UW Medicine UNIVERSITY OF WASHINGTON MEDICAL CENTER

Frankie's Journey

A NICU alumni story

I HAD A HEALTHY PREGNANCY until around 23 to 25 weeks. My blood pressure was higher than usual, so I needed to see a specialist. I met my obstetrician and I never left the appointment. I was put on bed rest at UWMC, learned that Frankie would come via emergency Cesarean section, and that I had either hypertension or preeclampsia.

Just 2 weeks later, Frankie greeted the world at a whopping 1 pound 11 ounces. I was happy the night I delivered, relieved she was out.

Everyone at UWMC was awesome, but it didn't help the emotional roller coaster. Will she survive? That's what I needed to know. The machines, seeing how frail-looking the preemies are (they are not frail – they are strong ... the strongest!), alarms going off (how awesome to alert the doctors and nurses but as a preemie parent, they make you nervous) ...



Frankie in the NICU

You overhear some babies have to have surgeries (you panic, you are relieved it's not your baby ... but will it be mine?), people coming and going through the NICU (germs, germs, germs) ... You wonder, should I meet and introduce myself to other parents? What does it mean when you don't see a parent anymore or the baby has been moved?

It helped me to see Frankie every day and call the nurses every night. I never missed morning rounds with all of her doctors. I needed to hear from them!

I created a routine: Wake up, run (my therapy), leave house by 4:30 a.m., drive 2 hours to Seattle, join in rounds, have some kangaroo time with Frankie (some days it felt good, other days I was uncomfortable with her – it's not like snuggling a full-term baby), have my oatmeal in the hospital cafeteria, back up to see Frankie, and chat with nurse.

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

Nurses and doctors kept us informed about what was happening throughout Frankie's stay. The NICU is about protocol and a preemieappropriate plan. I thought that my baby was different from the others. Nope! Preemie babies have a development chart just as if they were born full-term and their moms had a healthy pregnancy. The NICU is a very advanced, scientific, machineassisted, doctor- and nursestaffed, 24-hour WOMB!

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

My tip is: "Ask for help." People want to help. Have someone be that voice for you. Maybe a family member, best friend, co-worker but tell those who are willing to help, how they can." My mom would say, "Get someone to mow the yard and pick up mail." I didn't have time to ask. So ask a friend, "Hey, can you take the list of these people and have them help out – call my neighbor to mow the lawn, and call my friend to get gas in my car and buy groceries." Step down for a while!

Then, leave by 2 p.m., quick bite, drive home, have dinner with husband, Facebook a Frankie update (this is so easy rather than returning everyone's calls), chores, sleep — and don't forget to pump every 3 to 4 hours — then repeat!

Frankie was transferred to another hospital for insurance reasons. I was very upset. I had a routine, had grown a relationship with staff, and trusted UWMC.

Frankie travelled to the new hospital in rush-hour traffic on a Friday in the heat of summer. She survived, of course, but it was hard not to think the worst.



Frankie at 2 years

It was not the same at the other hospital. Once Frankie could feed from a bottle or breastfeed, she would be sent home. We were shocked when the nurse said she is going home this weekend. What? I don't have anything ready. I was busy being a preemie mom.

I ordered everything online (yep, no baby showers, no fun trips picking stuff out, RUSH-RUSH-RUSH). When she came home on Saturday, she weighed 4 pounds. Sleep was already tough but feeding every 2 to 3 hours is really tough (she had to really work to eat), and I still needed to pump. Quality sleep does not happen for years.

I cannot believe we got through it. We didn't have the same support that I hope others have with friends and family. We struggled with some eating issues and are finally now sleeping through the night. In conversations with others, I find out they experienced the same. It's frustrating because you are tired and you want your routine to get easier - it does in some ways, and then it doesn't.

What I can share now is that my Frankie is not a preemie. She is like all the other little toddlers. We just got to meet her earlier than most parents hope to. She is special to us and we can never adequately thank staff at UWMC, at the other hospital, and her current pediatrician. She came into the world during the opening ceremony of the 2012 Summer Olympics, and now she is running circles around us. Being a preemie parent is not for the weak; preemies are not weak.

I am forever grateful that we live so close to a level 3 NICU. If I had to go through this again, I am sure I would see it through a very different lens.