

Kylie's Journey

A NICU alumni story

ON NEW YEAR'S DAY 2014, my husband and I found out we were pregnant with our first child. I had a very normal pregnancy and felt great, until my water suddenly broke at 28 weeks.

Doctors put IVs into both of my arms, pumping me full of magnesium to try to stop the contractions, along with steroids and antibiotics to help the baby. I was taken by ambulance to UWMC. The next evening, Kylie was born via emergency Cesarean section, weighing just 2 pounds, 8 ounces. I was terrified.

Doctors told me the odds of Kylie living and the odds of her having problems later in life (both large and small) – but nobody told me the success stories. Nobody told me about the babies who make it out OK, which would have given me a glimmer of hope.

Nobody prepared me for what it would be like to grieve no longer being pregnant, or how lonely it would feel to be pumping milk for my baby who was too little to feed, or how stressful it would be to care for my baby in the NICU, while also caring for myself and my marriage.

The first few weeks in the NICU were terrifying. Machines were constantly sounding off, medical professionals were coming and going, and I was busy staring at this tiny baby and mourning my pregnancy. My reality was nearly impossible to comprehend.

Eventually, we let our guard down and began to trust the process. I learned that not all sounds in our baby's room were bad; some were just more of a precaution or tracking Kylie's progress. And, I learned that if something goes wrong in the NICU, a huge team of medical professionals is nearby, so I didn't need to tense up when I was alone.

I also learned to be my child's biggest advocate. And I learned that if I had questions, I needed to ask them, and that my concerns would be fielded with warmth and thoughtfulness.

Kylie's journey through the NICU was a smooth one, all things considered. She was discharged after 66 days, and



Kylie in the NICU



Kylie at 8 months

many would say she “rocked it!” Although having a baby in the NICU was emotionally taxing, we found the staff at UWMC absolutely incredible. They became people we could lean on and trust, an extension of our family. They cared for my heart, and helped support my emotions through the toughest time in my life.

Coming home felt liberating, but I’ll admit it was a much harder transition than I had anticipated. I suddenly lost all confidence in my ability to be a mother because I no longer had nurses there to validate me. Over time, I regained trust in myself. As I look back, I just wish I hadn’t been so hard on myself.

Today, Kylie is 8 months old and is the happiest and healthiest baby. Nobody would ever know that she was born 3 months early. Like all premies, she is a fighter and is destined for great things!

What is one thing you wish someone had told you about the NICU?

From Kylie’s mom: I wish my husband and I had been told success stories. Right from the beginning, we knew the odds of our child living or having problems – and since we had never even thought about premature birth, we were terrified. But we now know that the success stories are also plentiful. It would have been invaluable to hear the stories of other families who went through the NICU journey and came out of it OK.

From Kylie’s dad: I wish I had known the NICU protocol. My wife gave birth via emergency Cesarean and was completely put under, so initially I had to care for both her and our little baby. I would have loved to better understand what our life would be like in the NICU. It would have been nice to know that we had our own room, and certain other details such as the nurses’ schedule and doctors’ rounding times, and that we could call the nurses 24 hours a day, 7 days a week to check in.

What is one survival tip you would like to pass on to a new NICU parent?

From Kylie’s mom: Trust the nurses, the care team, and the process. The NICU team is there to do everything in their power to make sure your baby comes out of this alive and healthy. You will feel as though the monitors and machines are constantly beeping. There will be many fearful moments, and you will feel unsure and scared. Lean on the NICU staff and know that they absolutely have your best interest in mind.

From Kylie’s dad: Take care of yourself. Trust the nursing staff to care for your baby if you need to take time away and do something for you and your spouse. When the baby finally makes it home, it’s exhausting and you are on duty 24/7. Self-care time will be very limited once you get home.