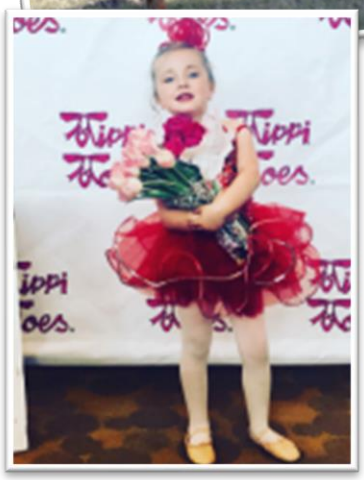
Show With Your Heart Taylee's Story

Show With Your Heart was created to raise awareness about Congenital Heart Defects. **ONE out of ONE HUNDRED babies is born with a CHD every day. There is no prevention. There is no cure.** One hundred percent (100%) of the proceeds from the show go to The Children's Heart Foundation. Their mission is "to advance the diagnosis, treatment, and prevention of congenital heart defects by funding the most promising research." To date, they have funded over $13 MILLION(2023) in CHD research and scientific collaborations. Thanks to research, there has been a 37.5% decrease in deaths over the last twenty years.

On November 16, 2012, Taylee Michael made her appearance into the world. According to ultrasounds, a healthy baby girl. However, that was not the case. After 2 hours, she was still sleeping and not hungry. "Let her sleep, not all babies are hungry after 2 hours" was the statement from the nurses. At 3 hours, I woke her up. She made a choking sound as I tried to feed her, so I immediately called the nurses in. They took her to the nursery to check her over. A few minutes later they brought her back and said she was fine. I told them I didn't like the color of her feet. Their response was "some babies just have feet discoloration after they are born." Mother's Intuition is real. The Mama Bear in me came out and I let them know this was not normal, this was not my first child, and they would go down and check her out. At 6 hours old, she was intubated and rushed to Driscoll Children's Hospital NICU. The following 24 hours were dark. I had no idea if I was ever going to hold my baby again. Her dad had been on his own there with her. He was in a whirlwind of all the updates and talking with specialists still not knowing what was going on. Not to mention her brothers didn't understand why they couldn't see their new sister. The day we had all waited for in excitement was a day that forever changed our lives.

As a mother, I was lost. Congenital heart defects did not run in our family. I did not statistically fit the type of mother to have a child with a CHD. As a family, all we had was the internet to turn to for understanding CHD's. While we are absolutely blessed that Taylee is living her best life, I don't want another mother to experience what I did.



One in every 3,413 babies in the United States is born with Transposition of the Greater Arteries. This is a condition where the main arteries are switched. In some cases, they can be switched back. This was not the case, as Taylee is diagnosed with Complex TGA. Aside from the switch, she also has a valve that does not function and a hole between her two lower chambers. It is tough to research and learn more about her condition as she has yet to follow the written

standards. Throughout every hospital stay and doctor's visit, every conversation includes "Well, with most children...., but with Taylee..." Yep, that's our Taylee, writing her own book as she goes along.

Every baby is born with a PDA allowing the blood to skip circulation to the lungs. Not long after birth it closes, and they are on their own. Luckily, Taylee's was still open, and the doctors were able to keep it open with medication. At 5 days old, an incision was made behind her scapula and a BT shunt was placed to give a pathway for her blood to transport to the lungs. We were told she would be living in the NICU for an additional two weeks before she would go home. A week later we were home. The longest time we were away from her was for a couple of hours to eat a Thanksgiving meal with the boys.

There were no hospital photos taken, no newborn photo-shoot, she didn't even get to wear the outfit my mom made her to come home in. On the bright side, we were blessed to be bringing our baby home because so many are not that fortunate.

By the time Taylee was 6 months old, her fine motor skills were impeccable, she was doing everything a six-month-old should. She was sitting up, happy, playful, and running on 78% oxygen. At that time though, she was ready for her first **open heart surgery**. They performed a Glenn procedure which was basically to "re-route" her blood flow. We stayed in the PICU for several days. We would laugh as the interns made their rounds and the doctor would once again have to say "Well, with most children...., but with Taylee..." Over the next couple of years things were a little different. She had to go the therapy to learn how to properly swallow and eat. (Eating is one of her favorite hobbies now!) She also had to have physical therapy at 17 months to learn how to walk. We will never forget that her first steps on her own were in the pig barn while holding a show stick!

We knew another surgery was in her near future. Their plan was after she was age three to do the final procedure. Most CHD babies stay petite and need more time to grow. At two and a half years old, our not so petite princess was ready for her second **open heart surgery**. The Fontan procedure was performed. This procedure was to help oxygenate the blood without having to pass through the heart. Since then, she has been running on 85-90% oxygen and doing everything that kids her age can do. I know I said "final" surgery, but I say that loosely as it was the final of the three that were planned. What does her future look like? Well, we take it one day at a time and know that at any point in her life she will have other procedures and/or surgeries done. She stays on medication twice a day, has a thorough exam every six months, and has yearly blood tests to check other organ functions as well.

In her seven years of life, she has shown pigs all over Texas and in Iowa, ridden horses, gone fishing, danced ballet, danced with Princess es, played T-ball, learned gymnastics, snow tubing in New Mexico, and is currently learning to play the guitar. She plans to be a Chef on a cooking show when she's grown! She understands she has a "special heart," but that has only made her braver and stronger.

This first part was written five years ago. Since then, Taylee's heart has changed but thankfully, research has advanced.

Taylee's Story Part 2

We coasted along for a couple of years. Her lips would always turn colors depending on her activity. In 2020, her lips becoming purple and staying brighter while inactive became more noticeable. Her oxygen started staying in the 75-80% range. These were acceptable numbers for her condition, so no alarm was sounded. However, her doctor started monitoring her heart closer and he wanted to start being proactive as the Fontan procedure can cause problems. The hole between her two lower chambers was also being monitored as she needed the blood flow.

In the summer of 2021, we were sent to Houston to a team of cardiologists who work alongside ours in Corpus. Taylee's left chamber was overworking and becoming muscled up. The thickness of the muscle was not allowing blood to pass through as needed. The hole between the two chambers was also getting smaller. The procedure she would need done is **very critical**. The team would spend that summer researching and monitoring to make sure Taylee was a candidate. While most are not wishing for their child to go through such a scary surgery, we were. If her heart was not capable of the operation, she would eventually be on a heart transplant list.

November 13, 2021, we got the phone call. Not only were they confident that the procedure could be done, but they also needed to do it immediately. December 16th she was handed over for the fourth time (Her 3rd open heart). Each time we hand her over, it isn't just for a surgery. They are ***stopping*** her heart to work on it. There are so many side effects to this. While the medical effects of her surgeries and medications is a long list, the social and emotional effects are just as long.

We knew this surgery was just step 1. Step 2 was going to come when her heart was ready. They went in and enlarged the hole between the chambers and made a few minor adjustments. Her Fontan fought the procedure and she had to stay on a pacemaker for a few days. It was going to take time and consistent monitoring. The hardest part about this surgery for Taylee? That would be spending Christmas in the hospital. This was also during the time visitors were not allowed. So, no family other than mom & dad. Luckily Santa and the Elf on the Shelf found her!

Six Weeks later she was cleared to start trying to do normal things… Well, they didn't define "normal," so Taylee was in the ring showing her pigs & lambs. Obviously, brother was there to help her, but she was not going to miss her chance to be in the ring! She continued to do all the things she loves without restrictions.

After just a year and a half, her heart had moved in the right direction for part 2. The doctors prepared us for many scenarios. "There will be a part 3, maybe a part 4." Her surgeries are all being *written by her heart* and its timing. We went in late June 2023. We had her best prepared as a parent can prepare their ten-year-old child. During preparation, Taylee developed an allergic reaction to the soap they cleaned her with and the leads for monitors burned and blistered her skin. It was an awful experience. She had to go home and then be rescheduled for six weeks later. Six more weeks of explaining what will be happening and why. Six more weeks of her anxiety building. Her concern? "Will I still be able to start school on time?"

On August 3rd she had her fourth **open heart surgery**. They went in and closed her Atrial Septal Defect. They closed her up and had her sitting up to eat two days later. By day 3 they had her getting out of bed and moving. Day 4, they decided that her heart was doing everything they needed it to and that it was ready for part 3. Yes, just 5 days after her 4th **open heart surgery**, she was going to be opened up again for her **FIFTH**. On August 7th, she had her Fontan removed, a valve from a bovine put in, and her heart now has 4 working chambers!

The recovery started all over again. Three days later they had to go back in as her chest had larger blood clots than the chest tubes could remove. *Three times* in the matter of 10 days, her chest was opened. At this point, she had lost her drive to get out of bed and get moving. Luckily, we had a wonderful set of physical and occupational therapists. One of them said "If you want to get strong enough to show your lambs, you have to get up and move." That did the trick! The lambs were what got her moving and at home, they were what got her to heal both physically and mentally.

This journey is not over, we are just in another chapter. There is not an end point for surgeries. There is no cure.

We do though, have a gracious God, a talented team of doctors & surgeons, and the biggest support system from family, friends, & the livestock community.