

# Kaya's Fight

Everything seemed very healthy throughout my pregnancy other than some minor high-blood pressure concerns, but I had always had high blood pressure growing up as a kid, so no one took notice. I remember it was the week before our "intended" baby shower was scheduled, and I had come down with some very severe pains one night below one side of my ribs. After a few minutes, I started getting really scared as the pain got much more intense and more frequent. I immediately called Essa at work and asked him to hurry home. I then called my doctor, and he suggested I give it a bit more time and if the pain doesn't go away, go to the emergency room. A few minutes later, Essa came in with obvious concern in his face as he saw that I couldn't sit still, and was clearly in tears due to the overwhelming pain I was feeling. I told him what the doctor had said, but he wanted nothing to do with it and forced me in the car right away so we could go to the hospital.

We made it to St. Elizabeth Hospital at approximately 11:30 p.m., by 11:35 p.m. I was admitted to an emergency room and had my blood pressure taken. As the nurses were signing me in, they checked the reading on the blood pressure machine and immediately looked at Essa and asked him if I had experienced any seizures, and if so how many and how severe. Essa looked at the nurse with a dull stare in his eyes like he wasn't sure how to answer. My blood pressure reading came back at 226 over 129, a reading that far exceeded the point of a person having seizures. Luckily my body hadn't let it get to that point. After doing a few more labs, they determined the cause almost immediately. I was diagnosed with severe HELLP Syndrome.



Within minutes nurses were calling the three hospitals in the region best known for their Neonatal Intensive Care Units and especially the ones that had a Level 4 Triage Unit for me. They were extremely concerned with my deteriorating health. I was transferred via ambulance to University Hospital and taken immediately to the ICU closest to their NICU. As soon as I was admitted, another set of labs was taken. As we waited, we spoke with several different doctors, surgeons and anesthesiologists, all of whom explained what was happening and how serious the situation was.

At that point, Tate, a fellow from the NICU down the hall, came to speak with us and gave us the honest truth... he said that Kaya was going to be born extremely

early and would have approximately a 40 percent chance of making it. As he was finishing his sentence, a horde of even more doctors than the first round came rushing into the room and interrupted our questions with an immediate hurry to get me into surgery. Apparently, the second lab results had come back, and within less than an hour, the situation had reached a critical stage for both of us, as my body was beginning to shut down. They rolled me out of the room and immediately into surgery. I still remember the tears in my dad's eyes as he watched them take me away.

Approximately 15 minutes later, Kaya was born. She weighed in at 1 pound, 6 ounces and within a few days got down to 1 pound, 1 ounce. The doctors that delivered her all told us that they never know what to expect in those types of circumstances, but they had never expected her to come out screaming. From what we were told every single doctor in the room was shocked to hear her powerful little lungs. We were obviously glad to hear about it, as it gave us at least a small bit of hope.

There were a lot of promising signs in the first few days, but all of the doctors had informed us that the initial 48 hours are what they call a 'Honeymoon Stage.' With all of the adrenaline and hormones that occur shortly after being born, the baby's body tends to do rather well. Kaya's honeymoon stage lasted a little over a week. This, again, gave us more hope... but things then began turning for the worst.

Kaya was very touch-and-go after the first week as her lungs began retaining too much water and it was getting harder and harder for her to breathe. There's no way to explain the feeling you get when you're finally discharged from the hospital (without your baby) and receive a 4 a.m. phone call informing us that Kaya had coded during the night, and needed to be revived. We received that phone call several times over the next few days and were more scared than ever that she wasn't going to make it. That next week they had switched her from the usual respirator to an oscillating respirator, in hopes that it would allow her body and especially her lungs a bit more of a chance to breathe and more time to grow. As things started to seem like they were getting better, the doctors had detected some kind of infection and diagnosed her with NEC, or necrotizing enterocolitis, which has taken the lives of many premature babies as there is no known cause or cure. It truly seemed like every time things started to look up, we had yet another scare, whether it be another infection that they couldn't determine the type or cause, or Kaya requiring another blood transfusion due to a low red blood cell count.

After several weeks of her pushing and fighting to make it just another day, we were finally able to hold Kaya for the first time and were honestly somewhat forced to do so. Her neonatologist was adamant about her next phase of treatment, which they referred to as "Kangaroo Care." Apparently, the best treatment Kaya could



receive at that point was our love. She weighed just a little over 2 pounds, and I can still feel her tiny little fingers gently feeling her way like she knew it was me. It was one of the most amazing feelings I have ever felt. The most amazing part about that day is that the second I lay back in that chair and started feeling her heart beat against mine, I could clearly see the reading from her heart monitor begin to level out. From what the nurses had told us, our skin-to-skin treatment was going to be the only thing that would help her keep fighting. It shows her that you're really there for her and that she can truly feel your love, and that love tells her brain

to create all of the things her body needs to help her grow faster and survive. After that day Essa and I were taking every chance we could to hold her. Essa was there three times a day anyway but was always going to or from work, or picking me up to bring me back to the hospital. We used to look forward every single night to going back to that hospital to hold her, or even to just watch her sleep.

After several more weeks of infections, treatments and rounds with the doctors, she had been diagnosed by her ophthalmologist with R.O.P., or retinopathy of prematurity. She had to undergo two laser eye surgeries to stop her from going blind with what they determined was a common occurrence with micro-preemies called retinal detachment. From what we were told, the controlled environment and oxygen provided to a fetus in the womb no longer exist after premature birth, so the blood vessels behind the eye grow sporadically, detaching and causing complete blindness, obviously a grave concern. These two eye surgeries were also no walk in the park as it required her being put BACK on a respirator because she had to be sedated, after being taken off of it just weeks before. She did not like this very much as she extubated herself after both surgeries. Again, we knew we had a fighter on our hands.

From then on things began to look brighter and brighter. Kaya finally graduated from her incubator as she was able to maintain her own body-heat, and wear actual baby clothes! I was one excited mommy.

After a grueling 163 days, Kaya finally came home.

It was a lot of preparation, to say the least, as she was coming home on oxygen and with a heart monitor. After several months of frequent doctors visits and nervous minutes in waiting rooms, Kaya was finally able to breathe on her own and lose the oxygen and her heart monitor.



Today, Kaya is doing better than we could have ever hoped for, thanks to the amazing doctors and nurses at University Hospital, and especially Children's Hospital. They helped us SO much in the first six months of Kaya's life and to this day, by treating her as if she were their own. Thank you to the people who gave blood to help my baby girl when she needed it the most, to breathe. Thank you to all of the mothers out there that saw the need to donate their breast milk as well because they too saved Kaya's life. We are all so thrilled with her progress, and although we would like her to gain a little more weight (who wouldn't?), she's a very happy and healthy little miracle.

