**FREEARM ARTICLE**

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You have your plan set, then, by no fault of your own, it is dramatically swept away. It’s caught up by some strange wind and blown right out of the window. That is what happened to Misti and Will Staley when their son Freeman was born.

Misti thought she and Will had their plan in place to prepare for their new baby. Misti had eaten healthy during her pregnancy, purchased glass bottles (no plastic leaching chemicals into her baby’s breast milk), and had a stack of cloth diapers ready. Misti and Will had arranged to have a midwife assist them through natural childbirth in their home. Then, after 30 hours of labor, on April 25, 2015 they were finally able to receive their son into their arms.

But just three hours after Freeman was born, he was on his way to the hospital in their hometown of Helena, AR. Three hours after that, he was life flighted to Arkansas Children’s Hospital two hours away in Little Rock.

From the very beginning, Freeman had problems with his breathing. The midwife also noticed that Freeman had a hole in the back of his palate as she suctioned him. While at home, he was continually being given oxygen as his breathing was labored. After he left the hospital in Helena and arrived in Little Rock, Misti and Will were informed by doctors they had a “very sick little boy”.

**NO SIGN OF PROBLEMS**

It was all such an overwhelming situation, especially when they learned the depth of the health issues. What had caused this? Misti had five ultrasounds throughout her pregnancy. They were all routine and showed no abnormalities. Nothing foretold of any medical issues.

DNA testing showed that Freeman had Beals Syndrome also known as congenital contractual arachnodactyly (CCA). It is an inherited disorder. Affected individuals display ear deformities and occasional cardiovascular defects. However, Freeman showed no typical physical signs of the syndrome – no crimped ears, clawed hands, clubbed feet or scoliosis. But tests done on Will and Misti showed that Misti had Beals. Then her parents were tested. The test revealed her dad had Beals. It was unexpected since neither of them had any physical signs of the syndrome.

Freeman’s health issues were massive. He had coloboma (missing pieces of tissue in structures that form the eye), a horseshoe shaped kidney, an extra rib, chronic lung disease, and a small cleft pallet. He was admitted to the Neonatal Intensive Care Unit (NICU). Within five days of arrival he went through extracorporeal membrane oxygenation (ECMO); a treatment that uses an outside pump to circulate blood through an artificial lung back into the bloodstream. It provides prolonged cardiac and respiratory assistance. Freeman eventually was removed from ECMO but stayed in NICU for three and a half months.

The sight of seeing their tiny baby hooked up to tubes, wires and pumps was, as Misti says, “super-scary”. And living through the experience was also a rollercoaster.

“Good days, bad days, really bad days, then back to good days. Freeman had seven surgeries in only three months,” recounts Misti.

Even with the support of their parents and extended community, Misti and Will spent 5 – 15 hours per day in the hospital. They were fortunate that Will’s parents live in Little Rock. Both Will and Misti have flexible jobs. Will manages his own graphics business which allowed him flexibility in traveling and working in Little Rock and Misti teaches after school art and mural workshops with kids 7-18 years old.

**TRIAL AND ERROR**

After three and a half months in Little Rock, Misti and Will were able to bring their baby back home to Helena. But their joy was soon tempered by the day to day management of his care. It was exhausting and cumbersome. Freeman was discharged with a g-tube, bolus gravity feeds for day and pump feeds for night, oxygen, and lots of meds.

“Once we came home from the NICU we would be sitting on the couch trying to hold Freeman, hold his syringe, put meds in, put milk in…we spilled so much milk.”

It was extremely difficult to coordinate, carry and be mobile with all the medical equipment. Sometimes Will would hold the pump feeder to allow the breastmilk filled with meds to flow through the tubes while Misti held Freeman. Other times they would tie up the pump with ribbon to the crib or prop up the feeding pump on the back of the couch or the wall to allow for consistent flow.

Based on their creative instincts of how a pump feeder could be better to allow for mobility and flexibility, Will and Misti began to talk out what a better feeder design could look like. With their art and design background they began to come up with concepts.

One day Will went out to the garage with his dad and they connected two small pieces of wood with a hinge to create an upside down “L”. They taped it to the back of Freeman’s crib. It freed Misti to be able to read to Freeman and sooth him as he ate. The configuration also allowed for a quick swing out of the way if Freeman started to spit up and aspirate.

After five weeks at home Freeman had to return to the Arkansas Children’s Hospital and this time stay in the Pediatric Intensive Care Unit (PICU). Will and Misti were back to where they started and again on the rollercoaster. Freeman was intubated for two months.

The hassle with the feeding tubes weren’t just at home. In the hospital, Freeman’s bolus syringe feeds were always tied with a ribbon above his crib or taped to the chair or wall. Nurses couldn’t hold the syringe because they had other babies to take care of, too.

Misti and Will spoke with both medical personnel and parents with children in the PICU about what they thought would be helpful. But while they had obtained quite a bit of research and some ideas, they still had a sick baby to think about.

During the subsequent months stay in PICU, Freeman developed other serious conditions. he received a trach the day before Thanksgiving in 2015. Later, he developed holes in his lungs and needed chest tubes. Then, his gastrointestinal tract stopped working.

On February 15, 2016 Freeman passed away after five months in PICU.

**IDEA TAKES FORM**

And while they were not emotionally ready to take on the challenge of creating a medical device immediately after Freeman passed away, they still thought about the other parents they had met in the hospital and their issues with the medical equipment. They never stopped brainstorming about what a product should look like.

In January 2018, they officially started on the road to creating and bringing the[**FreeArm**](http://www.freearmcare.com) medical device to market. Readied with their personal experience and the research they had gathered while in the PICU, they embarked on a one-year intensive journey. Their initial step was to participate in a rigorous business accelerator program through the Arkansas Small Business Technology and Development Center (ASBTDC). It is a free service paid for by tax dollars to help entrepreneurs develop their business ideas. The ASBTDC was able to offer feedback and help them build a business plan. It was through them that they were introduced to the Delta I-Fund, the second step of their journey, where they were matched with mentors, provided advice and connections, and best of all, said Misti, startup capital.

Because of the research they had done with parents in the PICU, they came to the process with many ideas. Nonetheless, they wanted to hear every challenge that parents and adults with feeding tubes were experiencing. What type of clip works best holding the feeding bag? Should it clamp to tables? Should the arm be flexible?

“We interviewed over 100 nurses and parents to make sure that others were having the same pain points with tube feeding that we had. We also took all the feedback to heart and it really shaped what the **FreeArm** is today. Since the product is a medical device, the testing and licensing was much more stringent than for other products.

“When it came down to making a medical product, we knew there would be a ton of red tape, but we are really glad we did it.”

The entire process from planning to concept to market took approximately a year. At six months, they had a prototype and by the end of the 12- month period, they had a product that was being manufactured.

The **FreeArm** is now available for purchase by individuals and hospitals and clinics. Misti and Will have not stop innovating. They are in the process of developing more product lines. By the end of 2019, they will launch the **FreeArm Muscle**. A device that will hold more feed volume and heavier pumps.

“The pain of losing your child never goes away, but I am honored that Freeman taught us so much in his short life. The **FreeArm** would never be here if it wasn’t for Freeman.”

Parents can visit [www.freearmcare.com](http://www.freearmcare.com) to purchase the product. Misti has built a great community for parents with health compromised children. You can reach out to her at <https://freearmcare.com/contact> or on her Facebook page at <https://www.facebook.com/FreeArm> or on Instagram at <https://www.instagram.com/freearm.tube.feeding.assistant/>

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