations that need to be had for continuous improvement of self and systems and the betterment of others.

> And I have learned (and seen) the ripple effect of love and so much more.

I have learned the power of gratitude, and how gratitude in words must be married to gratitude we share in right-action for others.

I have learned the importance of seeking out and then fanning the flame of good (the Light) and how in doing so together we build a creative and innovative healthcare system which continuously seeks to transform and improve.

And I have learned (and seen) the ripple effect of love and so much more.

My vision for the future of healthcare is a future built on a foundation of love.

HEALTHCARING IS BUILT ON A FOUNDATION OF LOVE

- Thomas Dahlborg -

A future where healthcare is transformed to healthCARING.

Where "value" based care (with its primary focus on funding and revenue) is replaced with "values" based care (with its primary focus on love and compassion and caring and optimal outcomes for all).

My vision for the future of healthcare aka healthCARING is a future where we marry the best science, the best evidence, the best research, the best tools and tactics, with love and compassion and caring for all. Where all have access to the best care – the best caring.

And I envision us all achieving this vision together.

"Together with HEARTchange (with LOVE) we will transform healthcare to healthCARING for All." – TD

Tom Dahlborg

President & CEO
Dahlborg HealthCARING Leadership Group, LLC
Transforming healthcare to healthCARING.
Transforming value based care to values based care.
dahlborghlg.com

HEART TO HEART | ASK ANNA

THCC Interviews Anna Jaworski - Host of Heart to Heart with Anna

Heart to Heart with Anna

CHD Magazine: Anna, you have played such an important role in the lives of so many families impacted by CHD. Not only have you provided priceless information to the CHD community through the various interviews you have completed over the years, but you have developed relationships that have changed lives forever. The work you do makes you a valuable member of many medical support teams.

Year after year, you have been able to bring us inspiration, hope, personal experiences, and points of view from a variety of medical experts and CHD patients and families. We want to tell you we appreciate the work you do to provide the CHD Community with these incredible resources. Tell us, what keeps you motivated?

Anna: This is definitely a labor of love. It's so much fun connecting with different people in the CHD community. I've had a chance to "meet" some people I have admired since childhood (like Olympic figure skater Paul Wylie). I've interviewed some legends in the CHD community (Dr. Edward Bove, Dr. Gil Wernovsky, and Dr. Terry King, to name a few), and I've made a lot of new friends thanks to the podcasts.

I think what keeps me going, though, are the comments I get from people who let me know the podcast made a difference to them.

CHD Magazine: Can you give us an example of what you mean?

Anna: Sure! I once did a program about feeding tubes. I was so lucky that my Heart Warrior never needed a feeding tube, but after talking to a lot of friends who did have children with feeding tubes, I knew that those devices, while life-saving, were also life-inhibiting.

I had this outstanding Heart Mom, Christie Saunders, who came on the program to talk to me about her son, Bennet, who was born with Hypoplastic Left Heart Syndrome (HLHS). At five weeks old, he underwent a Nissen fundoplication and G-tube placement because of severe gastrointestinal issues. After many tears and much

struggle, he was successfully weaned from his tube when he was eighteen months old. She and Sabine Marinschek, a clinical psychologist and "NoTube" specialist working with babies and children with feeding tubes, shared how they worked together to help Bennet.

An episode following Christie and Sabine’s featured Chris Perez who was a dad to twins. One of his twins was born with HLHS. We became friends and at one point, when I was planning a vacation, I was looking for a Guest Host do a few shows for me, Chris offered to fill the role. I was so appreciative of his help.

He later told me that the feeding tube episode with Christie had changed his life and he wanted to give back. He and his wife listened to the episode multiple times. No doctor had ever talked to them about an “exit strategy” for his son's feeding tube before. Armed with the knowledge they gained by listening to Christie and Sabine, they finally felt they could wean their son off of his feeding tube.

That’s what keeps me excited about helping people share their stories. You just never know how one of these podcasts might help someone else.

CHD Magazine: That's amazing. You are touching so many lives! I have to ask. It sounds like we aren't the only ones who think you are doing an incredible job. I heard your program has been nominated for an award. Can you tell us a little about that?

> That's what keeps me excited about helping people share their stories.

Heart to Heart with Anna

Anna: Yes! It’s so exciting to be nominated, and also exciting to know that people in our community will have the opportunity to support the nomination by voting for us.

The most recent award we’ve been nominated for is People’s Choice Podcast Awards by New Media Productions. What I really like about this award is that even small podcasts, like the ones sponsored by Hearts Unite the Globe (HUG), are considered.

The process is unique. First, producers register their podcasts. Next, the podcasts are nominated by listeners. After the nomination process, judges select which podcasts move forward to the voting round. That happened on August 7th this year.

I am thrilled to say that all three of the HUG podcasts were nominated — in the health category “Heart to Heart with Anna: A Podcast for the CHD Community,” in the People's Choice category “Bereaved But Still Me,” and in The Spanish Language Podcast category “Guerreros Del Corazon.”

CHD Magazine: Congratulations! Correct me if I'm wrong, but this isn't the first time one of your HUG podcasts have been nominated, is it?

Anna: No, we’ve been nominated in the past and have even made it to the final slate! “Heart to Heart with Anna” and “Bereaved But Still Me” have also been nominated for the WEGO Health Awards with “Bereaved But Still Me” making it to the finals! This was quite an honor!

CHD Magazine: This is all very exciting. How can we vote for you?

Anna: We’ll see if People’s Choice Podcast Awards select our podcasts. Voting happens at www.podcastawards.com from August 8th - September 13th. I hope people will vote for the podcasts that make the final slate. The winners will be announced Live on September 30th at 6 PM PST at the Podcast Awards Ceremony on International Podcast Day.

CHD Magazine: We are thrilled that the work you are doing is being honored in this way as it has truly been an honor to get to know you and your podcast programming. You have so many amazing stories to share.

Anna: I truly feel called to do this.

CHD Magazine: Given the theme for this month's magazine, I would be remiss if I didn't mention the story of the mom from Africa - the one you shared with us in our Heart Month 2022 issue.

Anna: Yes, she reached out to me after hearing my show.

CHD Magazine: Her son needed surgery to survive and she didn't have the resources to get him the help he needed.

Anna: I know, it was heartbreaking.

CHD Magazine: Well, she sure did reach out to the right person because you connected her to the doctors, to the resources, and it saved her son's life!

Anna: These are the reasons I will keep doing what I am doing and part of why the HUG network means so much to me.

CHD Magazine
with
Anna Jaworski

Heart to Heart with Anna

Join us in our next issue as we hear more from Anna Jaworski from Heart to Heart with Anna. Do you have questions for Anna? Submit them on our website for our next interview!

Heartsunitetheglobe.org
BabyHeartsPress.com

VIETNAMESE CARAMELIZED & BRAISED CATFISH

Here is one of my favorites

Amy M. Le

VIETNAMESE CARAMELIZED & BRAISED CATFISH

AMY M. LE

Vietnamese Caramelized & Braised Catfish

Amy M. Le

Vietnam is known for its rich culture, traditional ao dai dresses, and amazing foods. One of the best comfort foods is braised catfish in a clay pot, served with rice and pickled vegetables to balance the sweet and salty flavors of the fish. It is traditionally cooked in a clay pot but in modern times, the Vietnamese braise the fish in a large saucepan. Enjoy this recipe from Snow's Kitchen: A Novella and Cookbook written by Amy M. Le.

Ingredients:

2 pounds catfish filets
3 tablespoons salt to clean the fish
3 tablespoons oil
6 cloves garlic (minced)
1 small onion (minced)
1 bunch green onions (chopped)
2 teaspoons salt
2 teaspoons ground black pepper
1 tablespoon thick caramelized sugar or thick soy sauce
3 tablespoons fish sauce
1 can coconut soda, water, or Sprite

Other:

chili peppers (sliced) or flakes
large clay pot (or a large saucepan will do)

Sides:

Rice
Pickled veggies (mustard greens or Napa cabbage)
Stir-fry vegetables
Broth-based soup
Sliced cucumbers and tomatoes

Delicious

Vietnamese Caramelized & Braised Catfish

Amy M. Le

Directions:

1. Sprinkle 3 tablespoons of salt on the catfish filets and rub the salt all over the fish. Rinse in warm water and pat dry with a paper towel.
2. Marinate the catfish in salt, black pepper, fish sauce, and thick caramelized soy sauce for five minutes.
3. In a large saucepan, heat the oil on medium-high heat.
4. Open the windows and turn on the fan. It will smell pungent but I promise the braised catfish will be so delicious.
5. Stir-fry the garlic and onions for 2 minutes. Reduce the heat to medium.
6. Add the catfish filets to the saucepan. Do not crowd the pan.
7. Pour in the coconut soda, water, or Sprite and cover with a lid. Simmer for ten minutes.
8. If anyone asks what the smell is, blame it on them, your pet, child, or spouse.
9. Gently flip the catfish filets over and simmer another ten minutes with the lid on, over medium heat.
10. Taste the sauce. It should be a balance of sweet and salty. Add salt or sugar as needed.
11. Remove the lid and continue simmering. Spoon the sauce over the fish repeatedly for ten minutes.
12. Garnish with green onions. If you like it spicy, add chili peppers or chili flakes.
13. Turn off the heat, put the lid on, and let it continue to cook for another 5-10 minutes.
14. Optional – transfer the catfish and sauce to a clay pot.
15. Serve the catfish with a bed of rice or your favorite sides!

From the Kitchen
of Amy M. Le
Amy-m-le.com

Amy M. Le

From the Kitchen
of Staci Mauney

Stacimauney.com

Ground Turkey & Veggie Stir Fry

Staci Mauney

I've dealt with migraines for over 25 years. For almost two decades, I had up to 25 migraine days per month and took daily medication to reduce the number and severity of those migraines. After working with a neurologist, the number of migraine days went down to less than 15 per month (15 is the number considered to be chronic), and eventually, I had just two to six migraine days each month—a fantastic reversal.

But the last few years have been difficult for all of us. Stress is one of many migraine triggers, and I noticed an increase in migraine days—sometimes as many as 14 per month. When I started skirting the line to be considered a chronic sufferer again, I decided it was time to make a change. While I'm not opposed to taking medication again if I need it, I wondered if there might be another option.

I joined a health coaching group called "In the Balance" that focuses specifically on helping women with migraines take charge of their health and make lifestyle changes that include water intake, food choices, sleep routines, and exercise, just to name a few. I've completed the first month of a four-month program and have already seen a decrease in the frequency of my migraines by increasing my water intake and making healthy food choices.

Ground Turkey & Veggie Stir Fry

Staci Mauney

While I've eaten a healthy diet for many years, I do like my carbs and sugar! Since I'm working to reduce both my carb and sugar intake, I decided to try this low carb, low sugar meal presented by the leaders of In the Balance. This heart-healthy meal is a good choice for anyone, and the flavor packed into this simple meal makes it a keeper.

Recipe:

1/2 cup brown or jasmine rice
1/2 lb. extra lean ground turkey
1 1/2 tsp. extra virgin olive oil
1 bell pepper (medium, diced)
1/2 yellow onion (chopped)
2 large garlic cloves (minced)
2 cups baby spinach
1 tbsp. tamari

Cook the rice according to package directions. (I use brown rice cooked in low-sodium chicken broth for more flavor.)

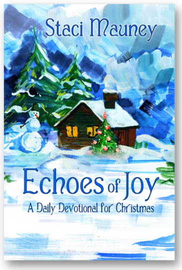
Over medium heat, add the turkey to a pan, breaking it up as it cooks. When it is cooked through, transfer the turkey to a bowl or plate and drain any excess drippings from the pan. Set aside.

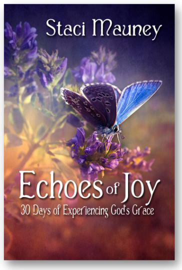
Pour the olive oil into the same pan. Add garlic, bell pepper, and onion, stirring often, for four to six minutes or until the vegetables are tender. Add spinach and cook until it has wilted. Add the cooked turkey back to the pan and stir to combine. Stir in the tamari (I used low-sodium soy sauce) and continue to cook for another one to two minutes or until the tamari has been absorbed into the meat and vegetables.

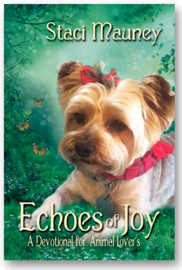
Serve over rice and enjoy!

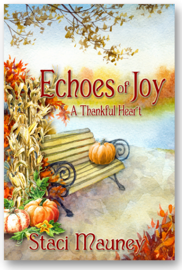
Staci Mauney

From the Kitchen
of Staci Mauney
Stacimauney.com









JR'S KINDNESS

ANNA JAWORSKI

“You need to go home and rest,” J.R. said kindly.

“How can I rest when the doctor told me that Alex would most likely die before his chance for surgery?” I asked the nurse.

“His case is the first one tomorrow morning, and it’s already after midnight. I promise I’ll call you if anything changes.” Turning to my husband, J.R. said, “Please take her home and bring her back at 6 AM.”

Frank dropped me off at the front doors of the hospital bright and early the next morning. I ran to the elevators but they seemed stuck on upper floors. Impatiently, I dashed the four flights up the stairs instead of waiting. By the time I was on Alex’s floor, my heart was racing and I was out of breath. I dashed down the hallway and then J.R. blocked my path. “Good morning,” he said smiling.

I must have looked panic stricken because he didn’t even wait for a reply from me. “I have good news and bad news,” he said.

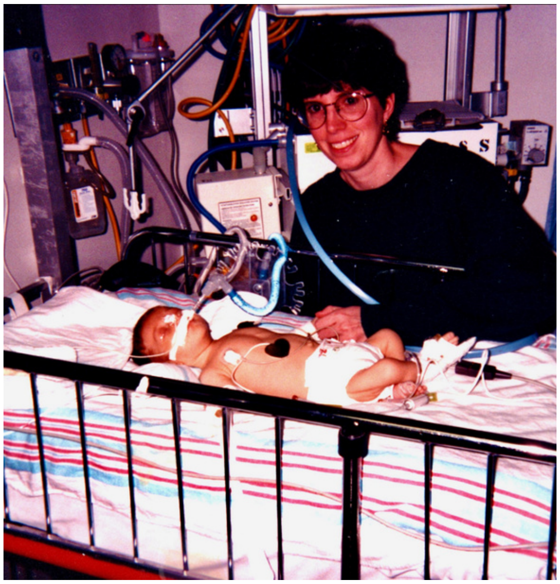
“Bad news? What’s the bad news?” I asked.

“I didn’t get a chance to bathe Alex. The good news is that he had an uneventful night and he’s doing fine.”

My heart was finally slowing down as I followed J.R. into Alex’s bay. He handed me a basin of warm water and a wash cloth. As I cleaned Alex’s chest, I knew it would be the last time I saw it without a scar down the center. When I was done, J.R. took away the basin and told me to stand with my arms out.

JR'S KINDNESS

- Anna Jaworski -



I did as told and he picked Alex up and gently laid him in my arms. By this time Frank was right behind me. The night before I had told J.R. that my arms literally ached to hold my baby. I had told him that I had been caring for Alex for two months, that Frank and I knew something was wrong but nobody believed us — not the newborn follow-up nurses, not the lactation consultants, and not the pediatrician. Now our baby was facing his first of three scheduled surgeries and his odds for survival were abysmal — 5%, the surgeon had said. Five percent chance of survival.

I bent my head closer to my sleeping boy and kissed his head. “You have to be strong,” I whispered. “I can’t imagine my life without you. I love you, Alex.”

I realized that I was being selfish and asked Frank if he wanted to hold Alex, too, but he just stood behind me and held me.

My son is now twenty-seven years old and that scene is from October 1994 but it still makes me cry just thinking about it. I knew it might be the very last time I would hold my son alive. J.R. gave me something to hold onto during that long eight-hour surgery. I could still smell my baby, feel my baby, and I knew I’d had a chance to tell him that I loved him before he went into the operating theater for the battle of his life.

Tender mercies such as J.R.’s decision to let me bathe my baby and hold him, even though he was on a ventilator, are kindnesses too rich for words. They are felt in the heart and remembered in the mind forever.

FAST FORWARD

…

MOVING TOWARD NORMAL

-ANNA JAWORSKI-

MOVING FORWARD

- Anna Jaworski -

We were very blessed to have an amazing surgeon, fantastic doctors, and the most attentive nurses taking care of our son after his congenital heart defect was diagnosed and plans for surgery were detailed. I could probably fill a book with story after story of kindnesses shown to me by people who worked at the hospital, but certain kindnesses really stand out.

One morning, several days after Alex's surgery, I stood by the window looking out. The image outside looked like a scene from a movie. People hustled to and fro, often carrying cups of take-out coffee. It was autumn in San Antonio, so most people wore a light jacket and they carried satchels or purses swung against their hips as they hurried toward the front doors of the hospital. *How can everything seem so normal when it's anything but normal here?* I wondered. *Don't these people know that there's a sick baby here? That my baby could die?* It seemed wrong for the world to carry on as usual when I knew my world could fall apart in a heartbeat.

> I KNEW MY WORLD COULD FALL APART IN A HEARTBEAT
>
> -ANNA JAWORSKI

I heard a noise and turned around. "Good morning," Julie said cheerily. I walked back to my son's bedside watching the nurse take vitals signs and chart the numbers. She was smiling and seemed so happy. "Look at him!" She said proudly. "He's doing so well."

I needed to hear those words. Alex was still on paralyzing drugs. He was still in a medically-induced coma. I hadn't seen his eyes open in six days. This was good?

"It's time to give him a bath," she said as she busily gathered the equipment she needed.

"Can *I* do it, Julie?"

She stopped what she was doing and turned to look at me.

"I have been giving him baths for two months," I explained.

She nodded and brought me a basin and a washcloth. I looked at Alex dubiously. In this hospital in the 1990s, when a baby had a medial

MOVING FORWARD

- Anna Jaworski -

sternotomy, the doctors put a long bandage on top of it covered in iodine. That meant that Alex's chest was mostly brown.

I started cleaning Alex's chest and the water quickly went from clear to brown. Julie gently removed the bandage and I kept cleaning. After the bandage was removed, I could see dried blood on Alex's chest. I never was good with blood and my hands shook a bit. It was the first time I saw my son with his brand new scar.

Julie took the basin from me quickly and then grabbed my arm. She guided me to a chair and smiled. "We did it!" Then she said quietly, "Are you okay?"

I nodded. "I didn't pass out," I said with a smile.

"You did great," she said as she emptied the basin.

I'm not sure Julie knew how important it was for me to give Alex a bath. I had started to lose confidence in myself as a parent. Just when I was beginning to wonder, "Can I do this?" Julie announced it was bath time.

I knew from that minute forward that I could handle taking care of Alex and that I wasn't alone. There were others there to help me — to make sure I didn't falter. Her can-do attitude and cheery disposition took away some of the dark clouds I felt were looming overhead. She went on to tell me just how well Alex was doing, and in a soft moment of encouragement, she filled my heart with hope.

Maybe everything was going to be alright after all.

Anna Jaworski

Author of The Heart of a Father, The Heart of a Mother, and soon to be released, The Heart of a Heart Warrior. She is the Executive Producer of Heart to Heart with Anna, and the Bereaved but Still Me Podcast shows. Anna is also the CEO of Hearts Unite the Globe and Co-Founder of The Heart Community Collection. Printed by Permission of Baby Hearts Press.

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Time Together

LAUREN AND MATT BACKE

Hands down! Meeting incredible people - doctors, nurses, fellow heart families - and learning about amazing organizations has been one of the biggest positives for our family that has come out of my daughter, Everly's, CHD journey.

We have been blessed to be surrounded by truly wonderful and supportive family and friends, but there are a few organizations that have shown us so much compassion and support over the past five years, and for that, we are so grateful.

Organizations like Brave Gowns that get kiddos into soft, comfortable gowns that provide privacy, LJ's Healing Hearts that provides financial assistance and well-being support to CHD families, The American Heart Association: Kids Heart Challenge that helps teach students about being healthy and also raises funds for life-saving heart research, and so many more that are near and dear to our heart.

One organization that we learned about during Everly's prenatal diagnosis was the Ronald McDonald House Charities.

Time Together

LAUREN AND MATT BACKE

We are lucky that we have a great support system of family and friends willing to help; however, without Ronald McDonald House Charities, Everly's three open-heart surgeries which she had before turning one-year-old - coupled with other procedures, surgeries, illnesses, and hospital stays, would've been far more difficult for us.

We live sixty-five miles away from Ev's primary hospital which is about two hours each way with our Chicago area traffic.

For five and a half years it was just our little family of three. My husband, Matt, my son, Jack, and myself. It was rare that we ever spent time away from Jack, other than maybe a night or two, when suddenly we were faced with the reality that we didn't know how many days and nights it would be before I would get to see him again. Ronald McDonald House gave us the opportunity to be able to spend time with both kids.

Everly was born before the pandemic which allowed Jack to visit her inpatient frequently. Ronald McDonald House gave us the opportunity to take turns staying with each of our children.

Matt would bring Jack up on the weekends and I'd get to spend the night with Jack at RMHC while Matt would spend the night in the hospital with Everly.

> "RONALD MCDONALD HOUSE GAVE US THE OPPORTUNITY TO SPEND TIME WITH BOTH KIDS."
>
> - Lauren and Matt Backe -

Time Together

LAUREN AND MATT BACKE

Everly's need for a second open heart surgery came on somewhat unexpectedly between Thanksgiving and Christmas. Everly spent the majority of November and December inpatient, which meant a lot of traditions that Matt, Jack, and I were used to doing together were becoming things that just Matt and Jack did together and/or Grandma, Grandpa or family and friends did with Jack. This also meant a lot of online ordering for Christmas gifts from a hospital room with directions for Grandma on which wrapping paper to use on which gifts, etc. Thank goodness for Grandmas and Grandpas, truly.

While we sat in the hospital, I wondered if Everly would make it home for Christmas and how/where we'd celebrate and where we'd have Santa come. That Friday night before Christmas, My husband, Matt, and son, Jack, came up for the weekend and we were able to be together as a family of four again.

From Everly's hospital room you could see Jack's room at RMHC and I realized that it didn't matter where we celebrated or where Santa came, we could all be together. RMHC did an incredible job of transforming the house into a winter wonderland. They hosted a party complete with Ronald McDonald himself and Santa and Mrs. Claus. Jack loved it! And I loved that I still got to see him visit Santa that year since I'd been living in the hospital with Everly for the past month.

Watching one child struggle for her life and also being away from your other child while feeling like he needs you, too, was really hard.

Time Together

LAUREN AND MATT BACKE

We know that Everly will have another surgery in the near future and while we realize that hospital visits will be different because of COVID, I'm not as upset about being away from Jack as I was leading up to Everly's birth. I know that because of RMHC we will be able to see each other, and I will be able to spend time with him.

Because of RMHC, I had a place to eat, food in the fridge with my name on it when I finally made it back to shower at 2am, and a place to get an hour or two of sleep. We are so thankful for organizations like RMHC that think of so many ways to help make a really difficult time a little bit easier.

When you walk into RMHC, you feel like you are walking back home. Jack loves RMHC and has incredibly happy memories of it. As a result, he likes to do things to help RMHC so more families like ours can stay close together when a child is hospitalized. He's recruited his family, friends, and community members to collect pop tabs. Pop tabs are recycled by the RMHC's recycling partner, United Scrap Metal.

The charity receives the market value of the recycled materials, plus a charitable match from them. Now that Everly's older, she also helps with the pop tab collecting and weighing. They've collected over 2 million pop tabs so far! Jack also likes to bring family and friends back to RMHC to cook meals and cookies for families staying there. He can't wait to take Everly there one day soon to cook a meal as well. She's looking forward to that too!

Lauren and Matt Backe

AN UNEXPECTED LECTURE HALL

FROM A HEART DAD & NURSE ANESTHETIST

- Frank Jaworski -

My son, Alex, experienced his second hospitalization for surgery when he was ten months old. My wife, Anna, and I had a plan for taking care of him in the hospital - as much as we could. Even though we knew we would mostly be observers, we felt that one of us should be with him all the time, so after the day of surgery we took shifts. Anna would be with him from 7 a.m. to 7 p.m. and I would take the other half of the day, the night shift. I was accustomed to this as back at home I was working in the adult cardiac ICU on night shift.

While Anna was at the hospital on days, our other son Joseph would be with me (when I wasn't sleeping) and my mother-in-law, who we were staying with in San Antonio, for the hospitalization.

Anna would come to the hospital at 7 a.m. with Joseph, and I'd come down from the ICU and meet them in the cafeteria for breakfast. Then, Anna would go up to the unit and I'd take Joey home. Reverse the process when we met for dinner at 7 p.m.

> "
> AS IS USUAL IN THE ICU, AROUND 3 A.M. THE PARADE WOULD START, EVERY HALF HOUR OR SO SOMEONE WOULD COME TO HIS ROOM...
>
> - Frank Jaworski
> "

This way, one of us would be with Alex and one of us with Joey all the time. On the night shift I had permission from the nurses to stay in Alex's room, and I'd mostly sit at the foot of the bed and read to him if he was awake, or when he wasn't (most of the time) I'd talk with the nurses and look over his chart in fine detail. I'd review the day's lab results, compare x-ray reports and read the orders for the next day to see what was coming up. As an experienced adult cardiac ICU nurse, I knew enough information to ask the right questions.

As is usual in the ICU, around 3 a.m. the parade would start, every half hour or so someone would come to his room to draw blood for labs, shoot x-rays, or take an EKG. After that, the med students would show up first, checking the morning's results and looking in on Alex, followed by the residents and finally the staff surgeon and the cardiac surgery fellows. The staff surgeon, Dr. John Calhoon would be followed by all the rest of the residents and students who hung on his words and tried to answer his questions.

Several days after surgery, when Alex was off the ventilator and doing well Dr. Calhoon stopped to greet me and ask what kind of night Alex had had.

AN UNEXPECTED LECTURE HALL
FROM A HEART DAD & NURSE ANESTHETIST

- Frank Jaworski -

He did this every morning during rounds. This was purely courtesy as he already knew, but he was that nice of a person.

Then he said “Hey, Frank, I was about to walk the students over to one of the classrooms to give them a lesson in the basics of pediatric cardiac surgery, would you come along?” I said sure, though I didn’t know why he wanted me there. When we got to the classroom I sat in the back as Calhoon talked for about ten minutes, occasionally asking questions of the group to see what they knew.

Then he asked me a question about Alex’s care specifically related to one of the areas he’d just talked about. After I responded, he asked, “Frank, would you come up to the lectern? I want you to give them the parents view of this process.”

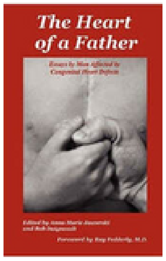
I was surprised, but I was tired and caught off guard, so I agreed and went to the lectern. I started by explaining my background as an ER and ICU nurse and how I understood some of what was being done to Alex but I learned more every day. I don’t remember all that I said. The students and residents asked some very good questions about how my wife and I felt about Alex’s care and how well the staff communicated with us. They asked if I had any advice for them in dealing with parents. I told them to give parents all the information they ask for and take the time to explain things when asked. I also told them not to tell parents more than they ask for, because it could be very scary, and to be aware that some of the things the young doctors saw as simple and normal could be terrifying depending on what words they used.

> They asked if I had any advice for them in dealing with parents.

When I was done, Dr. Calhoon thanked me and shook my hand. I went back to the ICU and he, and the cloud of followers, went on their way.

I believe that he asked me to participate in that lecture for two reasons. I think he knew, that because of my background, I was a medically informed observer serving in the role of parent, and believed I might have something useful to say. I also think he wanted me to be distracted from Alex's needs just for a while, to regain some feeling of control over the situation by giving my feedback where it might help. I feel that he was doing me a favor.

We were amazingly lucky to have Dr. Calhoon taking care of Alex, both for his skill and knowledge, and his compassion. He is a great example for other doctors to look up to.



Frank Jaworski

HEAR MORE FROM FRANK IN HIS CONTRIBUTION TO
THE HEART OF A FATHER

BABY HEARTS PRESS

MEET THE TEAM

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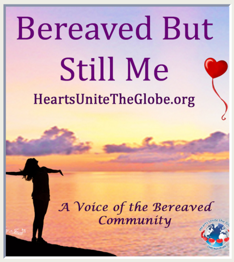

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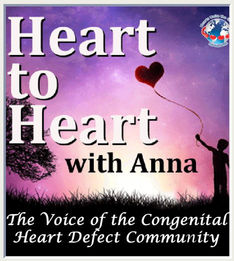
HEALING HEARTS
VIETNAM

BOOKS THAT HEAL

heart like a mother



Kikilishop

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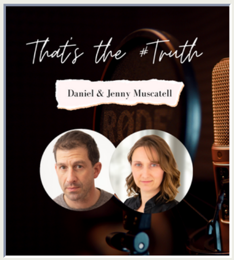

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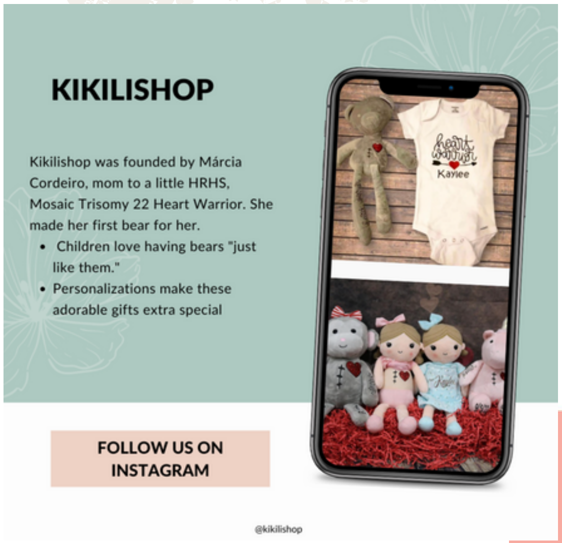
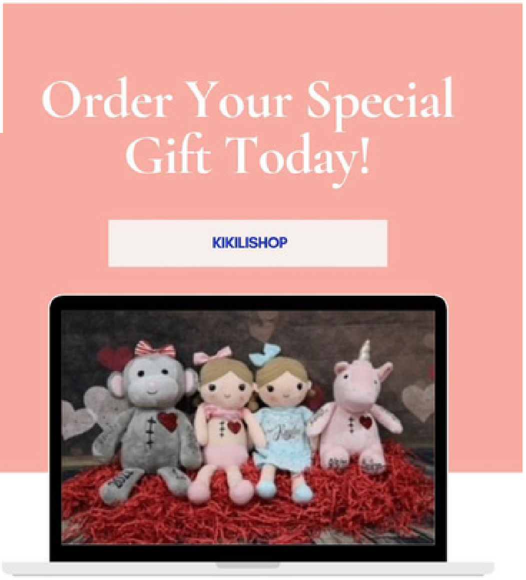


KIKILISHOP

Kikilishop was founded by Márcia Cordeiro, mom to a little HRHS, Mosaic Trisomy 22 Heart Warrior. She made her first bear for her.

- Children love having bears "just like them."
- Personalizations make these adorable gifts extra special

We have been so inspired by these gift designs specially made for those affected by CHD.



Order Your Special Gift Today!

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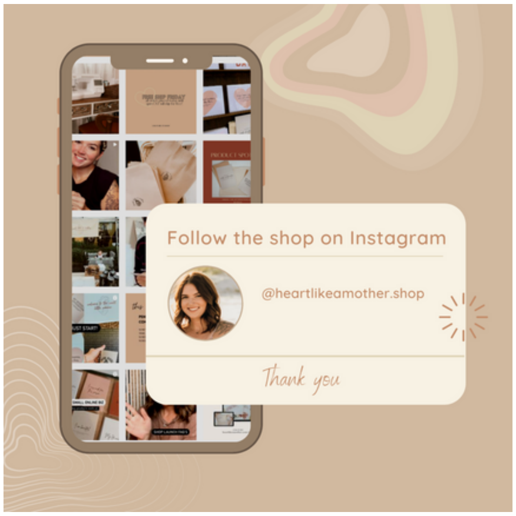
These collections are beautiful. We hope you enjoy the assortment of personalizations that come with many of these products.

Visit our website today to order your personalized gift!

Gift Shop

If you're shopping for the perfect gift for your heart warrior family, we recommend these precious selections.

Heart Like a Mother has created these beautiful Mommy and Me affirmation cards. A great addition for any hospital stay basket, or any day that needs a pick-me-up.



Little Hearts
soap shop

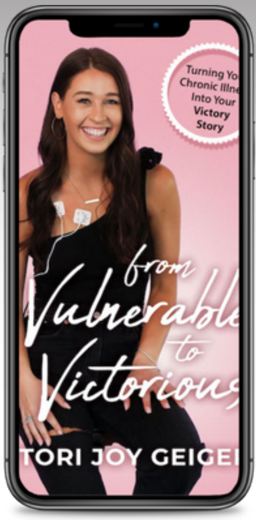
Connecting family, friends, and loved ones in order to show love and support to little warriors fighting big battles. Great for fundraising, unity, and awareness.

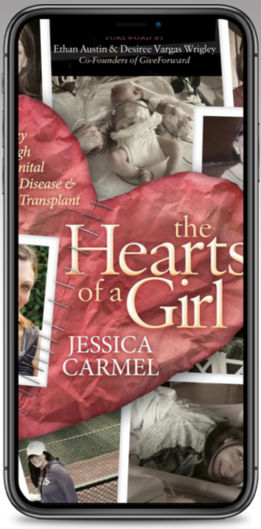
When you see this bracelet on your wrist, please say a prayer and send some love to (Warriors' Name Here)

#loveforWarriorsNameHere

THE PERFECT GIFT

just for you





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Engaging

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Heartfelt Encouragement

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Messages of Hope

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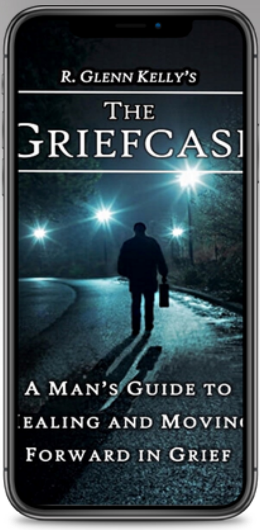
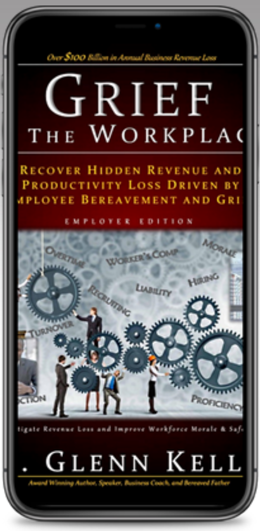
Grief Support





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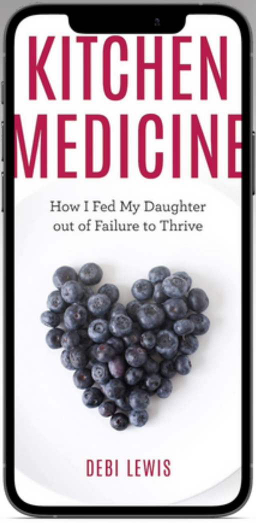
Resources



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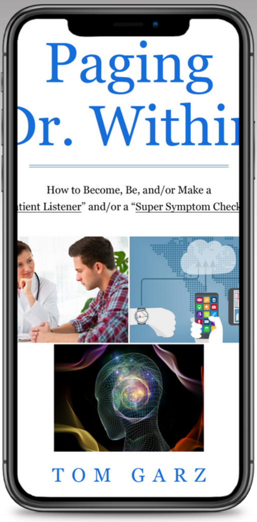

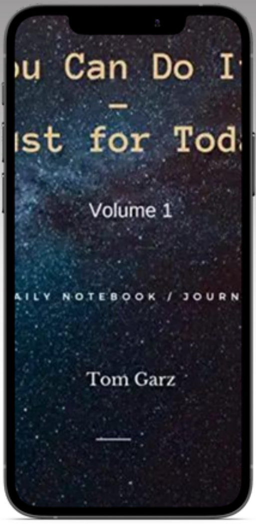

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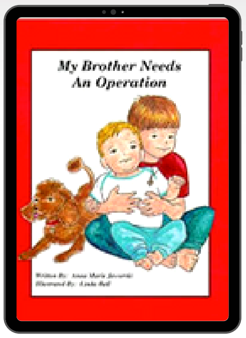
Childen's Books



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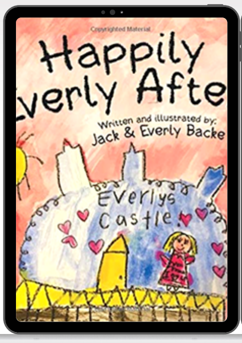

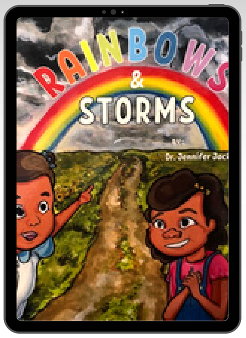

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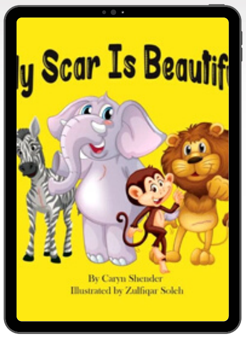

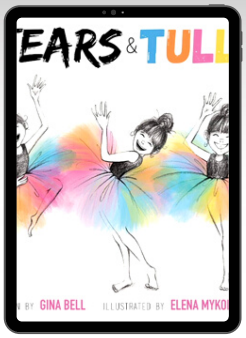

The Heart Community Collection

SUBMISSIONS

At CHD Magazine™ we believe our voices are stronger together. We welcome new articles and ideas from writers, bloggers, and enthusiasts.

Articles should be about 500 to 1,000 words in length and free of grammatical and spelling errors. Accepted pieces will be published in our magazine and may be syndicated on our social media pages. We will be in touch if we choose to publish your piece.

Authors retain rights to their pieces, which may be published elsewhere. If you are interested in writing for the magazine please submit your article for consideration via www.theheartcommunitycollection.com. We would love to hear from you. Because of the number of submissions we receive, we are not able to respond to all inquiries for publication.

Thank you for your interest in writing for us.

We are inspired daily by the voices, and more importantly the heart, behind those voices within our community of caring. It is our mission to provide quality resources to those impacted by congenital heart disease, to raise awareness, and to bridge the gaps of isolation caused by living with a chronic illness.

As a publication we do not advocate for any specific ideology, but consider this platform one of raised voices and personal stories shared with the intention of helping others through difficult roads. Letters to the editor are encouraged via our website and will be considered for publication in future prints.

CONTACT US TODAY
THEHEARTCOMMUNITYCOLLECTION.COM

TEAM/PARTNERS/COMMUNITY

Thank you

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CHD MAGAZINE™

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