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This powerful story is more than just a birth narrative – it is a journey through fear, uncertainty, and ultimately transformation. What began as a pregnancy marked by high-risk diagnoses, prematurity, and the challenges of giving birth far from home became the foundation for a new mission.

Stephanie's experience – filled with worry, NICU alarms, and the constant weight of "what if" – shaped her into something more than a survivor. Today, she is a guiding force in improving care for infants born too soon: a passionate parent advocate for monochorionic twin pregnancies, a researcher advancing our understanding of rare complications like TTTS and TAPS, and a voice for families navigating the NICU.

Her story reminds us that empowering parents, during one of the most vulnerable times in their lives, can inspire change well beyond the walls of the hospital.

Two Tiny Heartbeats: A Journey Through a Twin Pregnancy and Care In a Dutch NICU

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Lessons I learned from a rare twin pregnancy and a Dutch NICU. To be honest, when I became pregnant, the chance of having twins wasn't even remotely a factor in my head. In fact, when the ultrasound technician told me there were two babies in there (after a previous scan had definitely only found one), I might have accused her of lying in rather colourful language.

Twins had never, ever been on my radar, and there were none in my immediate family, and the fact that we had been warned at our first OB/GYN appointment that we were now high risk, catapulted us into a new world. We started to learn more about multiples, and a whole new language evolved. Our twins were monochorionic, diamniotic, sharing a single placenta but having their own amniotic sacs. From the first conversation with our doctors, we were educated about the possibility of a premature delivery, because this was indeed probable with our babies. However, when prematurity is accompanied by a rare complication, and coupled with being a foreigner in the country you are giving birth in, the situation becomes a confusing, and sometimes terrifying place.

Twins with a rare disease, born at 31 weeks, in a hospital 16,000 kilometres from my family and friends in a country where I didn't speak the language. This is my story.

A difficult diagnosis

At 24 weeks, we went for a routine scan. We'd been scanned routinely every two weeks, and things had been going fine. But this appointment was different – the ultrasound technician called the doctor in to take a look. "We think you have developed twin-twin transfusion syndrome (TTTS) and need to send you to a specialty hospital."

We'd heard of TTTS, but had not expected to be diagnosed so late (or even at all, given that there was only a small chance



With the girls in the NICU

of it happening), and yet here we were, driving down to the National Referral Center for twins in the Netherlands, as fast as was legal, and terrified of the "what next".

When we arrived, our diagnosis was confirmed, along with a secondary diagnosis, something even rarer called Twin Anemia Polycythemia Sequence (TAPS). This disease came with additional worries and fears – it had only been recently described, and there was not a lot to know about it. Our care team were excellent though and explained everything carefully. Again, it was reinforced to us that the girls would be born prematurely, but the waiting game was in full swing.

For us, we were fortunate that the TTTS resolved spontaneously. This happens in rare cases, however our TAPS

progressed steadily. Each appointment was just a waiting game, and then at 31 weeks, we were admitted as the ultrasound showed grim signs for our recipient twin. I was admitted, had my first round of steroids, and was told within 48 hours, we would have our babies.

One of the things that was reassuring at the time was the opportunity to visit the NICU the night before the girls were scheduled to arrive. It gave a sense of control – that things were already being planned and we could meet some of the team that would be waiting for us. I will never forget seeing those two empty incubators, side by side, and the sounds and smells of the environment.

And then they were here

The girls were born on a cold December morning, I remember the rush of people into our room, the monitoring, the chatter and the building anticipation and anxiety over the “what next?.” The conversations, the lights, the smell of the operating theatre, this all added more feelings of being overwhelmed and worried. The moment they lost my husband somewhere in the hospital, and had to find him to bring him back, the moment the drapes went up, the tugging, the pulling, and then, the first twin was born. It’s a girl! She didn’t cry. They popped her over the curtain to say hello, and I remember hearing someone singing happy birthday in the background. Next thing I knew, our twin’s sister was born. She was very displeased with the early delivery, loudly protesting her change of environment. They popped her little red face over the curtain, before whisking her away.

Then, they brought our twin that was delivered first back to me to say “hello.” A little, pale face resembling a troll doll looked grumpily at me. I cried and told anyone who’d listen she looked like a potato. But she was safe and stable, although needed a blood transfusion. Both girls were whisked off to recovery, with my husband following, leaving me alone in the operating room, processing everything that I’d just been through. It wasn’t until three hours later that I was reunited with my girls in the NICU. I was still unable to move, still very much in shock, but when they placed both girls on my chest for kangaroo care, somehow, this all didn’t matter. That moment was a milestone for me – everything that I had been through over the past couple of months no longer mattered. This was a moment which didn’t erase the past, but it made it easier to live with. This is the moment where I became a firm, fast supporter of kangaroo care, especially for multiples, and that there were no barriers when it comes to supporting two babies or more.

Life in the NICU

Our first NICU was attached to the hospital that had monitored us from our initial diagnosis. This was an academic hospital, and everything was on a schedule. It wasn’t that we weren’t involved in their care, but rather we were vulnerable first-time parents who had been through a tense pregnancy,



A collection of items showing our complex journey through my pregnancy

and we felt more hands off. What was wonderful was that kangaroo care was encouraged, and our team kept us updated and informed.

What was also amazing was the use of video cameras, where my family could log in from the other side of the world and see the girls. When we couldn’t be there, it was reassuring to be able to tune in and see them on the screen. We were given a phone number too, and told it was ok to go out and call in anytime – something that I needed to be reminded to do. I remember the day one of the nurses in the unit told me – you need to go out and see the city. Go have a cup of coffee, it’s ok, we will call you if you’re needed here. I went out and went to the baby store and bought two outfits for the girls. The outfits were miles too big, but it was a sense of accomplishment to buy something for them after so much uncertainty.

We had conversations with the team about their futures, about what would the future hold, and the answers were always “We’re not sure, but we’re going to look after them.” It was refreshing honesty, but at the same time, not always reassuring. But we knew we were getting good care.

And then the day came, where we had the conversation about transporting them to another hospital which was closer to home. If all were going well, this would happen in the next few days. On Christmas eve morning, we got the call. One of our twins was already on her way in the ambulance to our hometown, and the other would follow her in a few hours. Our girls came “home” for Christmas.

Being closer to home

You would think after the emotional climax of the last section that this would be an inspirational and moving moment ... it wasn’t. You see, while we knew one baby was on the move, we did not know if she made it. Or if her sister made it. No one had called us to let us know they had arrived. So, after lunch,



Stephanie with her daughters today

I went down to the hospital and asked at the desk of the children's ward if our daughter's had arrived.

The shock and embarrassment were evident when they realised that no one had called me. I was taken to the NICU immediately and reunited with my girls – who were indeed there, in one piece, and had already been visited by Santa! A small gift was on their cabinets, and the team were very quick to fill us in, tell us the routines, and make us feel at “home.” What was a huge relief was the fact they were so close by. What we were not prepared for was the shift in responsibilities.

At the bigger hospital, it was a lot more hands off. While we could do things like diaper changes, etc, the daily weigh checks and temperatures were always handled by staff. Procedures – and there were many due to the nature of TAPS – were always done when we were out of the room. Here, we were encouraged to be in the room, and to do more and more of our daughters' care-giving activities. We became part of the routine, temperatures, feedings, bathing, even holding and comforting the girls during painful procedures. It felt amazing to be hands on parents.

Of course, things are never quite straightforward, and we knew that it was highly likely that one twin would come home before the other. But when this happened, the staff were amazing and made accommodations that we could still bring our daughter that had been discharged into the unit when we were there for her sister. Small moments like this meant the world. And finally, both girls came home.

Twins in the NICU

What is interesting is the difference in having multiples in the NICU, as opposed to having a singleton. You have days when there are ups, downs, and a whole rollercoaster of emotions just like everyone else – but add in days where ups are happening simultaneously with downs, and you are experiencing worry, and amazing milestones all at once. We were fortunate that our babies were always placed side by side, meaning that we could spend time with them together, shifting our focus between them with ease, but sometimes this is not always the case.

It is also important to recognise the twin bond, but to treat the babies as individuals. This might not sound clear, but giving them time together, but also, when it comes to updates, ensuring that you speak about them as individuals. Another interesting thing is visitor rules. Many NICUs have a one parent/baby rule, but multiples are sometimes treated as a unit with only one parent for both babies. This does not carry forward to the real world and it can make the stay stressful as one parent tries to do the work of two.

It takes a little out of the box thinking, as twins are not the rule in the NICU, but they are more likely to end up there.

When you do not speak the language

Adding to all this was the fact that I did not speak Dutch confidently. In fact, I spent half of my Dutch classes in the throes of hyperemesis (Surprise! Did not mention that one previously) and still to this day do not remember how I passed my B1 exams (language proficiency). I did, however know exactly where each and every rubbish bin was along the route to my class.

Navigating a complicated pregnancy is hard enough, but then the additional stress of prematurity and NICU in your second language is a challenge.

Parents who are not confident in the local language have an additional stress – they are already scared and worried and adding in the fact they have to translate everything in their heads, and concentrate on asking questions confidently to be understood adds to what is already a tough situation. I was fortunate, as most Dutch people speak English well and my husband is a native speaker. There were occasional language barriers and tough situations arose like the night one nurse told me that I'd lived in the Netherlands for 18 months, therefore I should speak Dutch and refused to speak with me in English. I was processing everything that was around me, and trying to translate in my head was not really on my list of priorities. I wanted to be there for my children, and this caused me additional stress. The space in my head for translations was taken up by their needs, their care, and their progression (and rubbish bin locations from Dutch school days!), and this created additional stress.

The one point I think that I need to share here, is that when you realise a patient is navigating things in a second language is to take the time to check they understand you, that they have the space to process information, and that resources are available in their own language – or if someone is able to translate. It makes a world of difference and lightens what can be an additional burden.

Rare is an additional burden

On top of everything else, having a rare disease diagnosis added an extra layer to our days in the NICU. The academic hospital understood the disease and were experienced to a degree with treating it. However, at the local hospital, we were an oddity and

felt like we had to repeat everything over and over and found ourselves frequently reminding people of the right diagnosis.

The fact that so little was known about the disease, and that there was a lot of uncertainty around long term outcomes which added to our stress. To this day, there are still a lot of unknowns, but we face those with the attitude of veteran rare disease parents. But back in the NICU, we were dealing with an additional layer of stress and unknown.

Parents in this situation need support when they are dealing with a rare diagnosis. While specific information is not always available, listening to parent concerns and helping them learn more about their infant's diagnosis will always be of benefit.

And parents, if you are in this situation, I urge you to find communities and support networks. Peer support, particularly regarding rare diseases, connects you with people who understand and have been down the same path. It is essential complementary health care.

And all the other things I want to say, but cannot fit into a heading...

I do not look back on my NICU experience as a negative time in my life. It helped shape the direction I took in my life and who I am today – a parent of twins, a parent advocate for monozygotic twin pregnancies, a researcher, and a charity founder.

Involving parents in the care of their NICU babies empowers them. It shapes how they remember their situation, and it gives them the feeling of control over a situation that sometimes feels out of control.

Kangaroo care has all the scientific benefits we know about, but what it also offers is something that is not peer reviewed – the feeling that no matter what we have been through, that right now, in this moment, things are going to be ok.

Multiples are not scary. They need some additional considerations, but the reality is, it is just about taking a few additional steps to ensure that the needs of these babies and their parent are met.

For family and friends – do not forget to ask how the parents are as well. Everyone is asking about the babies, but that small question of “How are YOU?” can make a world of difference. Take them out for coffee. Bring them cake. Talk about the normal thing. WE need to hear about the outside world as well, as our lives are just a room full of beds, babies, machines, and routines.

And as a parent that has experienced life in the NICU, you never, ever forget the smell of the hand sanitizer. It comes back and there are moments where you are transported back to the darkest days, the sounds, and those feelings are overwhelming. But you learn that this passes, and that life goes on. You remember things in different ways...you have an experience that shapes who you are, and how you navigate the world for the years to come.

There are two things in life for which we are never truly prepared: twins. The quote from humourist Josh Billings could not be any more accurate. I was definitely not prepared for twins, but I'm grateful for the lessons they taught me.

Mission

To improve the future for all infants in hospitals and their families with individualized, developmental, family-centered, research-based NIDCAP* care by providing and assuring the quality of NIDCAP education, training and certification for professionals and hospital systems.



Vision

A global society in which all hospitalized infants and their families receive care in the evidenced-based NIDCAP* model.

*The Newborn Individualized Developmental Care and Assessment Program (NIDCAP) Model:

- Infants are considered individuals, persons, collaborators in care, supported and nurtured by their parents, enhancing their healthy overall development, well-being, and full potential.
- Families are considered infants' key nurturers, advocates, and primary caregivers as well as collaborators in care decisions.
- Infants, families and professionals are integral partners of the Health Care team.
- Hospital environments and culture support and nurture infant and family relationships, and promote individualized strengths, health, growth, and development.
- The NFI provides the framework for NIDCAP care with educational resources, formal training and mentoring to healthcare professionals and families.

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