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The experience of navigating the NICU as a parent can be frightening, overwhelming, and filled with uncertainty. It can also be a life changing experience that drives one to seek out opportunities to create a positive difference for others. In this story, we hear firsthand how this mother was able to gain strength from her lived experiences and maintain a positive attitude which ultimately sparked her commitment and desire to make a difference in the lives of NICU families.

A Mother's Perspective of the NICU Experience: Passion for Advocacy Ignited

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Our story starts with our first ultrasound for our first pregnancy at eight weeks when we found out we were having twins! I just remember seeing a lot of white on the screen and holding my breath in anticipation of the tech saying that something was wrong. But instead, she said “well you have a couple little nuggets in there.” We were in shock! They knew immediately that they were identical because they were sharing a placenta. Shortly after we learned that this also meant that they were at risk for Twin-to-Twin Transfusion Syndrome (TTTS). We were told that we would have to have ultrasounds every two weeks starting at 14 weeks to monitor for TTTS. At our 16-week ultrasound, we found out that we would be welcoming two sweet boys into our life! We made it past 24 weeks when the chance of developing TTTS was higher and thought we were in the clear! Other than there being two babies, it seemed like a pretty uneventful pregnancy. I felt great and the boys were growing perfectly. But that all changed at our 28-week appointment.

In mid-July 2019, my husband Dylan went to Fort Carson for his two-week annual training for the Army National Guard. My parents came into town to visit while he was gone. I was looking forward to taking them to one of our ultrasounds at the perinatologist to see their grandsons. On Tuesday at nine in the morning, we went to my 28-week appointment. I remember driving there in a state of ignorant bliss, no idea that an hour later my whole world would be turned upside down. During the ultrasound, the tech immediately noticed that there was a large fluid discrepancy between the boys. Ryan, the recipient twin had lots of fluid, while Mason, the donor twin, had very little. They immediately called the Children's Hospital Colorado (CHCO) Fetal Care Center for a consultation, and I had an appointment scheduled for the next morning. My parents and I were in shock as we drove home...I had to make the hardest phone call of my life to my husband to let him know that things weren't good, and he needed to come home. He came home that night and the next morning we went down to CHCO. After a long ultrasound and a fetal echo, the boys were



Skin cuddles with mom

diagnosed with stage 3 TTTS and starting to show signs of stage 4. TTTS has 5 stages. Stage 1 is a large fluid discrepancy between amniotic sacs and stage 5 is the death of one or both twins, so it was a pretty severe case. We were beyond the point where they could try to close some of the connections via laser surgery, so we were told that I would be admitted for continuous monitoring and get two doses of steroid and deliver about 48 hours later. Mason had different plans, however. I started having severe contractions at about one in the morning, and despite medication to reduce them, Mason was having consistent late decelerations with each contraction. At 3:30 in the morning the attending let me know that it was time, and they were born less than 30 minutes later just before 4 am on Thursday. So, between the ignorant bliss of thinking that everything was ok before my 28-week appointment and the boys' birth was 43 hours. It was the biggest whirlwind of our life.

After the hustle of surgery was over and getting to quickly peek at the boys on their way to the NICU, I was taken back

to my room to recover. Once I was settled, Dylan hurried over to the NICU to check on the boys and I was alone. The nurses came in for their interval checks, but it was just me, feeling like, how could this possibly be real life? I didn't realize how much that moment impacted me until I was preparing for my c-section with my third son when I was sitting in my OB's office crying over the thought of not getting to hold him or having him taken away - I was still feeling that pain from the first hours and days in the NICU.

My in-laws brought us donuts the morning my twins were born, and I remember taking a bite and my first thought was that I would feel the boys start kicking because they always wiggled when I ate sweets. And then my heart sank because they weren't inside me anymore, but they were *supposed* to be.

It was three days before I was able to hold Mason and a week before I was able to hold Ryan. Mason kept us on our toes with an unplanned extubation while I was holding him triggering them to call a code blue. Twenty-four hours later, he was taken to the OR for emergency surgery for a bowel perforation. He had an ostomy for eight weeks until he went back for surgery. Following the second surgery, however, he developed a central line infection that spread to his blood and lungs setting him back in his respiratory progress. Talk of a trach and g-tube started, but after a final round of steroids Mason made a huge leap and weaned down to low flow. Meanwhile, Ryan had a couple of steps back with the initial attempt to extubate him on his second day of life. He ended up on an oscillator and on nitric oxide for about a week. He steadily made big gains after weaning to low flow by around 34 weeks gestational age and was our feeder-grower until he discharged in mid-October - right around my due date. Mason took another month to be ready to go, but we finally walked out of the NICU for the last time with both of our sweet boys on November 15th. We had watched so many other families walk by our room with their sweet kiddos for the last time and yearned for that moment. It felt like it would never come. And then it DID! That moment felt better than I could have possibly imagined.

Reflections

Our NICU experience was the most challenging, devastating and transforming experience of my life. We were in the NICU for 114 days before we finally went home, and during that time, I only went one full day without seeing them. And while it was exhausting to be there for 12-18 hours a day every single day, I feel so fortunate to have been in a situation that allowed me to do that.

When you think about becoming a parent, you expect to be with your baby all the time. So, when you are away from them, it is a strange feeling of wondering, am I actually a parent? Is this real? Are those *really* my kids? And even though we were there every day, it was very hard for us to feel bonded to them. At the time, I thought that I was. I cared about them,



Skin to skin time with dad

worried about them, and spent every day with them, but didn't realize how long it took me to bond with them until I had my third son. I realized how quickly I bonded with my son, Owen, compared to my twins. But I don't think that is surprising. While I was excited to see my twins and touch them and hold them for the first time, it wasn't what I had hoped and dreamed for when becoming a mother.

In the NICU there are wires and alarms and tubes everywhere. And while they may be cute in their own way, they are not the chunky, peaceful, newborn that you imagine curled up, sleeping on your chest. All I wanted to do was hold them and snuggle them and nurse them, but I couldn't - the first few days all I could do was cup their head and hold their feet, with my arms in the isolette standing there with swollen tired feet, pain in my stomach from my incision, and tears in my eyes. Honestly, I would finally walk away when I was just too heartbroken to stand there anymore.

And then we could finally hold them, and it was wonderful. Those moments of finally getting to kiss our sweet babies and see them lying on our chest after days of waiting were so amazingly, and inexplicably sweet. But days turned into weeks and weeks into months and a lot of days, despite being there all day and having that time, I didn't even want to hold them. I didn't want to sit there by myself with the deafening sound of the CPAP in my ear, staring at the monitor in fear that they would brady for hours on end. I just wanted my life to be different than it was. I felt so much sadness and guilt every day. I felt guilty that I wouldn't want to hold them, or I felt guilty if I only had time to hold one and not the other, so sometimes I would just not hold either if I didn't have time to hold both of them. I also had a really hard time figuring out a good schedule for myself that worked around care times and pumping and trying to fit in a meal and being available for rounds.



Discharge home November 2019



First day of school, 2024

The nurses, and providers encouraged me to be involved and to advocate for my babies – and I definitely did! I was there for rounds almost every single day. And while I absolutely felt that my thoughts and opinions were heard and considered and validated during rounds, overall, we were not in control of their care. And that’s not necessarily a bad thing! I can’t emphasize enough how in awe we were of the care and skill of the whole team that took care of our boys. The NICU specializes in growing these babies to get them home and thank God because that is way beyond my scope as a parent. But at times, it didn’t feel like they were my boys-it felt like they were babies that, while following strict rules to care for them, I was supposed to love deeply and devote all my time and energy toward with the hopes that one day they would be big enough and strong enough to come home and *then* they would be my babies, but they weren’t really mine yet.

I am so wholeheartedly thankful to the bedside nurses who helped us to slowly overcome those feelings. Our primary nurses were the shoulders we cried on, the ones who could make us laugh even on the really hard days, and the ones who could make us feel like parents. Those nurses helped us to see past the lines and monitors and tubes and told us how sweet and adorable our boys were even when it felt like our family and friends couldn’t. That is just another thing that you grieve - you look forward to your family getting to snuggle and love on your newborns, but our parents didn’t hold our babies until they were 10+ weeks old because they were so afraid to hold them, so afraid to hurt them, or make them sick, so afraid of how fragile they seemed. We tried hard to love our boys, we worried about them constantly and tried to convince ourselves that we really were their parents. But at the same time, we had to release control of their care to other people, and that is so unnatural. I feel like many providers in the field know that, but the way that the tension feels in your heart is something that I

believe can’t truly be understood unless you have been there.

While in the NICU, I was able to connect with another NICU family in a similar situation and I also had a mentor through Children’s Hospital come meet with me. I was so grateful for those connections because often those conversations with strangers were way more powerful and reassuring than conversations with even my closest family and friends. Our family, especially, didn’t want to see us hurting and wanted to try to say something to make us feel better, something to take away the pain. But we were hurting and there wasn’t anything that they could say to make the pain and sadness go away. We were hopeful and terrified, so grateful they were alive and also mourning their journey. We knew that every minute we had with them was a gift but that in an instant everything could change. It’s just hard, every single day was so hard.

When Mason was still admitted and ready to be discharged, we fought for the discharge to be on a Friday night instead of Saturday morning so that we could have a whole weekend before my husband had to go to work that Monday. We were asked “you have already been here this long [114 days], what is one more day?” And while I can understand why they would think that, they need to understand that it never gets easier. It’s not just one more day. It’s another day of being away from home, another day of suppressing our parental instincts and letting other people be in control of our babies, another day of not getting to snuggle up on the couch and just be together as a family because the cords don’t reach, and another day of walking out of those hospital doors without our babies. That feeling is so unnatural, and it never gets easier – I would say it just gets harder and harder because as you do start to bond and become more attached to your baby it hurts so much more to leave them. The beginning of our time in the NICU was mentally and physically draining, we were running on adrenaline, and we were tired from hearing all the alarms and standing up at the isolette and just the roller

coaster of good and bad days, and good and bad moments, that many families describe. But a few months in was hard in a different way. We were more bonded to our boys and just becoming so worn down and tired of being there. We were starting to feel more protective of them and more comfortable participating in their care. They were also nearing being ready to go home so they weren't as fragile as they were when they were first born, so we were just ready to take them home and stop having their care controlled by someone else.

We did fight that last fight and we discharged in the evening of Friday November 15th – and it was one of the sweetest days of my life. Removing the pulse ox and monitor wires, getting them dressed in their matching outfits that we picked out for them when we found out we were having boys, loading them in their car seats, walking down the long NICU hallway and out the doors, riding down the glass elevator with both our sweet boys, walking out the double glass doors of the hospital and to the parking garage, and finally driving away – driving home. It was so familiar since we had walked that walk and driven out of that parking lot probably 200+ times except this time we were *actually* going home. We arrived at our house to balloons and signs and a big group of friends playing “The Boys are Back in Town” ecstatic to welcome us home at last. I still can't listen (or even think) about that song without tearing up. It was a moment that I will cherish forever.

But the journey didn't end there by any means. And while it was so sweet to be home, it was also very hard to take on the role of caretaker that a whole team managed at the hospital and do it on our own. We had weekly well visits and weight checks, and follow up with various specialists, and evaluations with early intervention. I think we had 15 different appointments in the first four weeks we were back. Meanwhile, we were averaging probably two hours of sleep a night total. It was really hard, but we also chose to see the joy and appreciate that not everyone gets to bring home their kiddos from the NICU, and we did, and we are eternally grateful for that. My husband is quick to start sleep talking or do nonsensical things when he is in that in-between sleep and awake state or when he is woken up. We have some funny stories from our 2AM baby adventures – one of the funniest times were when he would scoop up an oxygen tank off the bed, instead of the baby and start patting it over his shoulder and bouncing. Over the past months and years since being home, we have had the pleasure of watching these amazing boys grow and develop into the hilarious and sweet boys that they are. They are feisty, and opinionated, and loud, they are the sweetest one minute and tantruming the next, and I'm here for all of it. It's definitely not easy and being overwhelmed is just a regular part of my life, but a day does not go by that I don't appreciate and admire how far they have come.

As if our life wasn't busy enough we were blessed (and surprised) to find out that we would be expecting another boy and he arrived just 17 very short months after the twins were born. That pregnancy could not have been more uneventful, and Owen stayed put until my scheduled c-section at 39 weeks.

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He was born and less than 48 hours later we were walking out of the hospital doors with him to go home. It was a very, very different experience. Although I am so thankful to have my twins and so thankful to have been blessed with a second and uneventful pregnancy, the first year with all three boys was a really hard year. For the first few months after Owen was born, I was both overwhelmed with joy and gratitude for how infinitely better our experience with Owen was compared to being in the NICU with the boys, and also devastated because I didn't really know what I had missed, and I realized that I had missed some of the sweetest, most amazing moments with the twins because they were born prematurely.

While I wouldn't choose to go through NICU again and wouldn't wish that experience on anyone, I am also grateful for what we have learned about our children and life in general. I am grateful for the strength Dylan and I have gained as individuals, as parents, and in our marriage, and I am also grateful for the way my life trajectory has changed and for my growing passion to help other NICU families. Families in the NICU are experiencing a weight of pain, fear, and grief that is hard to even fathom. It is lonely and heartbreaking even on the good days. While we may never be able to take away that pain completely, I wholeheartedly believe that supporting parents and connecting them with other NICU families both during and after their NICU stay will not only lighten the burden of the NICU but also have lasting impacts on the family in the weeks, months, and years to come.

Emily Fawaz lives in Fort Collins, Colorado with her husband and three children. During her twins 16 weeks in the NICU, Emily developed a strong passion to support and advocate for NICU families. She participates in various programs to support NICU families, including providing lived expertise, and guidance, and serves as a parent leader in several capacities. Emily is an occupational therapist and supports NICU families in a professional manner as an OT in Early Intervention.