

The impact of a preterm birth on a family can last a lifetime

Like every parent of a preemie I never planned or expected to be one. Lots of pregnancies are planned, which is a REALLY good thing, but none with the hope or intention of an NICU (Neonatal Intensive Care Unit) experience. This seems like a pretty obvious thing to say but you may be surprised how many people lose sight of this. Once pregnant some women find out that they are in a high risk pregnancy and then are given the opportunity (if you want to call it that) to prepare, as best as anyone can, for a possible early delivery. Many other couples are blind sided by an abrupt end to a somewhat typical pregnancy experience.

I guess I can say that we were the fortunate ones who had a high risk pregnancy and knew early on that there was a chance we would have an NICU experience. But to honest with you, it was not until just a few weeks before I delivered that I even imagined what life would be like in the NICU and once there I did not even consider what life would be like once we left the NICU. You see, I spent the first 5 months of my pregnancy waiting for the other shoe to drop. Praying that we would have A live baby. No parameters, just a LIVE baby. I told myself, and truly believed, that I could handle whatever medical challenges a baby may have just as long as my baby was alive. Our doctors, like many other physicians, gave us the worst case scenario throughout the pregnancy and we were told that we would be lucky to have a baby come home with us. I concentrated throughout the pregnancy on remaining pregnant and complying with my doctor's recommendations trying hard not to imagine the "what ifs". I was afraid to imagine what could happen. I was afraid to hope. I was afraid my entire pregnancy.

We were already the parents of a beautiful 2-yr-old little girl when we learned that we were pregnant again. This was a much anticipated and planned pregnancy and we were thrilled. But at the end of my 1st trimester I miscarried. We were devastated beyond words. We had planned to call the baby Emma Claire and she remains until this day in our hearts. About 2 months later I signed up to donate blood in her memory. While filling out the paperwork I came to the question, "Are you pregnant?". I checked "No" but while laying there with the needle in my arm it occurred to me that I really did not know for sure. My body had not returned to normal after our loss and I really was not 100% but just figured that I was not. I waited a few more weeks and then took a home pregnancy test. I was not hoping to be pregnant. Actually it was probably the last thing on my mind. I was no way near ready to consider having another baby and opening up my heart to a possible loss once again. Both my husband, Jack, and I were still very much grieving.

The stick turned blue. Yep, I was indeed pregnant. I was not happy nor was I sad. I think just numb (and very SICK). I went in for my first OB appointment when I thought I was about 10 wks

along. The OB thought that I was somewhat large for that gestation and may actually be a bit further along so he sent me for an ultrasound several weeks later.

It was then that we found out that my dates were in fact correct and I was actually pregnant....WITH TRIPLETS! A real game changer as they say. Well, this explained so much. First and foremost why I was so really, really sick all day long. (Not your typical morning sickness). Later I would find out it was actually called hyperemesis. I lost 10 lbs. before this passed. It also explained why I was so exceptionally tired. So much more so than with my first but I chalked it up to having a 2-yr-old at home.

As my pregnancy progressed I was put on limited activity (that was not hard given how I was feeling) and later full bedrest. Bedrest was a totally different story. This was life altering. I had a toddler; how was I supposed to take care of her while my husband was at work if I was on bedrest? She was still a baby herself. Still in diapers and needing to be lifted into her crib for naps and was still in a high chair. How as I supposed to NOT lift her? I tried my best but ended up going into preterm labor at 20 wks.

I was put on medications and allowed to go home but my daughter went to live with my parents in the next county since I could no longer care for her myself. I was sad beyond words. My heart just ached. A few weeks later I learned that I had gestational diabetes. The diet stunk but the good news was that I was told that I might have large for gestational age babies. The bad news; they might have some trouble breathing after they were born. The following week I was put into the hospital for the duration of my pregnancy. I was 2 cm dilated and contracting. I was only 26 weeks into my pregnancy. I was so very, very afraid that I was going to deliver. This was before I had ever heard of a baby, never mind triplets, being born this early who could survive. Fear does not even come close to what I both Jack and I felt.

The medications I was on made my heart race and increased my anxiety (which I did not even know I had until now). I cried at the drop of a hat which was so really unlike me. I felt completely out of control which is so unlike the person I had always been. I didn't even look like me. Have you ever seen a woman mid-pregnancy expecting triplets? Trim I was not. I was confined to a hospital bed and had to use a bedpan. I was told to lie on my left side with only 4 15 minute breaks to sit up and eat meals. I was completely and totally dependant on others for everything! The absolutely only thing I felt any control over was that I was the only person who was given the enormously wonderful gift of feeling these three little beings move and kick inside me. Throughout the day the nurses would come in and ask how everyone was doing. I knew who was awake and who was asleep. I treasured every movement and was in total awe of my babies as they grew. I

had a little instigator who would get everyone going and then fall asleep (later known as baby "A"). He was the same guy that at 28 wks decided it was time to break out of there and tried with all of his might to do so. I was told that I was having 3 boys but throughout the pregnancy I just really felt like the little one laying across my rib cage was a little girl. My old Irish grandmother would tell me that girls were closest to their mother's heart and this little one could not get any closer. When the nurses would listen to the heart beats each shift they could not help but hear this little one's heart beat as they were looking for mine and when they looked for this baby's mine was always in the background. This baby (baby C) was so close to me that all of the moving around caused one of my ribs to break and made breathing difficult and caused such pain with every movement. My third little one (later to be known as baby B) just took my breath away. He was always so very, very quiet. He was my biggest and easiest going and seemed to seldom move. I worried about him constantly throughout my pregnancy. I was always so relieved when they would find his heartbeat since I so infrequently felt him move. I was always so afraid that he may have died and I did not know it.

The pregnancy was EVERYTHING!

I never imagined, nor prepared for after delivery: emotionally or logistically.

Ask me anything about a multiple birth pregnancy. I read everything I could get my hands on.

I was afraid to think about the possibility of life afterward.

On a beautiful August morning I went into labor. I was almost 32 wks and no amount of magnesium sulfate was going to make it stop. Jack rushed to be at my side and the delivery itself was nothing but a quick blur. I heard my little instigator (baby A) cry as he entered the world. The most beautiful sound you ever could possibly imagine. His birth was followed quickly by sudden silence and a flurry of activity as his identical twin (baby B) was quietly born. He did not cry but I was assured that he was alive as they whisked him away. I did not get to see him. He was my quiet one. A moment later it seemed like attention was now focused once again on my belly as I heard someone sigh (humfff). My little one closest to my heart it appeared was not quite ready or willing to make an entrance. After what seemed like an eternity, but was more like another minute or so, a little cry and then silence. I panicked. What was wrong? I even tried to sit up to find out. Nothing was wrong; it was just that everyone was surprised that baby C was a GIRL. Oh, is that all. I knew that already. They brought her to me and she was completely perfect in every way.

As the babies were being looked after and moved to the NICU Jack and I named them.

As I was moved into recovery a doctor came to speak with Jack about our quiet one (Baby B). He was indeed our biggest and apparently also our sickest. They wanted to do a spinal tap on him and needed Jack's consent. They left and the next 48 hours became a foggy memory. Because my blood pressure dropped I was not able to get up or go down to the NICU to see the babies for

several days. I relied on Jack to describe them to me and tell me what was going on with each. This was such an unbelievably unsettling feeling. Up until this moment everyone asked ME about the babies now I did not even know what they looked like. Being wheeled into the NICU I didn't even know which babies were mine.

When my babies were in the NICU I felt as if I was a bystander in their lives instead of being their Mom. I was not allowed to hold them, to nurse them, to kiss them. I stood back and watched caring strangers tend to all of their needs and my heart broke. We were on a roller coaster in a foreign country, always afraid of what was around the next bend while trying to understand a totally unfamiliar language and somehow stay connected to our little 2-year-old at home.

Whatever little control I may have felt like I still had while pregnant was completely taken from me once I delivered. The NICU was overwhelming: the sounds, smells, temperature, the language, the machines and most of all the people. The medical staff was extremely intimidating no matter how kind they tried to be. Even though I had a high risk pregnancy, and you would think I had months to prepare for an NICU experience, in reality I had months to fear an NICU experience and was completely unprepared. I did not know what questions to ask. I did not know what was important and what was not. I had learned how to advocate the best I could during my pregnancy for myself and my babies but I did not even know where to begin in the NICU.

Our babies were born back when they used soap and water in NICUs. It was 1987. As it turns out my babies were very, very typical 32 weekers although they were extremely large (because of the gestational diabetes) which was a gift. Because of the hyperemesis I was only able to gain 32 lbs from my pre-pregnancy weight and that had been a concern of mine. The boys both needed ventilators but my daughter did not need any additional oxygen support beyond the first day. They each received blood transfusions several times which was a really big concern for us. As I just mentioned, my children were born in 1987 and there was still much fear over donated blood being tainted with the AIDS virus. We would not deny their receiving blood but we wanted to know when they were getting it. Unlike a spinal tap, blood transfusions were not considered invasive procedures and therefore we did not have to give consent each time they received them. The hospital we delivered at did not have the option for us to give direct donor blood but we asked. When I asked my doctor about how we would know if they were getting tainted blood he said that we would find out within 7 yrs. SEVEN YEARS! Can you imagine? This is what he said.

The medical staff was polite and nice and didn't really seem to care if we were there or not. Often it seemed as if we were in the way and when we visited our babies the staff stepped away. They

may have thought that they were giving us space and privacy but we needed someone there to explain and teach us what was going on. Our experience was prior to Family Centered Care in the NICU and we can only hope that many of our experiences would not occur today, but having toured NICUs over the years I am sure that they still do.

Once our daughter, my smallest although my healthiest, was in the feeding and growing stage I asked if I would be allowed to nurse her at the breast. A few days later when I asked again the nurse checked with someone and got back to me. She seemed somewhat distracted. As it turned out my wanting to nurse at the breast was somewhat unusual in the NICU and appeared to be a real bother for the nurses, although they did not say it. They had to find a rocking chair to bring into the NICU (there were no chairs in the pods) and then get the screen from the unit closet to put in front of me for privacy (which at that point I really did not care about). And when my daughter lost weight after my first attempt at the breast it was like there was a sigh of relief from the nurses so that they did not have to do that again.

The advent of Family Centered Care in the NICU has made such an enormous difference in so many ways that in this day and age you just could not imagine. As an example, our pediatrician checked in on our babies while they were still in the NICU and stopped down to see me one morning. He was going over what was going on with each of the babies when he said that one of my son's ventilator oxygen settings was pretty high. I got upset hearing this since he had been doing better and just the day before they had started lowering them. I asked him again if he was sure and, oh yes, he was. It was then that I asked if we could continue this conversation in the NICU. I doubt if you have even seen a c-sectioned triplet mom skedaddle faster down to the hall than I did that day. As it turns out he got baby A and baby B confused and it was our other son that had the high oxygen settings, which he had had the day before and there was not much change.

After I was discharged I made it a point to call the unit every morning to check in on how everyone was doing that day. One time a few hours after I had called I came into the unit and went straight to one of my son's area since he had had a bad night. When I entered the room his heating tray was empty. I looked around and I could not find him. My heart just stopped. I looked around and could not find a nurse to speak with. I went back out to the desk and must have been white as a ghost since a nurse came running up to me. I asked if something had happened to him since I called earlier that day. I was afraid to say it out loud but I thought that he had died. As it turns out he actually was doing a bit better and they had moved him to another room. Something like this would not be expected to happen nowadays but just recently I spoke with a mom who had a similar experience.

The day before I was discharged from the hospital a nurse from the NICU came to visit me late one evening. She had heard that I was going home the next day and wanted to give me something. At that time cameras were not allowed in the NICU but there was a Polaroid camera on the unit and she had taken a picture of each of my babies for me to take home. Can you possibly imagine what a treasure these were? I carried them everywhere with me. When I used the electric breast pump I held them. When I slept they were under my pillow. When I awoke I kissed the photos and my tears blurred the color.

I found that providing breast milk was the ONLY thing I could possibly do that no one else in the NICU could do. It felt as if it was the only way I could be a part of my babies' care, a part of their lives. Pumping became second nature to me and my days after discharge revolved around pumping, eating, drinking and visiting the babies. Every drop was like liquid gold. I just did not produce that much. One evening when Jack and I were with the babies, they must have been about 2 wks old, we decided to each visit with one baby first and then go to the room or pod that sickest baby was in together. They were each in different rooms which was sometimes hard. When I entered the room I asked the nurse if she had had enough milk for that day and she did not answer. She looked at the other nurse and then they approached me together. I knew something was wrong but could not imagine. Was there something wrong with my milk? Did something bad happen during a feeding? They were sorry but they had to throw out all of my milk from this day. It was not that something was wrong with it but rather they had left it out too long to thaw and it was no longer good. I looked at them in disbelief. This may seem like a very small thing to you but please keep in mind this was the ONLY thing I felt like I could do for my babies and now it felt like this too was taken away from me. I literally sat down on the floor of the NICU and cried. The nurses did not know what to do with me (or for me). They did not want me upsetting the other parents and they certainly did not want me sitting on the floor. One went to call the social worker immediately thinking, I guess, that I had just totally lost it. If you speak with parents who have had a baby in the NICU for more than a couple of weeks they could each probably tell you when their "melt down" occurred. This was mine. When you hit the wall and all of those emotions you have kept bottled up and hidden so that you appear as if you are holding it together just come pouring out of you. There was no way to stop it. It just happens and there is no turning back.

Coming Home

While I had been in the hospital Jack had bought a house for us. I had not seen the house but I knew that it was just a few towns over from where my parents lived. All I asked for was a large kitchen, a fenced in back yard and all of the bedrooms on the same floor. He found one within our

budget that fit the bill. When I asked what color the appliances were he said “dark”. Were they all the same color? Not sure. What color were the rooms? “light”. I told myself, “Let it go”. No big deal in the bigger scheme of things. We were all set to go to closing when the babies were about 3 weeks old (Still over a month from their actual due date). We got a call as we are getting ready to leave our apartment and go to the closing. It was the hospital. Good news! Our daughter was ready to come home. Wonderful!! When? Today you say? I felt like such a terrible mother when I thought to myself, if I should ask if they could keep her just one more day. This way we would have enough time to put together a crib. I didn’t though. We were thrilled although I did ask what time was the latest we could come down to pick her up. Does that sound terrible?

The closing went smoothly and we stopped to get something to eat. Jack went to a pay phone to check in with the NICU to see how everyone was doing. He came back with a very concerned look on his face. Everything was fine he said but the nurse told him that there was some sort of a flu or virus going around and one of our sons was pretty stable so they think he can come home today. We should get another infant car seat and put it in the car. When we arrived at the NICU late that afternoon we were happy beyond words. We were so really, really excited and yet very sad for our son who would have to stay by himself. As it turns out that was not to be the case. When we started going over all of the discharge information a nurse came into the room. She said that there was a chance he could come home with us today too. I started to cry and hug her. It was not because I was upset because I did not have any baby clothes with me for him and that he would have to come home in his t-shirt and diaper. No, that was not it. It was not that we only had one crib and all 3 would have to sleep together until we got more. No, that was not it either. It was that he had been on a ventilator until just 2 days before this and I had never once held him. I was going to hold my son for the very first time the day he came home from the hospital. Can you imagine? This baby of mine who was so quiet and I had to make a special effort to feel him move while inside me. This little baby that I had never even heard cry at almost a month of age was going to be placed in my arms.

My three babies were coming home with me and were now going to be truly, truly mine for the very first time. I was over the moon.

Once home we noticed that the boys had different hairstyles. This was from the IVs that they needed to put in their scalps. As it turned out these unsightly hairstyles were a blessing. This was how we were able to tell the difference between the boys the first few weeks after they were home. We VERY soon learned to color code EVERYTHING.

The challenges of a preterm birth do not end once you leave the NICU

I had been a mom of a newborn before I knew, or at least I thought I knew, what to expect. I knew that they would need to eat more frequently because they were so much smaller than their older sister (they came home from the hospital at about their birth weights, a little over 4 lbs each).

We were not prepared for reflux, projective vomiting, and the frequent, frequent cries of a neurologically immature preemie. And this was still a month before their due date. They were not even supposed to be here yet!

When they were 3 months old, just before Thanksgiving, they each became very ill. It started out like a cold but it only got worse. The ended up having RSV (Respiratory Syncytial Virus). For each Oct-Nov and March-April after that until they were 4-years-old we had really sick kids. Bronchiolitis and/or pneumonia hit us every year and it was heart wrenching to see our little ones so really, really sick.

Like most parents of preemies we waited for the other shoe to drop. I learned that after an NICU experience it generally takes about 5 years for a mom to stop waiting for something awful to happen. During this time we were fortunate to have the help and support of the folks from the local early intervention program working with us daily. Our trio was delayed on most developmental milestones as would be expected.

When they were about 7 months one of our sons developed echolalia. This was our son who was neurologically immature. He cried often and startled easily as a newborn. When he was about 18 months old he stopped talking and when he was 2 we were told that he had a neurological disorder totally unrelated to his prematurity that may require services for the rest of his life. Fortunately, his identical twin does not have this disorder.

At 3-years of age all three were diagnosed as being hearing impaired. Our son with the neurological disorder was diagnosed with moderate loss as was his sister. Our other son was considered moderate to severe loss. They all had what was called Fluctuating Conductive Hearing Loss. This was most likely due to their prematurity. This was extremely hard as a parent to see them struggle to help others understand their thoughts as their speech became more and more impaired. The 3 of them were VERY, VERY lucky to have each other. Transitioning from Early Intervention to special education with the school district was somewhat stressful. It really does not matter to those supporting your child at this point that he was premature. What matters now is that he is now classified as learning disabled.

Later they would struggle terribly with reading because of this. Even though they were bright young children school became a constant struggle for each of them. We worked closely with early intervention services and later with special education services within the schools. We learned about IEPs and becoming your child's best advocate. We learned a whole new language once again.

If you do not speak clearly or have difficulty understanding what is being said you will logically have difficulty sounding out words as you begin to learn to read. You will have difficulty spelling words correctly since you cannot sound them out correctly. You will have difficulty reading out loud and by the time you have completed 3rd grade and are no longer learning to read but rather now reading to learn you will have an extremely tough academic course ahead of you. This does not say anything about the struggles they would have outside of the classroom because they could not hear what their peers were saying all of the time and their peers could not always understand what they were trying to say.

Because of our NICU experience I think we were much better prepared for these challenges than parents who have term infants who are healthy and later get a diagnosis. Having 3 children with special needs and needing additional educational support was not easy. Not by a long shot. But we also know how insignificant our challenges have been compared to so many other parents of preemies. Each of our children are physically healthy and have average or better than average intelligence.

Going out into the world

When each of my children was born I wanted what most parents want for their children. My dreams for them were simple and truly, I believe, not extreme.

I prayed that they would be healthy or at least well enough to live pain free. I prayed that they would one day be able to live independently, hold a job and become productive members of society. Hopefully, each of them would feel a responsibility to help others out along the way. And somewhat greedily, I also prayed that one day they may know love and be loved as they have seen with their own parents.

I did not ask for them to become rocket scientists or Noble prize winners although I had a tinge of envy when other children would come home from school with their Honor Student bumper stickers. I prayed that they would hopefully be AVERAGE students. I embraced average and was even thrilled when they finally made it onto the average range on the growth charts as toddlers.

My middle 3 children have had to work harder than most of their peers for whatever grades they have received. They have known what it is like to be an underdog, to be out of the loop or singled out because they could not hear or just did not understand.

When in other homes parents may have had high expectations for their childrens' futures and stressed the importance of being at the top of your class in order to get a good job and become rich one day. We stressed how important it was to do your best and be a good person while helping others along the way.

I am not sure if ANY of my children will be rich but I do know how very, very fortunate we are compared to so very many other parents of preemies that our children have grown and ARE able to live independently, hold down jobs and be productive members of society. I know that not all parents will be given this tremendous gift.

My triplets are currently seniors in college. This is an amazing feat for any parent to be able to say but for us this is exceptionally poignant considering one of our children, up until high school was, for the most part, non-verbal even though his hearing was by then considered within normal range. There was a time in late middle school that we were so afraid of what the future may hold for him as his neurological challenges seemed to impact every part of his life.

Today, he is president of the student government at his university and is frequently called upon to speak on behalf of the student body.

By the time our other two were 9-years-old they were finally discharged from the hearing and speech program and were considered hearing within an acceptable range. Because of their early hearing loss though, both have struggled academically.

In spite of all of this our daughter will be graduating from college this May with an advanced degree in social work and will be attending graduate school hoping for a combined degree in public advocacy and social work.

Her brother is currently a senior at a distinguished military college and is considering accepting a commission into the Coast Guard upon his graduation.

Not bad I think for 3 little preemies that started out as underdogs.