



#everyhourstronger

Having a baby in the neonatal intensive care unit (NICU) is a heart-wrenching, anxiety-inducing, and challenging experience. No family wants to have a less-than-perfect baby at birth, and yet every day, babies are born prematurely or with other health complications who need additional intensive care. When this happens, parents find themselves visiting their newborns in the NICU instead of taking them home to the nursery room that they so lovingly decorated and prepared for their baby.

Amanda shares her personal journey – from the moment she was rushed to the hospital, to the emptiness she felt when her baby was whisked away after being born, to the unpredictability of having a son with special healthcare needs. But through it all she has learned that she is stronger and more brave than she ever thought possible. And so is her son.

“Congratulations and I am so sorry.” These were the first words my friend and fellow mom of a micro preemie said to me after my son was born and they are so true. The journey into parenthood is challenging, and when the journey begins with the NICU, it is terrifying.

At 3 a.m. on the first day of my 26th week of pregnancy, I woke up bleeding with what we later learned was a placental abruption. My husband and I rushed to the hospital where we were told I was in preterm labor. My only thought was, “I can’t be in labor. We don’t even have a car seat.” I was in disbelief, and it was surreal to see the doctors and nurses rushing around while I was still trying to figure out what was happening. IVs were placed, magnesium was started as a neuroprotectant, steroid shots were given to help with lung development, and the NICU team came to speak with us. They told us about the different organ systems that would be monitored after our son was born and what were possible complications. My only question was, “what is the chance he will live?”

As a child psychologist working at the time in a rehabilitation department for children with various types of brain injury, I knew too many stories of children born prematurely and with medical complications. My mind flooded with worst case scenarios. Fear swept over me. This could not be happening.

Once magnesium was started, my labor slowed and I spent four days in the hospital, always within “6 hours of delivery.” The NICU team visited several times to answer questions as my husband and I adjusted our expectations of birth. We were going to have a micro preemie. I kept reminding myself that every hour I stayed pregnant gave him just a bit more time to get stronger, and it kept me going. I did a few “bucket list” items like having my husband read a story to my belly.



Amanda and Kayden

When my body and my son’s body could hold on no longer, I had an emergency c-section. My husband was with me at his birth; I heard my son cry and then he was whisked off to the NICU with my husband close behind, and I was alone.

I went to the recovery room and then learned how to pump. Four hours later, they wheeled my bed to the NICU where I saw my son for the first time. He was intubated, under blue lights, so tiny, and the most beautiful (slightly alien-looking) child I had ever seen.

The first week of the NICU went well. Premies are born with a valve in the heart that hasn’t closed yet called a PDA (patent ductus arteriosus) and my son’s closed after receiving medication. He was weaning down on breathing support at a steady pace and we felt hopeful we would have an uneventful NICU stay and were amazed at the strength in that 2lb 10 oz child fighting to live.

We helped with diaper changes and our son’s first “bath.” We prioritized bonding and self-care. My husband made sure we

slept at home and left the hospital. All the monitor beeping in a NICU can become overwhelming at times. We learned about bradycardia episodes and how to help when they happened. We held our son for the first time three days after his birth. We wouldn't hold him again for two more weeks because the rollercoaster was about to take a turn.

Our son seemed sick. He was more lethargic, he needed more breathing support, and his condition was less stable. This means more alarms going off and more intense looks from staff. My son had a blood infection that began a chain reaction of terrifying moments. The PDA in his heart reopened, he was too sick for surgery to close, and too sick to be held. We comforted him through the holes in his incubator. He was reintubated and put on an oscillating ventilator. Our son had a spontaneous intestinal perforation and had to be transported with the Flight for Life team to a higher level of care NICU where he could be monitored by a surgery team. The hospital he was transferred to was the hospital where I worked.

We watched our son struggle for his life two floors under my office. We watched nurses "chase" his blood pressure all day. We watched him need resuscitation several times. We watched helplessly as he fought to hold onto life. I pleaded, "I just want him to live."

With medication and a skilled NICU staff, we saw our son recover from his blood infection, make it through heart surgery, heal from his intestinal perforation without surgery, and come off intubation. Although the rollercoaster did not end there, the scariest turn was over.

The late-night emergency calls from the hospital continued because of his underdeveloped lungs and the difficulties he had learning how to breathe with less support. As the days dragged on, we were surrounded by family, friends, texts, meals, and love.

I returned to work at the hospital after my 8 weeks to heal from the c-section and visited my son every day. I was grateful to be near him and came down to visit during the day and to pump. My husband and I became experts at giving our son a bath and changing diapers while navigating cords and breathing tubes. We learned how to comfort him during diaper changes and medical procedures and flooded him with love during kangaroo time. Our son had a hard time tolerating kangaroo time very long because of his breathing, so we found lots of way to let him know he was loved. We visited him every day and checked in every night until he was ready to come home, 105 days after his birth.

As we prepared to go home, my husband and I encountered changed expectations for what home would look like. We learned that breastfeeding would not be his feeding plan because he needed supplemented nutrition and that we would be going home with oxygen and numerous medications. We learned infant CPR.

We learned we could not put our son in daycare. We learned we would need to limit visitors and practice good hand hygiene, all the time. We learned our current lifestyle and the ideas we had about life with a baby were not a match for what our son needed. We began to make changes to support this new path.

The journey that started our son's life has continued to be a rollercoaster. He has needed multiple surgeries since his discharge and has had additional readmissions to the hospital, including one more ICU stay. Our son has broken a bone, sprained his ankle, needed glasses, and used supplemental oxygen for 18 months.



Kayden aged 4 days with parent's enfolding him

I often say our son has had a lifetime in two years. He continues to need a daily inhaler to help him breath. He has attended and still attends physical therapy, occupational therapy, developmental services, numerous doctor's appointments, and specialty visits. We have missed family outings and have stayed in our home during two respiratory seasons to keep him healthy. We have become experts in changing oxygen tanks, monitoring a pulse-ox, and checking for signs of respiratory distress. We have experienced first hand the impact of medical trauma on ourselves, our marriage, and our family. We have learned to look at the world differently. We have learned to be our son's guide and support through the hard times. We have learned how little we can actually control. And, as the scary moments become less frequent and less intense, we have learned that NICU families are brave, that we are brave, and that we will always be **#everyhourstronger**. Kayden is now two and a half years old.

Amanda N'zi, PhD is a licensed child psychologist. She works in private practice in Denver, CO.