



# “Spotlight on a NICU Family: Connor’s Story”

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Soon after relocating to California, my husband Tom and I learned we were expecting our first baby. We were thrilled and immediately set about taking predictions on gender, thinking about the perfect name, and joyfully adjusting to the idea of becoming parents.

We delved into the new world of shopping for strollers, car seats, mega saucers and all the other baby "must haves." I read baby name books, journaled my experiences, went to pre-natal exercise class and relished the miracle of being pregnant. I felt great and we looked forward to each checkup, so we could hear the heartbeat and learn a little more about how big the baby was and how the pregnancy was progressing. We began childbirth classes in December and anticipated a mid-February delivery.

Because I was 32 weeks along, we opted to stay in California for Christmas, instead of flying back east to see family. On Friday, December 22, 2000, some friends called an "emergency dinner party" for those of us left in town. We had a wonderful dinner and I remember the baby being quite active. In the middle of the night, the mild heartburn I'd had earlier (and attributed to a normal pregnancy symptom) became unbearable. Searing pain -- hard to breathe -- hard to think. Tears of confusion started. Tom said immediately, "we are going to the hospital." I arrived in the ER around 2:00 a.m. on the 23rd. The triage nurse asked me if I was pregnant and immediately sent me to the Maternal and Fetal Care Unit's assessment area.

My pregnancy spun out of control with a diagnosis of pre-eclampsia and HELLP syndrome. My blood pressure was skyrocketing, my liver function was failing and something was wrong with my platelet count. This baby was coming early. No matter what happened, I was not leaving the hospital before delivery. In order to speed lung delivery, steroid shots were started. Magnesium sulfate was administered to try to lower my blood pressure. It was all unreal. On top of that, my regular OB/GYN was in the Caribbean and his associate was now taking care of me. Only, in my magnesium sulfate haze, I didn't remember meeting him. Bless his heart, he took it all in stride.

On Christmas Eve, we spoke with our family and friends and settled in to rest. Suddenly, the pain was back. Searing, burning pain like a knife or two going through the area between my ribs. I know now it was epi-gastric pain, one of the worst kinds of pain. I couldn't even rate it for the nurses. Strong drugs did nothing to curb it.

A rush of activity and suddenly my doctor arrived -- and it was time to deliver. The doctors were predicting a 4 lb. 6 oz baby. Naively, I thought the baby would be 5 lbs and somehow that it would all be fine. (I thought 5 lbs was a magic number.) Many people had talked to us about survival rates of 32 week babies and other issues but it didn't really sink in. I just thought it would all be fine.

Our son Connor was born at 11:17 pm on December 24, 2000. He weighed 4 lbs. 2 oz. and was 18" long. He was wrapped up and brought to me to kiss and somehow, I managed to touch his nose. Tom was by his side for assessment and then Connor had to be intubated. He was taken to the NICU.

As we learned over the next few days, Connor had a severe case of Respiratory Distress Syndrome and pulmonary interstitial emphysema. He simply was more critically ill than expected for his gestational age and weight. However, there were signs of his spirit; Dr. Baserga nicknamed him "Tiger" because he pulled one of the tubes out.

The initial ten days of Connor's life were spent trying to find the right respirator for him. The one that worked we named "the jet engine" for the sound it made. It was hard to believe that was keeping him alive. My husband instantly learned how to interpret the machines, while I spent time trying to read to Connor, touch him when I could, and find out when I could hold him. My empty arms ached with the need to hold him. We quickly learned the routine of the NICU, got to know the staff caring for Connor (and for us), and tried to understand what was happening.

After coming off the respirator, he spent one day on CPAP and then switched to a nasal cannula. After gaining back the weight he lost, he took his own time learning how to coordinate the suck/swallow/breathe reflex. While on the feeding tube, he seemed to take bottles better for his nurses and he frequently slept through our lactation consultations. We waited for results of ROP and other examinations. We watched the As and Bs list grow longer, and then finally shrink. Ultimately, Connor spent 46 days in the unit. A week before his due date, Connor finally came home. It felt right; it felt strange; it felt scary.

Then we were parents of a premature baby - who couldn't go anywhere, except back and forth to the doctor for weigh-ins. After an assessment by the Regional Center, an occupational therapist came in once a week to work on Connor's muscle control and track his developmental milestones. The first few months were filled with a different kind of stress.

Slowly and surely, Connor began to gain weight and he soaked up all the love and attention we had to give, which was plenty. As his primary care nurse Kathy "KJ Johnson had told us, "These kids do better at home." Thankfully, this was true for Connor.

As we all know, the NICU experience is life changing. My husband and I remain deeply grateful for all the care and love given to Connor and to us by the NICU staff and the parent support group. Dorothy Williams gave blood for Connor's transfusion and in an instant, became a member of our family. Many nurses and respiratory therapists gave us quiet and calm explanations of procedures and setbacks. Doctors made themselves available for consultation and cheerleading.

It is hard to believe Connor is turning three in December. He is a loving, affectionate boy who is full of energy, energy his parents wish we had! Connor's favorite activities are playing at the beach or park, watching airplanes take off and land, and riding his tricycle. He loves books, firetrucks and animals. We are happy to report that Connor is "in training" to be a big brother in February and we know his sweet nature will make him a great one.

In time, I found myself pulled back to the NICU, but this time to share my experience and to try to help others. In the spirit of the holidays, please take a moment to reflect on your NICU experience and determine how you could give back. Donate a book about premies or special needs children to the parent resource library. Become a supporting member of Good Beginnings. Give blood. Donate gently used premie clothing. Make a donation in honor of your NICU graduate's next birthday. Bake cookies for a staff appreciation day. Register with Escrip. And always, take a moment to hug your graduate.