

## A Father's Journey

By Kevin O'Regan

Our story began early on the morning of July 18th, 2019 when I was awoken by a startling scream. My wife Nikki had woken up in the middle of the night to discover she was bleeding, a lot. Nikki was just four days into her 27th week of pregnancy with our twin girls. In a haze of sheer panic, Nikki waited in the car crying as we called our next-door neighbor to stay with Ben and Lily (our older set of twins) until Nikki's dad could drive from his home two hours away to stay with them. With our eldest in our neighbor's care, we rushed to Abington Hospital – Jefferson Health in Abington, Pennsylvania.

Nikki was immediately placed in the triage portion of the maternity ward. We felt as if our worst nightmare was coming true again, as another frantic visit 11 months ago ended in the tragic loss of our daughter Sophie at term when it was discovered that there were knots in her umbilical cord that had suddenly tightened. Thankfully, after what seemed like an eternity, the medical team were able to find heartbeats for both babies, and so far, they were doing fine.

The focus now turned to Nikki to try and ascertain the reason for the sudden heavy bleeding. In past ultrasounds, it was identified that Nikki had a very marginal placenta previa. Although the doctors had originally told us this would likely rectify itself in the next few weeks as the babies grew, without another known cause, they believed this was the likely reason. While the doctor prepared us for an emergency caesarian to deliver the girls, time passed, and after an hour or so the bleeding slowed down and panic was averted for the interim.

After a few hours in triage, Nikki was transferred to the maternity ward for additional monitoring where the conversation turned from an emergency delivery to the possibility of moving Nikki to a "Mom Unit" for the remainder of her pregnancy. That evening I drove the 10 minutes back to our house to check on the kids (and Nikki's dad). After speaking with Nikki and preparing for my return to the hospital early the next morning, I received a frantic call from Nikki telling me she started bleeding again and that I needed to get to the hospital as soon as possible for delivery of our girls.

As I walked into the maternity ward, I saw the Obstetrician (OB/GYN) outside Nikki's room; she was the same OB/GYN that delivered our eldest twins, and I took much comfort in that as we both knew her very well. Nikki's doctor told me outside her room that we had to move ahead and deliver the babies for Nikki's safety given the volume of blood she was losing. I recall tearing up and thinking to myself that I couldn't let Nikki see me crying as I had to be strong for her since I knew she was very



*Proud Dad with Maty and Lucy at 33 weeks PMA.*

scared. After taking a minute to compose myself, I walked into her room, held her hand, and the adventure began.

We were whisked off to an operating room and before I knew it, Lucile 'Lucy' Sophie and Matylda 'Maty' Maura had entered the world topping the scales at a whopping 2 pounds, 6 ounces (1179 grams) and 2 pounds, 3 ounces (1043 grams). Each baby had their own team working with them and I got a brief second to see each baby (and cut Lucy's umbilical cord!) before they disappeared to the NICU. I was genuinely surprised by how big they looked, or maybe long is a better description given how skinny they both appeared. In my head a 27 weeker was going to be tiny, and in the grand scheme of things they certainly were, but it was a small comfort to see that they resembled a full-term baby much more than I expected.

After staying with Nikki as she moved through recovery and was transferred to her hospital room, I set off to the NICU to get an in-person update on Lucy and Maty. The NICU was already familiar to us, as our other set of twins, Ben and Lily were born



*Bringing the girls home.*

at 35 weeks, 6 days in the same hospital where they spent 5 days in the NICU. Their time in the NICU, however, was not due to prematurity. Ben had a broken humerus from a traumatic delivery, and Lily had low glucose levels. Thinking back on our first experience with the NICU as worried first-time parents, those 5 short days felt like a lifetime. Little did we know the months of NICU life that were to come.

When I arrived Maty and Lucy were in their incubators surrounded by medical equipment with all kinds of tubes and wires connected to them. They were stable, and according to their nurses, doing as well as could be expected. The array of equipment and sounding alarms everywhere was overwhelming - as a parent you want to protect your children from harm, and that day, I felt absolutely helpless.

For the first few days we could only touch them through the walls of the incubator, holding their tiny hands as their little chests rose and fell with each CPAP assisted breath. Finally, after two days, they were stable enough to be held. I still remember the image of Nikki holding them for the first time. After a troubling year for our family, she had never looked so happy.

At first our time in the NICU moved slowly with what seemed like little progress from day to day. In my limited experience of illness or hospitalizations, there are usually typically signs of change that either signal improvement or regression. In my NICU naivety, I was expecting a similar sign with the girls in those first few days or at least some indication that they were going to be ok. Obviously, no one can predict the future, but I longed for a crystal ball for a peek of what was to come, some indication that the long road ahead was going to ultimately end

with all of us going home together, happy and healthy.

Both my wife and I have an extensive science background, so we questioned everything, wanting to understand the how and the why behind each and every decision and change in their care. We always made sure to be present for daily rounds so we could be part of the conversation and advocate for the girls. Personally, I became focused on the numbers on the monitors. Their heart rate, respiration rate, oxygen saturation - those were the numbers I lived by for three months. Initially every alarm was terrifying, who wasn't breathing, what were their vital signs?... was their oxygen saturation level dipping?... was I holding the girls incorrectly? Over time I came to understand that each alarm wasn't a cause for panic, just a signal to assess the situation and address any issues accordingly.

Being a small part of Maty and Lucy's daily care made a huge difference. I looked forward to just doing things like changing a diaper or taking their temperature; these small things in the crazy situation made me feel more like a normal parent in a far from normal situation. The highlight of course was holding them, feeling them breathe against your chest - they felt so small, so fragile, yet so incredibly strong and resilient.

Of course, the NICU experience is full of ups and downs. You hope for consistent steady progress, reduced breathing support, gradual weight gain and positive test results. Each battle that the girls won came with new challenges for them navigate; it truly is a rollercoaster. It was important to try and stay positive, but at the same time to temper your optimism and try to maintain an even keel so you could enjoy the progress without getting too down about the setbacks.

Our NICU had a tradition of printing out signs to celebrate various milestones – a pound gained, a bottle finished, and so on. As a parent, as simple as it seems, you wanted to see those signs next to your child’s incubator so badly. Given the layout of the NICU, we could see other babies ahead of ours in their journey. Although the plethora of signs at their stations were always a source of jealousy, they also gave us hope that our girls would someday soon reach these seemingly small but important milestones.

Slowly we began to chat with some of the other NICU parents. The more familiar a face, the less awkward we felt saying hi or chatting to them briefly without disturbing their privacy. Those conversations helped. It’s a unique experience and chatting to someone going through the same gamut of emotions was a welcome distraction.

In the initial weeks of our journey Nikki spent the day with the girls and I would go in for a few hours each evening after work to sit with them and hold them. Leaving them at the end of each visit was always difficult, hoping for an uneventful, alarm-free evening; yet our girls were never alone, and in many ways, neither were we. The entire NICU staff including the receptionists, the respiratory therapists, the doctors, and most importantly, the nurses who doted on them every day all became part of our family. Loving our children with us and for us, sending us pictures and updates in the middle of the night, talking to us about nothing and everything. They were fantastic and will hold a special place in our hearts forever.

As the girls progressed, we were able to play a bigger and bigger role in their care, feeding them bottles, changing their clothes, and my personal favorite – bath night. Despite the obvious physical improvements that the girls were making (weight gain, transitioning to a bottle, and breathing without assistance), our minds always turned to their development. Fortunately, our NICU had a Developmental Specialist on staff. She had spent some time with the girls throughout their stay, initially monitoring how they reacted to their care and feedings, but it was when she administered the Assessment of Preterm Infants’ Behavior (APIB) test that I was really intrigued. The idea of the test initially seemed a little bizarre as I couldn’t see how a preterm baby could possibly do any of the things being assessed. Yet, to my genuine surprise, each test elicited the predicted response, and it was immensely comforting to see that the girls were behaving as they should from a developmental standpoint.

After 75 days, the girls were finally given the green light to go home. Looking back on our experience in the NICU, we were incredibly fortunate for a relatively smooth journey and will always be indebted to the wonderful, caring staff we met and befriended. With their help, our girls have already overcome the greatest challenge of their lives and are now thriving one-year olds. Each day brings to light new facets of their personalities, and I can’t wait to see who they become in the years ahead.

*Kevin and Nikki live with their family and a very lazy basset hound in Hatboro, Pennsylvania.*



*Maty and Lucy – one-year birthday (9 months adjusted).*