



“Spotlight on a NICU Family: Jared’s Story”

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On November 19, 1996, following an uneventful pregnancy, I gave birth to a full term, healthy baby girl, Carly. After attempting to push her out for two hours, I had an emergency cesarean section due to the baby's dropped heart rate. After that experience, I thought that I had had my birthing "exception to the rule". Little did I know that less than two years later my son would be a much bigger exception. Since I had a "normal" pregnancy the first time, I cruised along in my second without any thought of complications.

When I was 31 weeks into the pregnancy, I gave birth to my son, Jared. I had no warning of any kind - no bleeding, spotting or pain. I was sound asleep when I awoke at 2:30 a.m. by a strong contraction that I recognized to be different than a Braxton Hicks. I waited fifteen minutes to wake my husband to call the doctor. The doctor told us that the feeling of preterm labor was not that unusual, that I was probably dehydrated but I should come to Cedars-Sinai to be monitored. Thinking that I felt better after drinking what seemed like a gallon of water, we arrived at the hospital. While the doctors were hooking me up to the monitors, my husband went to admissions to preregister me for when I would return to the hospital in two months to give birth for real.

When he returned to my bedside, I was dilated to 5 cm. and having contractions every three minutes. I asked the doctors what kind of medication I would receive to close me up so that I could return home. After the laughter subsided, I was informed that nature does not work that way and I would be kept in the hospital on Magnesium for two weeks to stop the contractions. That sounded kind of exciting to me as I had no idea what that entailed. After one hour on the Magnesium, I dilated to 7cm - I was then informed that I would be giving birth within hours. The NICU team came down to my room to explain the procedure and the possible outcomes. My brain was coming in and out of hearing the scary medical language.

Only six hours had passed since the first contraction woke me and Jared was born, October 5, 1998. Having no experience with premature babies or the Neonatal Intensive Care Unit, I could barely understand the trauma of the situation, and the dangers discussed could not possibly be happening to my baby or me. I thought small baby meant small clothes and premature birth only happened to drug mothers who abused themselves or did something to cause it.

The cause of Jared's premature birth still remains a mystery. There was no injury, infection or trauma that may have contributed to the early arrival. One explanation that I choose to believe is that nature sometimes intervenes to take control because external care may be a better place for care than in utero.

During Jared's five and a half week stay in the Cedars-Sinai NICU, I split my time between my twenty-two month-old daughter at home and visiting Jared. I spent so much time back and forth, I sometimes felt like I was everywhere and nowhere at the same time. I learned some medical terms but never really felt like I knew the questions to ask or that I even should. Everyday my body went through the motions, while my heart and

soul were removed so that I would not-collapse. I felt a lot of guilt not spending enough time with my daughter and not connecting to Jared. I began to feel like he was never mine from the beginning. Someone else was always taking care of him. It was only after I braved my journey home with Jared that I could begin my true connection with him. As much as I wanted him home with his family, I was so scared to be the sole caretaker.

Once Jared was home, I knew that his job was to grow bigger, get stronger and that would be the end of the prematurity consequences. When you hear about preemies, you only hear about size and never about development. At eight months old I noticed that Jared was very stiff and having trouble sitting without great effort to fold him into position. His pediatrician suggested an evaluation for the developmental delays and quality of movement at the Cedars-Sinai Pediatric Outpatient Rehabilitation clinic physical therapy for babies? I remember hearing in the NICU something about a state funded agency, Regional Center that would provide much needed services, but could not possibly imagine how that would apply to my situation. It sounded like food stamps for the crack moms. After my introduction to the Westside Regional Center, I realized in my later sanity that it opened up another world of direction and much needed support. It turned out that I had a wonderful experience with the Regional Center and Jared's careworker providing therapeutic services, orthotics and other related classes.

It became clear that through Jared's rough entry into the world his brain and muscle patterns were not fully developed or else damaged in the process. I started to hear a diagnosis that was very foreign and scary to me. I had heard the term Cerebral Palsy but certainly did not understand how that would impact my child.

My uneducated vision of CP was someone driving their wheelchair with a mouthstick. I now understand that for some that would be a great feat in itself! It took about one year to calm myself from a rollercoaster of panic and I learned that Cerebral Palsy was a term to describe a wide range of motor issues that in Jared's case did not affect his intellect.

Another chapter began in our lives as Jared started physical therapy to catch up his gross motor skills and occupational therapy for strengthening his oral motor skills to help feeding and later to articulate speech. It has now been three years of growing, learning, ups and downs, orthopedics for his feet and exposure to a world I knew nothing about. It is hard to trust yourself in a world totally foreign to you when you are the leader and student at the same time. How much therapy, doctors, intervention is enough ... or is it too much?

It is thanks to early intervention and an immense amount of support and direction from doctors, therapists and family that Jared is a running, playing, enthusiastic 3¹/₂ year old boy that will always have his own style and method of getting by like we all do. Finding your inner peace with what you are faced with, to any degree, and how you got there is the most important aspect of the journey of life. Sometimes the ability to visibly see limitations is the greatest reminder that we all have them and it only matters how you face the hurdles. The biggest piece of comfort that I learned was that however I got

through this experience was okay. I love Jared so much for how he lives and what he teaches me through his strength, I would never change a thing.

Now that I found my comfort place, I hope to offer a sense of peace to other parents undergoing a NICU experience. I have started as a Good Beginnings volunteer for the Parent to Parent program. Each week graduate parents will be available in the NICU family resource room for support and to help with needs that may arise with parents who have babies in the NICU. We are looking forward to a successful program that will be accessible to those in need.