AMELIA'S STORY

A Mother's Fight. A Daughter's Survival.
The Mission That Was Born From Both.

INVISIBLE WARRIORS

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Nobody Fights Alone.

CHAPTER 1

Before She Was Even Born, I Knew.

This story doesn't start in a hospital room.

It doesn't start with a diagnosis.

It doesn't start the night everything changed.

It starts before any of that.

It starts with a mother who knew something was wrong before she could even name what it was.

Getting pregnant with my daughter was not easy. I had endometriosis. I had surgery to treat it. And I was told that if I was ever going to have children I needed to try immediately. So we did. And about eleven months after that surgery I found out I was pregnant with my first child.

I was terrified. I was grateful. And from the very beginning something felt off.

My entire pregnancy I was sick in a way that nobody took seriously. Not normal first trimester nausea that fades. I mean couldn't keep anything down, gagging at everything, throwing up constantly, every single day from beginning to end. I lost income because I could not work. I could barely function. I told my doctors over and over again that something didn't feel right.

I was told to eat more protein. I was told to try nuts. I was sent home every single time.

What I needed was someone to look closer. What I got was dismissal.

Heart defects run in my family. My mother had been diagnosed with a congenital heart defect. My brothers had been diagnosed with CHD in their teens. It was documented. It was in my medical records. It was right there in black and white before a single prenatal appointment ever took place.

I asked my doctor for specific genetic testing. I wanted to know if this could be passed down. I wanted to catch anything early if it could be caught.

I was told no. Not because the test didn't exist. Not because it wasn't possible. But because my doctor decided there was no reason for it and cited my insurance as the reason it couldn't be done.

Nobody ever asked me what I was willing to do to protect my child. Nobody offered me the option to pay out of pocket. Nobody gave me the chance to decide for myself. The decision was made for me.

At my anatomy scan — the appointment that exists specifically to check that everything is developing correctly — the doctor wasn't even prepared for me to be there. She didn't know I was coming for an anatomy scan. She had to cancel another patient. She rushed through my appointment.

And toward the end of my pregnancy my last sonogram noted something concerning. A diminished head measurement. Noted. And then ignored.

Past 40 weeks my doctors put me on non-stress tests because my daughter wasn't moving enough. I had been reporting this. They finally listened enough to put me on monitoring. But even that monitoring couldn't get clear results half the time.

At my appointments they struggled to even find her heartbeat with a Doppler. It took them a long time to locate it every single time. Something that should have raised concern. Something that should have prompted more questions. Instead every appointment was five minutes. She's healthy. She's fine. Go home.

I failed the non-stress tests. Multiple times. Every time I failed I was sent to the emergency room. And every time I got there they monitored me and sent me home. No additional sonogram. No deeper investigation. No one asking why this baby kept failing.

The ER can only do what the doctor orders. And the doctor never ordered enough.

> ***A mother feels things that don't show up on paperwork. A mother notices things that a five minute appointment will never catch. A mother knows. And I knew.***

I just didn't have anyone willing to listen long enough to find out what I knew.

She was born on September 26th, 2022. And from the moment she entered this world the signs were there. She came out blue. Her breathing wasn't right. Her father asked — "Is she supposed to be breathing like that?" "That's normal with a C-section" is what they said.

She couldn't latch. She wasn't waking up to eat. She had blue lips. Blue hands. Blue feet. Blue fingernails. We were still in the hospital. Every sign was right there. In plain sight. In front of every person whose job it was to catch it. And not one of them did.

We went home. And I kept watching. Kept reporting. Kept showing up to every appointment with every concern I had. And I kept being sent home.

The system failed my daughter before she ever had a chance to fight. And she had no choice but to fight anyway.

Follow Invisible Warriors — Chapter 2: The Day She Was Born.

CHAPTER 2

The Day She Was Born

I wanted a natural birth. That was important to me. Not because I had something to prove. Not because I didn't understand pain. But because it was my body, my baby, and my choice.

What happened instead was something I never could have prepared for.

The pain I was in during labor was not just the pain of bringing a child into the world. Something felt wrong. Deep in the same gut that had been telling me something wasn't right for nine months.

That gut was screaming. And instead of listening to it the doctors decided my pain was a problem to be managed. Not a signal to be heard. A problem to be managed.

They pushed an epidural. I said no. They pushed again. I said no again.

> ***And then they said something that I will never forget for as long as I live. They told me that if I didn't calm down something could happen to my baby.***

My daughter — who was already fighting to stay alive inside my body without any of us knowing it — was used as a threat to force me into compliance. They weaponized my love for her to silence me. And it worked.

While all of this was happening the doctor who was supposed to be delivering my daughter was asleep on the couch.

My partner was the only one in that room fighting for me. They told me I was at 10 centimeters. I was at 9.5. They called the doctor in to pop my water before I was even ready. Amelia panicked. Her heart rate raised. And suddenly everything moved very fast.

The epidural dose they gave me was extremely high. I lost feeling in my legs completely. I couldn't push properly. I was rushed into an emergency C-section.

The natural birth I had wanted was gone in an instant. Not because my body failed. Not because I gave up. But because a series of decisions were made around me and to me without my full consent while my doctor slept on a couch down the hall.

She was born on September 26th, 2022. And the moment she came out something was wrong.

She was blue. Her breathing was not right. "Is she supposed to be breathing like that?" "That's normal with a C-section" is what they said.

> ***But it wasn't fine. It was never fine. And deep down I think I already knew that.***

She couldn't latch. She wasn't waking up to eat. Blue lips. Blue hands. Blue feet. Blue fingernails. We were still in the hospital. Not one of them caught it. Not one.

We were sent home. With a baby who was blue. With a baby who couldn't eat. With a mother whose gut had been screaming for nine months. And a discharge paper that said she was fine.

CHAPTER 3

The Year Nobody Listened

We came home with a baby who was blue. A baby who couldn't eat. A baby whose breathing wasn't right. And a discharge paper that said she was fine.

So I did what every first time mother does. I trusted the doctors. I showed up to every appointment. I raised every concern. And I waited for someone to finally tell me what was wrong. That someone never came.

From the very beginning Amelia struggled in ways I couldn't understand. She cried constantly. She slept more than felt right. She couldn't hold her head up at six or seven months old. She wasn't crawling. She wasn't reaching the milestones I expected.

> ***The self doubt that creeps in when nobody validates what you are seeing is something I would not wish on any mother. I thought I was going crazy. I questioned everything I was doing. I carried guilt that was never mine to carry.***

Because every single time I brought my concerns to a doctor I heard the same thing. Babies develop in their own time frame. She's fine. Go home.

At around eleven months old her pediatrician finally had concerns. Not about her heart. Not about her breathing. About her weight. She wasn't gaining enough. So the doctor told me to add an extra scoop to her formula.

That was the solution. An extra scoop and some solids. For a child who was in heart failure.

> ***They were so focused on the scoops and what she was eating that they never once asked why she wasn't gaining weight in the first place. A child in heart failure cannot grow properly. Her weight was a symptom of what was destroying her from the inside.***

At eleven months old her pediatrician called us. She said she needed to see Amelia back for a weight check. We told her we wanted a second opinion and asked if we could wait until we moved

to Florida.

Those words triggered the threat. She told us that if we didn't come in she would be forced to call DCFS.

> ***A doctor who had dismissed every single concern I had raised for almost a year. A doctor who had my daughter in her care while she was in heart failure and never caught it. That doctor threatened to take my child away from me when I asked for a second opinion.***

I asked her directly — are you suggesting that I am not feeding my child? She said no. It took me — a mother with no medical degree — to suggest the possibility of a medical condition before this doctor even considered looking for one.

We never made it back for that second weight check. Three days after Amelia's first birthday we ended up in the emergency room. With a diagnosis that this doctor — after almost a year of appointments — had never once come close to finding.

CHAPTER 4

The Night Everything Changed

DCFS was never called. They never got involved. Because the moment a real doctor looked at my daughter with real eyes and real care he found in one night what everyone else had missed for an entire year.

The threat that was meant to silence me meant nothing in the end.

The diagnosis said everything.

> ***It was never me. It was always her heart.***

Three days after Amelia's first birthday we ended up in the emergency room. And this time someone finally looked. A real doctor. With real eyes. Who took the time to actually look at my daughter instead of looking through her.

And in one night — one single night — he found what an entire system had missed for a year.

Her heart.

The thing I had been circling around in every conversation, every appointment, every concern I had raised since before she was even born. The family history sitting right there in my file. The signs present from the very first moment she entered the world.

Finally. Someone saw it.

And our world changed in the most devastating and most relieving way all at once. Because the answer — as terrifying as it was — was also the beginning of the first real chance she had ever been given.

CHAPTER 5

The Weight of What We Now Knew

After the pediatrician gave us the news she told us to prepare to be transferred to a more specialized facility.

The cardiologist came in. He did an echo. He was gentle. Thorough. He took his time. And then he showed me exactly what was happening inside my daughter's heart.

Two holes. A 14mm atrial septal defect. An 8mm ventricular septal defect. He explained that she would need surgery in order to survive. And then he told me something that cut through the fear for just a moment. Her survival rate was high. She had a chance. A real chance.

I want to tell you what it felt like to be in that room alone. Her father had just left. The cardiologist had just walked out. And I was sitting there with everything I had just been told settling over me like something I couldn't lift.

I broke down. I cried in a way I hadn't let myself cry through any of this. Through the pregnancy. Through the dismissals. Through the year of being told she was fine. It all came out in that room alone.

And then I realized my phone was dead. No way to call him. No way to reach anyone. Just me and everything I was carrying and a daughter who needed me to hold it together.

He was calm. He was strong. He was exactly what I needed him to be in that moment. He never left our sides. Not once. Through any of it.

They transferred us by ambulance. I replayed her entire life in those minutes. The blue lips at birth. The rapid breathing. The sleepless nights watching her chest rise and fall. The year we almost lost her without anyone knowing we were losing her.

> ***And I asked God why. And if any of it was because of something I had done — I begged Him to take it from her and give it to me instead.***

They told us that if we had waited one more day she likely would have died in her sleep. One more day.

They verified the size of the holes. They confirmed the pulmonary hypertension. The right ventricular hypertrophy. The heart failure she had been living in since the day she was born.

And they still didn't catch the third hole. The one hiding deep in the muscle of her heart. The one that would turn a few hour surgery into 14 hours.

But in that moment we just knew that our daughter was alive. That she was finally where she needed to be. That she finally had a real chance. And I held onto that with everything I had.

CHAPTER 6

Eight Months in a Prison We Couldn't Escape

They stabilized her. They gave us a plan. And then they sent us home. Back to the same world that had almost killed her. Back to figuring it out alone. Back to surviving.

We asked one thing. One simple thing. Please wash your hands.

Our daughter had been told she could die in her sleep at any moment. Her heart was still failing. Her immune system had nothing left to fight with. Every virus, every cold, every illness that walked through that door was a direct threat to her life.

> ***We were told no. My partner was looked in the eye and told — "I am not going to slow my life down so that your daughter doesn't get sick."***

Not slow her life down. Wash her hands. That was the ask. And the answer was no.

Kids were sent home from daycare sick and nobody said a word. And Amelia kept getting sick. Over and over and over again. Every time she got sick surgery got pushed back. Every pushback was another roll of the dice with her life.

Eight months.

I was angry. I felt trapped. I felt like I was in a prison I couldn't get out of. I had fought for over a year to get my daughter diagnosed and now that she finally had a chance I was stuck in an environment that was taking that chance away from her one illness at a time.

> ***I don't have words for what it is like to put your child to bed every night not knowing if she will wake up. To watch her breathe in the dark and wonder if tonight is the night. To love someone so completely and feel so completely powerless to protect them.***

This is something nobody talks about in CHD families. The toll it takes. Not just on the child. On the parents. On the relationship. On every single person trying to hold it together while everything falls apart around them.

She was diagnosed just after her first birthday. She didn't have surgery until she was 23 months old.

Eight months of a child living in heart failure because one person decided her life wasn't worth slowing down for.

Follow Invisible Warriors — Chapter 7: The Morning I Let Go.

CHAPTER 7

The Morning I Let Go

The night before surgery I didn't sleep. Not because I couldn't. Because I wouldn't.

I had just had my second child six weeks earlier. I was still recovering. Still breastfeeding. Still pumping. My body was doing everything it was supposed to do for a newborn while my heart was breaking for my firstborn.

The morning of surgery we dropped my six week old off at Grandma's on the way to the hospital. I had her in my arms one moment. And then I didn't. On the way to watch one daughter fight for her life I had to leave the other one behind.

I saw my newborn one time the entire hospital stay. One time.

The day before surgery they swabbed Amelia. Standard protocol. The next morning we found out the swab had never been entered into the system. Never entered. Like it never happened. What we found out after surgery was that Amelia had the rhinovirus. She went into open heart surgery with an active viral infection.

> ***I have asked myself one question every single day since. Did they do it to save her life? Because after eight months of pushbacks — maybe this was the only window they had.***

The morning of surgery I held her as long as they would let me. She was 23 months old. Almost two years old. She had spent nearly her entire life fighting to stay alive without anyone knowing that's what she was doing.

I memorized everything about her that morning. The way she felt in my arms. The sound of her breathing. The weight of her against my chest. Because I didn't know what she would feel like when they handed her back.

And then the moment came. I handed her to a stranger. A stranger who was going to stop my daughter's heart in order to save it.

> ***I felt everything and nothing all at once.***

They told us it would take a few hours. It took 14. Because when they opened her chest they found something nobody knew was there. A third hole. 6mm. Hidden deep in the muscle of her heart. A muscular ventricular septal defect that had never shown up on a single scan.

Three holes. Not two. Three.

I sat in that waiting room for 14 hours not knowing any of this. Just waiting. Just pumping. Just praying. Just holding onto the promise I had made her in that ER the night everything changed.

I will never stop fighting for you.

Follow Invisible Warriors — Chapter 8: The Longest Night.

CHAPTER 8

The Longest Night

Surgery was over. But it wasn't over.

They had found another hole. Hidden in the muscle of her heart. And the surgery that was supposed to take a few hours had become 14.

They brought us to a separate room before we could see her. To prepare us. We asked the surgeon the only question that mattered. Is she going to make it?

He said he didn't know. He said it was hour by hour. Day by day.

> ***After 14 hours of surgery, after everything her body had been through, the best answer he could give us was hour by hour. Day by day.***

Nothing could have braced me for what I walked into after that. My daughter's chest was not closed. They couldn't close it. Her body had been through so much they couldn't take her off the ECMO machine — the machine doing the work her heart couldn't do on its own.

Nobody is prepared to see their child's heart beating outside of their body. I don't have words for what that feels like. Nobody does. Nobody ever will.

That night I barely slept. I had to keep getting up to pump. I had to check on her. I had to watch the machines. Her temperature was still high and it wasn't going down.

I told her father the news that night. That if she didn't wake up the possibility of a heart transplant was on the table. And then we both did the only thing we could do. We talked to her. We needed her to hear our voices. We needed her to know we were still there.

The next morning her father woke me up. Amelia was moving her hands.

> ***Such a small thing. Such an enormous thing.***

In that moment I felt something shift inside me that I hadn't felt in a very long time. Hope. Real hope. The kind that tells you she is going to make it.

Three days later she came off the ECMO machine. And then they found the blood clot. A blood clot in her brain from the ECMO machine. One thing after another after another after another.

But she was awake. Her hands had moved. Her heart was beating inside her chest where it belonged.

She was still here. She was still fighting. And for the first time in her entire life I truly believed she was going to make it.

Follow Invisible Warriors — Chapter 9: Coming Home.

CHAPTER 9

Coming Home

People celebrate when heart families come home from the hospital. And we tried to. Because she was alive. Because she made it.

But nobody tells you what coming home actually looks like.

We came home to the same environment. The same house. The same people. The same hands that had refused to wash. The same environment that had stolen eight months of surgery dates from our daughter.

The fear didn't stop at the hospital doors. It followed us home. It sat with us every night.

> ***Your nervous system doesn't just turn off after something like this. It doesn't know how. It has been in survival mode for so long that survival mode becomes all it knows.***

I went back to work almost immediately. Not because I was ready. Not because I wanted to. Because I had to. That is a part of the CHD journey nobody talks about either. The financial reality. The impossible choices. The way this disease reaches into every single corner of your life and changes it.

We knew something had to change. So we made the decision to move. And everything changed.

The moment we left that environment Amelia stopped getting sick. For the first time in her entire life she had the space to actually heal. To breathe. To grow. To become who she was always meant to be.

She started walking. She started jumping. She started making progress in ways she had never been able to before.

> ***The moment we removed ourselves from what was hurting us everything started moving forward. Our relationship got better. Our peace came back. Our family started to breathe again.***

And Amelia — our warrior — finally had the chance to just be a little girl. Not the little girl who was in heart failure. The little girl who was always in there. Waiting. Fighting. Ready to live.

Watching her become that child is the greatest thing I have ever witnessed.

Follow Invisible Warriors — Chapter 10: The Answer That Raised More Questions.

CHAPTER 10

The Answer That Raised More Questions

After surgery I pushed for answers. I needed to know why. Was it genetic? Was it something I did? Was it something I could have prevented? Was it something that could happen again?

So I asked her surgeon to order a genetic test. And they found something.

A variant in a gene called FLNC. A de novo mutation. De novo means it didn't come from me. It didn't come from her father. It appeared spontaneously in Amelia's DNA. It came from nowhere. It belonged to nobody. It just happened.

We had made a promise before the results came back. If it came from one of us we were not going to blame each other. Whatever the answer was we were going to face it together.

And then the answer came back. It didn't come from either of us.

> ***Then where did it come from? There was nobody to point to. No family history to trace it back to. No explanation that made any sense. Just a mutation. That appeared from nowhere. In my daughter's DNA. Before she was even born.***

It is classified as a VUS. A Variant of Uncertain Significance. That means science does not fully know yet what this variant means for her future. There is no definitive answer. No clear roadmap.

And so I live hyper aware. Every single day. Every food she eats. Every chemical she is exposed to. Every environment she enters. Every decision I make as her mother.

> ***That is not paranoia. That is a mother doing the only thing she can do when science hasn't caught up yet.***

This is why I fight for milestone based research. Not for abstract science. Not for statistics. Not for awareness alone. For Amelia. My goal is to find answers for my daughter first.

The FLNC gene and what it means for children like Amelia is not yet fully understood. But we are going to fight like hell to change that.

Follow Invisible Warriors — Chapter 11: The System Failed Again.

CHAPTER 11

The System Failed Again

My second child was born in the same hospital where my first child was born. Not by choice. By necessity. I was already at a 10 on the way to the hospital.

Thirty minutes later my second daughter was born. Completely natural. The birth I had always wanted. The birth I never got with Amelia.

But instead of feeling like mine it was taken from me before I even had the chance to hold it. Because the same OB who had failed Amelia was there.

He cut the umbilical cord himself instead of letting my partner do it. He ripped my newborn away from me.

> ***A doctor who had hooked me up to every machine imaginable during two pregnancies but couldn't catch a heart condition that should have been found at birth — punishing me for proving his C-section was never necessary. That is not care. That is control.***

All they did was listen to her heart. No echo. No deeper investigation. Just a stethoscope. The same way they had listened to Amelia for an entire year before someone finally found what was really there.

And then a nurse admitted — out loud, to my spouse — that if a baby doesn't produce enough blood during testing they just mark it as passed. Because they don't want to poke the baby again and make it cry.

> ***I want you to sit with that. I would rather my child cry at the top of her lungs for an hour while they got the blood they needed than miss a heart defect that could kill her. I would choose that every single time without hesitation.***

To this day I do not know if my second daughter has a heart defect. She cries a lot. More than feels normal to me. And I sit with that every single day.

This is why I fight. Not just for Amelia. For my second daughter too. For every child whose heart has never been properly looked at. For every mother sitting with a question mark that the system refuses to answer.

The failures that almost killed Amelia are still happening. Right now. In hospitals everywhere. To families who don't yet know what they don't know. And I will not stop until that changes.

Follow Invisible Warriors — Chapter 12: Who She Is Today.

CHAPTER 12

Who She Is Today

Amelia — our warrior.

I want to tell you who Amelia is today.

Not her diagnosis. Not her scars. Not her variant. Not the holes that were in her heart. Not the machines that kept her alive. Not the 14 hours of surgery or the blood clot or the ECMO machine.

Just her.

She is happy. Nonstop. The kind of happy that fills every room she walks into.

She jumps. She rolls around. She climbs to the top and she stays there. Anything she is told she cannot do she takes as a personal challenge.

She has a condition that is supposed to make her body more stiff. She doesn't care. She defies every odd that was ever placed in front of her. Just like she always has. Just like she did before any of us even knew she was fighting.

> ***She calls the kitchen my kitchen. This child who spent the first two years of her life fighting to stay alive has claimed her kitchen. And she is not giving it up.***

She loves to cook. She loves to swim. She loves to go outside. Her favorite fruit is cherries. She is funny in the way that only she can be funny.

She is starting to talk. Starting to do everything. Every single thing they told me she might never do.

She has built the most beautiful bond with her little sister. A bond that started in the most painful circumstances and grew into something that no circumstance could touch.

The trauma is still there. I want to be honest about that because this story has always been about honesty. You don't watch your child's heart beat outside of her chest and walk away unchanged.

> ***The trauma lives alongside the joy. Both things are true at the same time. And that is okay.***

But when I look at her — when I watch her jump and roll and climb to the top of the mountain — when I hear her laugh — when she walks into the kitchen and announces that it is hers — when she reaches for her sister's hand — I feel everything.

She was not supposed to survive. She beat every odd that was stacked against her. And she did it before she was old enough to understand what surviving meant.

She will be my story forever. She is the reason I will never stop fighting. She is the reason Invisible Warriors exists. She is the reason I get up every single day and keep going.

CHAPTER 13

Why I Built Invisible Warriors

I built Invisible Warriors because I was alone.

That is the most honest answer I can give.

Through everything you have read in these chapters — the pregnancy, the dismissals, the birth, the year of being gaslit, the ER, the diagnosis, the ambulance, the eight months of waiting, the 14 hour surgery, the open chest, the ECMO machine, the blood clot, the rhinovirus, the genetic variant with no answers — through all of it I was alone.

Not because nobody loved me. Not because nobody cared. But because there was no community built for what I was going through. No one who had been through it standing beside me saying — I see you. I know this. You are not alone.

I needed that. I never had it. And I refused to let another family go without it.

I built Invisible Warriors so that Amelia's story could mean something beyond our family. So that the year of missed diagnosis could become a warning that saves another child. So that the eight months of waiting could become a program that supports another family through their own impossible wait.

> ***Every program we have built came directly from a gap I lived through personally.***

Food support — because I know what it is to not be able to think about eating while your child is fighting for her life. Comfort bears — because I know what it is to want your child to have something soft and safe to hold when the world feels anything but. Crisis support — because I know what it is to have everything fall apart at once and have nowhere to turn. Milestone based research — because I know what it is to have a variant with no answers and a daughter whose future depends on science catching up.

I built what I needed and never had. I built it so you never have to go without it.

But I am not done. I am working toward something bigger. Something that could change the moment a CHD diagnosis is made — or missed. Something rooted in the single greatest failure of

Amelia's story. Early detection. The gap that almost cost my daughter her life. The gap that I am determined to close.

This is not the end of Amelia's story. She goes to cardiology appointments every year. She carries a scar that tells the story of everything she survived. And she has a mother and father who will never stop fighting for her.

Her story is still being written. And so is ours.

> ***We are building something here that goes beyond awareness. Beyond fundraising. Beyond social media. We are building a movement that changes what CHD families experience from the moment of diagnosis through every chapter of their lives.***

If Amelia's story moved you — share it. Someone out there needs to know this community exists. Someone out there is sitting exactly where I was sitting. Scared. Dismissed. Alone.

Help us find them. Help us reach them. Help us make sure they know they are not invisible and they are not alone.

Because no family should ever have to fight the way we fought. And no child should ever have to survive the way Amelia survived.

We are Invisible Warriors. We were built from the hardest moments of one family's journey. And we will fight for every family that comes after.

Together we fight CHD.

Together no family fights alone. ■

Visit chdinvisiblewarriors.com to learn more, donate, submit your story, or support a family today.

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