

INSIGHTS



Family Reflections: Maternal contact in the NICU: Moms DO Know Best

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It was a very hot Virginia day in August 2003 as I sat in my Obstetrician's examination room with my husband. The doctor came in, greeted us, and proceeded to ask how I was feeling at 26 weeks gestation. I'm okay, I said, but mentioned my nagging worry lately that I was going to have this baby early. After all, I noted, I had been several weeks early myself. The Doctor listened and said that it was normal for me to feel that way, but that it was my first pregnancy and therefore I would be giving birth late. I heard her out and tried to calm my nerves.



Well, I got that maternity tour *live* as it turned out. I ended up going into labor on the way back from a day trip, but thankfully rushed back to our hospital in time. And after a lot of intervention over 30 h of labor, I gave birth to Becky at 11:50 p.m. on September 7, 2003 on Grandparents Day at 2 lbs 15.5 oz. We joke now that she was impatient to meet her grandparents and so got out just before midnight. In reality, we just wanted her to live and stay alive. As she took her first breath she let off a tiny little fierce kitten cry to the joyful "Ohhhh" of the large team assembled to whisk her away to the neonatal intensive care unit (NICU). The NICU was Becky's home for 38 days before discharge on medical equipment, medications, and specialist follow-ups along with a visiting nurse, a Durable Medical Equipment team, and more.



In those early foggy postdischarge days, I would never have imagined that my daughter would survive and grow into the most amazing 18-year-old and that I would be changed forever as her mother. Why? Because I learned very quickly how to advocate for her through the lens of trauma. And that I would be speaking out at conferences, publications, and even in architectural design meetings for the NICU preventing lasting trauma. This can be done in keeping mom and baby together at all costs, push for that mother/baby bond ongoing and not in short spurts, and provide proper follow-up for the baby and also for *Mom and Dad's mental health, too, long term*. Researchers must be at the forefront showing what a truly supportive program can do for a family long term, not to mention society as a whole. Otherwise, they will see what happened to us and see it continue with families globally.

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While I assumed the NICU team knew better than I did on how to take care of my daughter medically, my motherly instinct was on point from pregnancy to birth to NICU to home. I was just trying to get my footing and to trust my instincts as well as to get to know my newborn. As it turned out, I needed it because I was the one looking at the breast pump in my postpartum room the next morning and telling my husband I needed to try and help pump for my daughter. No one came and talked to me, I just pumped (haphazardly) and had my husband bring the small amounts of yellow liquid to the nurse to see if it would be useful. As the nurse rushed the colostrum down to the NICU she had me visit the Lactation Consultant's office to get a nursing bra and sign up for a rental pump for home. I felt empowered now but that was quickly dashed each time I visited my daughter in the NICU. Wearing a barcoded bracelet, being asked to scrub up to my elbows, put on a patient gown, having a front desk person call back to see if we were allowed in, and then given entrance through the large, secure automatic doors. This was all to see my own daughter. Trauma hit me every single time we visited her save for the first time I did Kangaroo Care with her. And that only happened because I asked for it every single time we visited without having a clue what it actually meant (my mother-in-law, a former registered nurse, is the one who mentioned it early on, wondering when they would let me do Kangaroo Care). I had a nurse bully me about breastfeeding instead of pumping when I knew my daughter was having trouble at the breast in the first place. And all we kept hearing was "She's doing great!" which we thought meant that everything was going to be just fine. Right.

Becky struggled through three heart defects, anemia, apnea of prematurity, bradycardia, severe reflux, sepsis, major feeding

issues, and respiratory distress syndrome. She came home on an apnea monitor and oxygen with feedings as well as medications and a team of specialists for follow-up. Oddly enough, despite my concerns about her development, the neonatal developmental team did not deem her qualified for early intervention (EI) services, but noted the local Health Department's monitoring program instead as well as the NICU follow-up program every 6 months. Becky landed back in the peds unit 5 days after coming home due to alarms on the monitor, throwing up feeds, and sleeping through feeds, all while we worked through zero sleep. I felt horrible putting her back in the hospital, but I knew that is what she needed. She came home on full-time oxygen and new medication as well as additions to her feedings. She went from strength to strength after that and a bottle change. Life at home was stressful the first couple of years due to the follow-ups, keeping our daughter away from people, and trying to stimulate her developmentally.

So outcome-wise Becky apparently had other plans with a total twist. At 18 months of age we had ten people in our living room playing with our daughter and assessing her for EI (she instantly received physical therapy, occupational therapy, speech for talking, and feeding), and that afternoon we visited the Pediatrician, as she had a continual cough after a small cold (I suspected RSV), who diagnosed her with reactive airway disease. After 7 months of EI, she was discharged.

Prior to preschool, I had the EI team out again as I was just checking to make sure everything was okay. It was. Becky entered preschool and at the first parent/teacher conference the teacher who told me preemies catch up by age 2 when I warned her to keep an eye on our daughter walked in leading with "Well, you apparently know more about this than I do." Becky was not talking in school. Fast forward she received ChildFind services up to Kindergarten where another team of people asked me how I thought Becky was doing. I was super honest saying I thought she was doing great, that she had read at 2 years old, but was a very selective eater, had been premature, and more. The school psychologist asked me if she looked me in the eye. I said yes, as my nerves took hold and my heart sank. Asperger's was diagnosed in Kindergarten and we were off and running on services. Add in attention deficit hyperactivity disorder in second grade when I pointedly told the pediatrician at well-check that I strongly felt this was definitely a case.

At 9 years old I took Becky to a Developmental Pediatrician to see if there were any other surprises we should know about by now. She said Becky was doing well and that my concern about potential cerebral palsy (CP) was simply a motor coordination disorder and to get her some occupational therapy. At 11, after watching her ankles squishing on an elliptical machine at the gym, I asked her personal trainer (yes, we had her with a trainer to keep her moving) what that could be. She suggested orthotics and so we ended up at an Orthopedic Surgeon for a consultation. During the appointment, I asked the doctor quietly if this could be CP. She said if it was, then it was very very very mild. We went home with a prescription for orthotics, but no CP diagnosis.

At 12, Becky agreed to have us enter her into feeding therapy with a speech therapist who specializes in sensory processing disorder. My pasta- and rice-loving child suddenly became a foodie in the other extreme. Meanwhile, the orthotics were very helpful and we went back at 13.5 for a re-scrip. A different orthopedic surgeon in the practice looked at the prior visit notes and asked my daughter to walk and run up and down the practice's hallway. Instantly I could see things were worse. Beside me, the doctor asked quietly, "How early was she?" My brain went into overload. "But the cranial ultrasound was clear." Back in the exam room, she lifted Becky's legs one by one to show me how the ankle locked up. "See that?" she said. "That is spasticity." Shocked, I asked, "So is this...?" "Mild Spastic Diplegia," she replied. As I took this in and tried hard not to explode, I heard a

little voice say, "Mom, What's going on?" Here I was with my daughter, the person I had advocated for her entire life, having to tell her as a teen that she had another disability. During this, we added scoliosis as a watch item to this and she went off for orthotics, braces and therapy, and a doctor's note to get out of Physical Education. I wasn't just mom. I wasn't just the advocate. It turned out I was right about so much along the way and allowed others to sway my thoughts. And yes, I was quite angry.

But I also want you to know that my daughter is not just a collection of diagnoses. She is an amazing young lady. Smart beyond her years (she read at 2 years and started taking college classes alongside her high school courses during her freshman year—*yes, you read that right*), my child who struggled to write her name and draw a stick figure person is now a flourishing artist of considerable talent heading toward a career in creature design for movies and video games. She is kind and generous and has empathy for others' struggles, especially that of the elderly and the special needs communities and has a strong interest in cooking to "make people happy." But her enduring love is for the animals whom she feels treat each other with more humanity than humans do. And she agrees wholeheartedly with me that children with special needs should be recognized for their gifts, too.

It is my belief that with solid research into areas like intensive mother/child bonding in the NICU and post-NICU and incorporating a mental health program akin to developmental programs long term, we could seriously blunt the cycle of extreme damage done to families. But I am "just the Mom," right? What do I know? A lot, as it turns out.

Deb Discenza is the mother to Becky, a 30 weeker now 18 years old. She runs PreemieWorld (<https://premieworld.com>), Crystal Ball Health (<https://crystalballhealth.com>), and is a co-founder of the Alliance for Black NICU Families (<https://BlackNICUFamilies.org>). She is the co-author of the newly updated book, The Preemie Parent's Survival Guide to the NICU, and serves on boards, committees including the Leadership Team at the International Neonatal Consortium.

COMPETING INTERESTS

The author declares no competing interests.

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