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# Neuro Brilliant

Magazine

MEDICALLY

COMPLEX

*Life*

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IMAGES COURTESY OF MISTI STALEY

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**H**ow many times can a story break your heart and feed your soul at the same time? Mother's Day was bittersweet for me this year as I put this month's story together. My team and I worked with tears in our eyes. I cried, the photographer cried, the copy-editor cried, the story reviewers cried, and my daughter cried too. Pretty much anybody that worked on the story with us this month felt touched by this family's journey.

These stories are what this magazine is all about: a glimpse into neuro-brilliant life where you see yourself and recognize another person's journey. We're a tribe of medically complex families who haven't had a magazine presence like this before. That's why stories like this are so important; they remind us we're not alone. They help us grow through other people's journeys, and show us that there is always another way we can view our lives.

I hope this story touches your heart as much as it did for us.

P.S: If you're a softy like me, make sure you have a tissue box sitting next to you.

Many blessings,

*Connie Mink*

Creator, Editor in Chief  
Neuro Brilliant Magazine

# MEDICALLY COMPLEX

# Life

One family's inspiring journey

**M**any have been there. You have your carefully laid plan set, looking forward to a long-expected happy event. Then, by no fault of your own, it is dramatically swept away. Your life vision gets obliterated by an eerie wind that blows it right out the window into a dark thunder cloud. That is what happened to Misti and Will Staley when their beautiful son was born. Misti thought she and Will crafted the perfect plan to prepare for their new baby. She ate healthy during her pregnancy, purchased glass bottles to avoid plastic residue, and had cloth diapers stacked instead of disposable ones.



IMAGE BY: @TDYULBANOVA FROM TWENTY20

They were heading into parenthood with high ideals. They even arranged to have a midwife assist them through natural childbirth in their home. Wanting to give Freeman a warm welcome into the world, they strived for the best of everything. Then, after months of anticipation and 30 hours of intense labor, they finally held their precious son in their arms. On April 25th, 2015, Freeman Ellis Staley was born.

From his first moments, Freeman struggled to breathe. The midwife also noticed a hole in the back of his palate as she suctioned him. She gave him continual oxygen while resting in his parents' arms. Little did Misti and Will know, this was the beginning of their medically complex journey. Three hours after his birth, they rushed Freeman to the hospital in their hometown of Helena, Arkansas. The doctors were overwhelmed, so they life-flighted him two hours away to Arkansas Children's Hospital. "They told us that we had a very sick little boy, and they would be testing him for meningitis and many other things that could be affecting his breathing," said Misti. "We gathered a few clothes and raced the 2 hours to Little Rock."

# 3 Months in the NICU

Their first day at the hospital felt like a tragic whirlwind of activity. As Misti and Will quickly entered the Neonatal Intensive Care Unit (NICU) at the hospital, their eyes filled with tears at the sight of their boy.

"Entering Freeman's room at the hospital with Freeman connected to every wire imaginable was hard, really hard. He was sedated and almost lifeless", Misti shared.

How could this be happening? Their pregnancy went according to plan. The ultrasounds came back normal, so what caused this? The answer is one that shook them both to their core. To find the answer, doctors tested Freeman's DNA. It was there, in the harshly-lit hospital, doctors revealed Freeman had Beals Syndrome.

An inherited disorder, Beals Syndrome, can present as crimped ears, clawed hands, clubbed feet, scoliosis, and cardiovascular defects. However, Freeman did not display any physical signs of having Beals, further confounding the new parents.

Tests done on Will and Misti showed that Misti had Beals. Then, when her parents received their

results, they revealed Misti's dad also had Beals. The results, like bullets to her heart, were shocking and unexpected. How could this happen to their beloved son? Freeman's medical complexities were severe. 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 palate.

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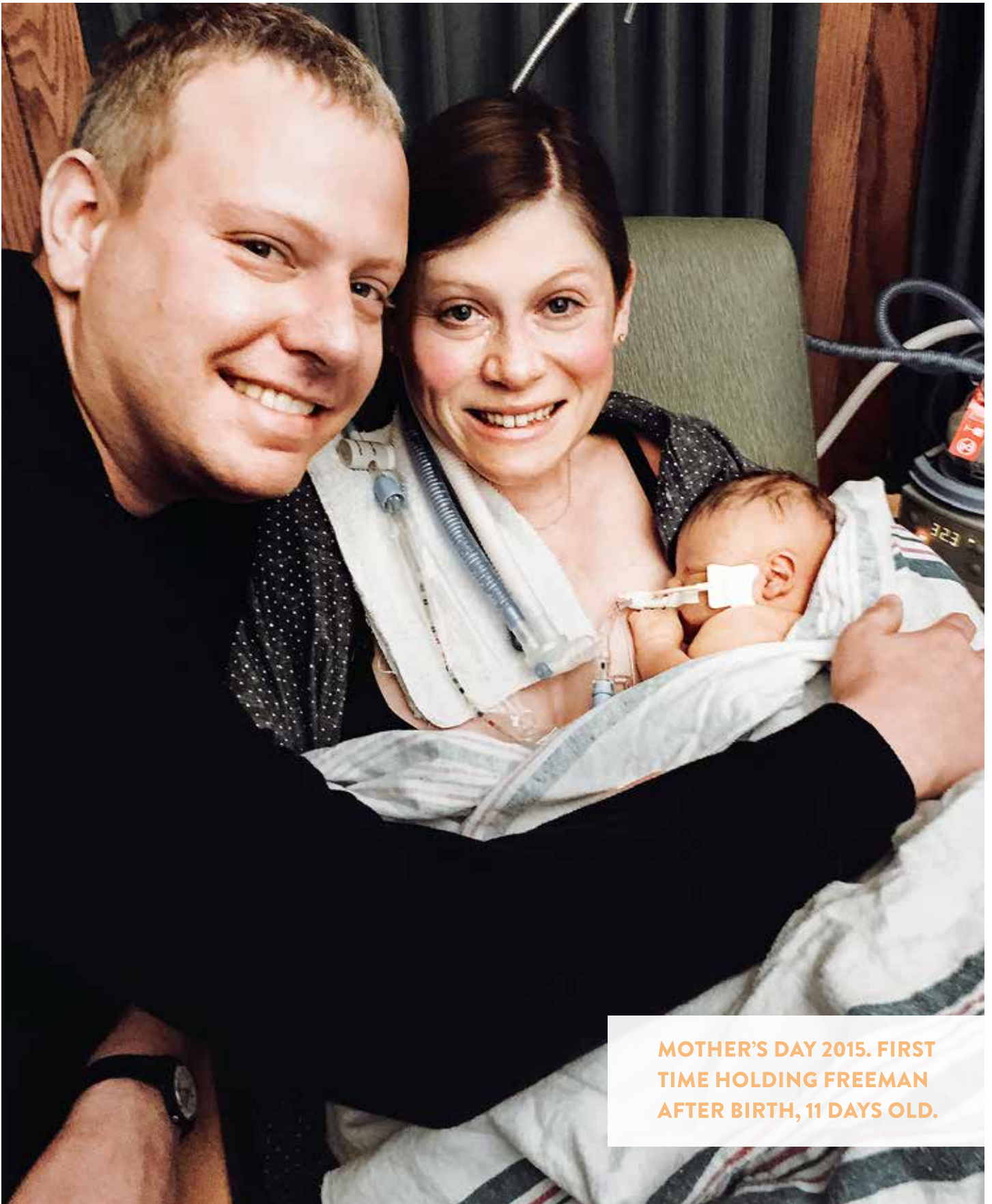
**"ENTERING FREEMAN'S ROOM WITH FREEMAN CONNECTED TO EVERY WIRE IMAGINABLE WAS HARD, REALLY HARD. HE WAS SEDATED AND ALMOST LIFELESS"**

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Within five days of arrival, doctors connected Freeman to Extracorporeal Life Support (ECMO). The machine took blood from Freeman's body, oxygenated his blood, and sent it back in through two tubes surgically placed in his neck. ECMO gave his heart and lungs a chance to rest.

Misti and Will felt crushed, seeing their tiny baby hooked up to tubes, wires, and pumps. Their hearts ached at the sound of each medical machine beeping by their baby's bedside. All they could do was hope the treatments would save their boy.

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



**MOTHER'S DAY 2015. FIRST TIME HOLDING FREEMAN AFTER BIRTH, 11 DAYS OLD.**







## medically complex **HOME** *Life*

After three and a half months in Little Rock, Freeman's health stabilized. He graduated from the NICU and could finally come home. They left the hospital with a g-tube, bolus gravity feeds for daytime, pump feeds for nighttime, oxygen, and lots of meds.

Shortly after coming home, Misti and Will discovered that parenting was about to become more complicated. Their days began to fill with learning the ropes of Freeman's medical equipment. Misti recalled:

**"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 challenging to coordinate, carry Freeman, 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. It was a constant ordeal to ensure he got everything he needed. Will and Misti began to discuss what a better

feeder design could look like to allow for more mobility and flexibility. They imagined a feeder that could let them cuddle and comfort Freeman as he ate. They could read him a book instead of having both of them awkwardly handle him through feeding. While they couldn't change Freeman's medical complexities, they could create something to make this life more manageable.

With their art and design background, they started to brainstorm concepts. Then 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 and were amazed by the results. It freed Misti to be able to read to Freeman and soothe him as he ate. The configuration also allowed for a quick swing out of the way if Freeman started to spit up and aspirate.

Their DIY hack enabled them to care for Freeman beyond addressing his medical needs. They sang and read to him as he rested happily in his crib. On his good days, Misti and Will loaded up all of Freeman's gear in the stroller and went for a walk. They enjoyed showing Freeman their community and getting some fresh air. While this life is not one that new parents imagine when envisioning their child's future, this life became the norm for the Staley family.



# Life in the PICU

As Will and Misti began to adjust to parenthood, the storm clouds of medically complex life started to swell again. After five weeks at home, Freeman returned to the Arkansas Children's Hospital. His health became so critical that he stayed in the Pediatric Intensive Care Unit (PICU). Misti and Will relived the heart-breaking pain of

watching their beloved boy back in the hospital. "Freeman was on a cocktail of morphine, fentanyl, antibiotics, and even rocuronium to paralyze him if his heart rate got too high and help his body relax. This always broke my heart," Misti shared. "I would convince the doctors to let me try and calm him by climbing in bed with him and rubbing his belly or legs and cuddle and sing sweet songs. This almost never worked, but as a mother, I needed to try."

"We were in the PICU for two months before I was allowed to hold Freeman. This was extremely hard, so we would read multiple books to him every day so that he could hear our voice[s]. His eyes were closed most of the time, but on those special days when his eyes were open for

a brief second, we rejoiced in showing him the pictures from the books that we were reading and trying our hardest to make him smile." Misti and Will spent day after day at the Children's Hospital. Surrounded by cold white walls inside the brightly-lit hospital room, they noticed that the feeding tube issues weren't just isolated incidents 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. As they waited for Freeman's health to improve, Misti and Will connected with nurses and parents in the PICU. They talked about the shared struggles with tube feeding and ways they could make it easier with better design. Misti and Will



knew they could create something that would give parents more closeness with their child, but they had a sick baby who needed them. Despite how much they wanted to help other PICU families, they focused on caring for their son. Their design ideas would have to wait.

During the subsequent months stay in PICU, Freeman developed other severe conditions. After being connected to a ventilator for two months, Freeman received a tracheostomy tube. Misti and Will hoped that it would help to regulate the pressure inside his lungs and oxygen saturation. But, only a few weeks after the surgery, his oxygen levels dropped again.

"[H]e developed a pneumothorax, a hole in his lung that allowed air to leak out of his lungs and into his lung cavity. This outside air pushed down on Freeman's already fragile lungs and





compressed them, making breathing difficult," Misti explained. "Freeman had an emergency chest tube placed. This was excruciating to watch. Freeman was given a bolus of pain meds, and a long needle was placed through his chest and into the escaped air pocket. The tube was then placed and attached to a bubbler machine. The leak in Freeman's lungs caused the water in the machine to bubble.

**WE WATCHED THAT MACHINE EVERY SECOND OF EVERY DAY, PRAYING THAT IT WOULD STOP BUBBLING, SIGNALING THAT FREEMAN'S PNEUMOTHORAX HAD HEALED AND HIS CHEST TUBE COULD BE REMOVED.**

[Doctors were eventually able to remove] that chest tube, but it took weeks, and Freeman gained two more chest tubes before his holes in his lungs healed."

Misti and Will weathered one medical complexity after another, swirling around in what felt like the chaos of a destructive tornado. Even in the shelter of the PICU, they still felt powerless to help Freeman. Then, his gastrointestinal tract just stopped working.


"[D]octors spoke with us about signing a DNR, do not resuscitate, and letting us know that there was nothing else that they could do to help Freeman. We didn't want to believe this, but the day after Valentine's Day 2016, Freeman passed away with Will and I both at his side. Freeman was freed from all of his wires and tubes, and we got to walk freely with him around the hospital room. It was a surreal moment [.]"



LIFE

AFTER

LOSS



Nothing could have prepared them for the excruciating heartbreak they felt as their baby boy left Earth. As Will and Misti drove home the night of his passing, they both felt an emptiness in their heart. While the tornado of medically complex life had passed, it left devastating destruction in their hearts.

On their drive home in the darkness of the night, Misti searched her heart for a way to grieve her loss and still celebrate Freeman's life. She looked over at Will and said, "Wouldn't it be nice to build something in Freeman's name, like a park?"

She wanted to help preserve Freeman's memory by giving to the community where she and Will planned to raise him. She wanted to do something to honor his life and the other kids in their community who left their families far too soon.

So, together, Misti and Will channeled their grief by creating The Freeman Playground - a place of fun and laughter in downtown Helena.

# CELEBRATING *The Freeman Playground* LIFE



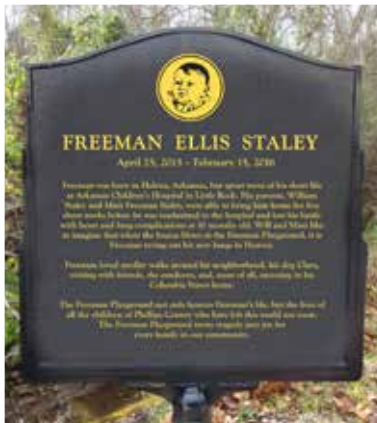


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In honor of PICU families, Misti and Will designed the playground to be wheelchair accessible, so everyone in the community felt welcomed. Once they finalized their plans for the park, Misti and Will sought help from their community to bring The Freeman Playground to life. Through families, friends, and the Helena community, they raised over \$250,000 to contribute to the park.

One year later, Misti and Will cut the ribbon and opened The Freeman Playground to the public, celebrating the opening day on April 22nd, 2017, the weekend of Freeman's 2nd Birthday. While Misti and Will wish they could see their son play and enjoy the playground, their hearts feel warmed that Freeman continues to touch the lives of his community and will do so for many years to come. Today, Misti and Will remain actively involved in their community and the playground.

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# FEEDING *Inspiration*

But Misti and Will were not done honoring their son. Shortly after the park opened, they picked up where they left off with creating a solution for tube feeding. They thought back to their days in the PICU, hearing about other family's challenges. On top of navigating the challenging world of medical complexities, families were overwhelmed. It wasn't easy for parents to comfort their children during feeding because their hands were full with managing their feeding tube. Misti and Will deeply understood the struggle these families faced, and they wanted to lend a helping hand.



In January 2018, they officially started down the road of creating the Freearm Tube Feeding Assistant. Readied with their personal experience and feedback from PICU families, they embarked on a one-year intensive journey. Because of the research they had done with parents in the PICU, they entered 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 worked best for holding the feeding bag? Should it clamp to tables? Should the arm be flexible? Misti recalls,

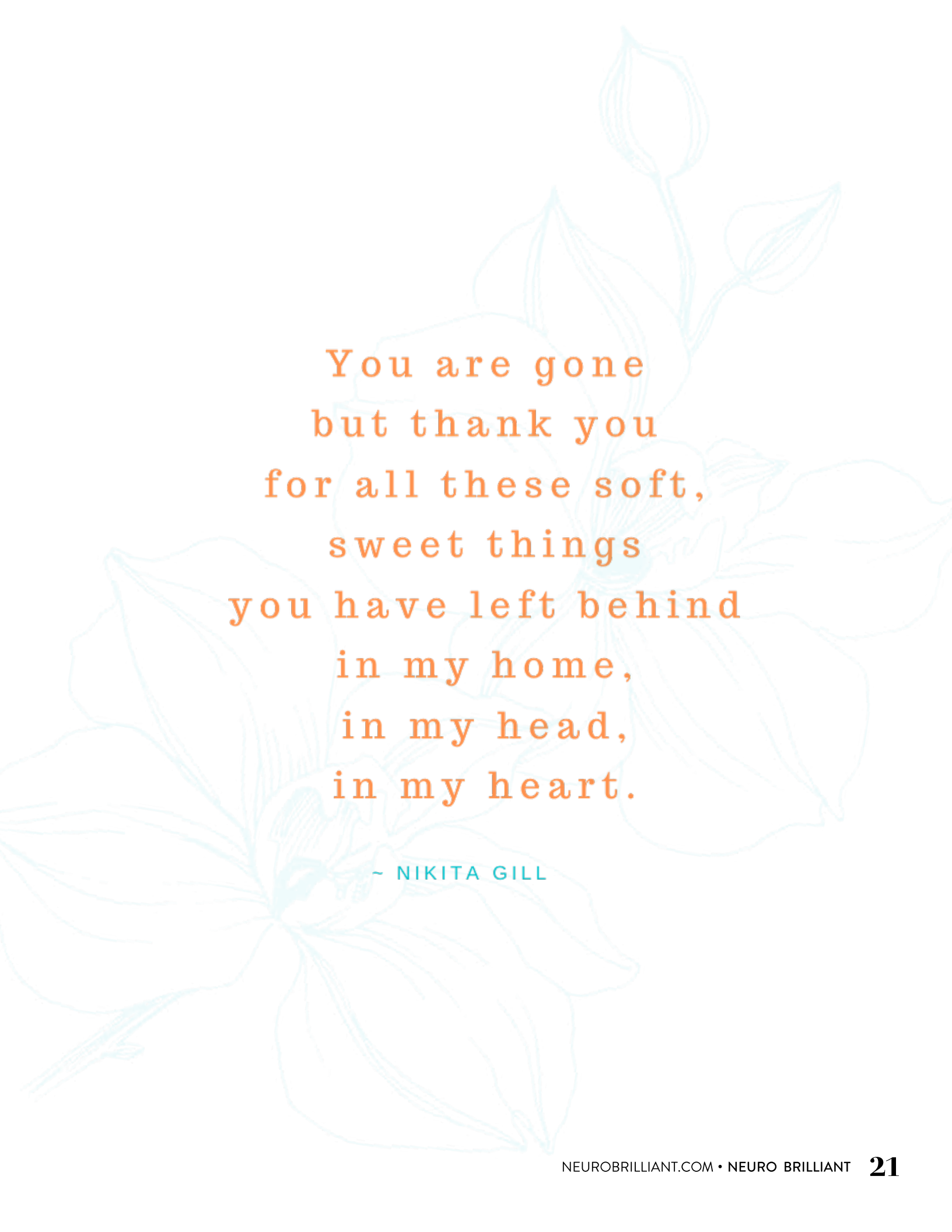
"We interviewed over 100 nurses and parents to make sure that others were identifying the same pain points with tube feeding we had experienced. We also took all the feedback to heart, and it really shaped what the FreeArm is today. Since the product is a medical device, the testing and licensing was 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 bringing their concept to market took approximately a year. At six months, they had a prototype. And six months later, their product was sent to a manufacturer. Today, there are two versions of the helping hand: The Freearm and the Freearm Muscle. Both are having a tremendous impact on the lives of medically complex families.



Misti and Will are working through the grief of losing their son by preserving his memory in meaningful ways. While they can't watch Freeman grow up with other kids, and live the life they once dreamed, they are creating a lasting tribute to their son's memory. Inspired by their beautiful boy, Misti and Will continue to serve their local community and medically complex families. The love they pour into their work demonstrates that Freeman is very much alive in their hearts and community.

"The pain of losing your child never goes away, but we are honored that Freeman taught us so much in his short life. We couldn't have created the FreeArm if it wasn't for our beloved Freeman." ■



You are gone  
but thank you  
for all these soft,  
sweet things  
you have left behind  
in my home,  
in my head,  
in my heart.

~ NIKITA GILL



# WHAT IS NEURO BRILLIANT LIFE?

Neuro Brilliant Life is an advocacy clothing line. We're here to spark conversations and spread disability awareness. If you enjoyed this story and would like to see more stories like this in our upcoming quarterly magazine, support our work at [neurobrilliantlife.com](http://neurobrilliantlife.com).





A CROSS-DISABILITY ADVOCACY CLOTHING LINE

[neurobrilliantlife.com](http://neurobrilliantlife.com)



Welcome To

Our Family



# Neuro Brilliant explained

written by CONNIE MINK

**H**ello friends! I'm Connie, the Founder and Editor-in-Chief of Neuro Brilliant Magazine, and I feel beyond blessed to be a small part of our beautifully brilliant community.

As you can see, I am surrounded by my beautiful kids, Madeline and Hayden. We do just about everything together, including writing children's books, composing music, and now, creating a special needs magazine to help other families, like our own, feel better connected.

So, where did our story begin? Well, about five years ago we packed up our home, put our things in storage, and set out with a simple dream to travel the world, experience the beauty of diverse cultures, and sprinkle in a little homeschooling along the way. Needless to say, it's been quite an adventure!

We've enjoyed our laughs and shed our tears, bringing us even closer together as a family. During our travels, Hayden, my neuro-brilliant autistic son, was diagnosed with tonic-clonic focal epilepsy. His unpredictable seizures brought new medical complexities aboard our journey, and I will admit there were several times where I was tempted to call it quits and head back home. But somehow, I just knew something deeper was brewing beneath the surface of the adversity his newfound epilepsy presented.

Thankfully, we stuck it out, stuck together, and continued our world travels. Our adventures have presented our family with some unique character-building opportunities and soul shaping experiences that have brought us closer together while unimaginably expanding our world views.

Together, we want to share, not only our own, but the heartwarming stories and brave journeys of so many amazing neuro brilliant individuals with you! So, we are combining our creative juices to create

Neuro Brilliant Magazine, a cross-disability magazine, designed to uplift, inspire, and empower neuro-brilliant families through the power of storytelling.

Our vision is to tell real-life, everyday stories of the medically complex journey in a deep and meaningful way. Stories that are honest, raw, sincere, and, on some level, provide eye-opening insights that aren't offered through any other special needs publication.

I'm passionate about openly sharing our community's neuro brilliant message, so that when you flip through the pages and read our stories, it feels like you are listening to a close friend. With the reading of each story, I hope a part of your humanity feels heard. Because once we are heard, it is so much easier to move forward in life - no matter where we are in our journey.

In this magazine, we also hope to shine a light on one of the biggest problems medically complex / additional needs families face all around the world - disconnection. We've been there! We've shouldered the stress, anxiety, fear, and disconnection that comes with being a neuro-brilliant family. Not only did we become disconnected from ourselves and our loved ones, we also became disconnected from "normal" society due to lack of inclusive spaces for families like our own. So we're here to shine a light on that - and many other topics to help our global community come together in meaningful ways.

Neuro Brilliant Magazine is where disconnection ends and inclusion begins. This magazine is designed for additional-needs / medically complex families of all levels and abilities. So, whoever you are and wherever you are on your neuro-brilliant journey, we welcome you to our family!

*from our hearts to yours*

*thank you*

*for your support*





## How did we do?

We're working hard to bring you quality content. If you have story ideas or topics you'd like to see us include, please let us know!

Let's connect at: [www.neurobrilliant.com/connect/](http://www.neurobrilliant.com/connect/)

To learn more about our mission as a special-needs family, visit:

[www.neurobrilliant.com/our-story/](http://www.neurobrilliant.com/our-story/)

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