

JENNA GENSIC

BABY BLUES (an excerpt)

My Life against the Grain: Surviving the Politics of Prematurity and Home Health Care

“Jeeennnnaaaa! Joooooosooooohhhhhn!” I jerked my torso out from under the covers and shook my husband awake. It was Nadine. She needed something. It was also 12:42 a.m. With a few thuds and dull claps, John fought the blankets and scrambled to the living room where our nurse Nadine was leaning over our son’s crib. When I caught up with him, I was horrified to find Mikan completely blue. Nadine had hooked up an ambu bag to his trach and was bagging him with intensity, the sweat dripping off her forehead as she compressed the large blue bulb. She stopped bagging for a second to listen to his chest with a stethoscope. Her brown bangs fell over her eyes as she frantically ripped the ear pieces away from her face.

“I only hear vent breaths! Call 911!” she ordered and ran to crank his oxygen analyzer up. Squeezing the soft plastic in and out, I calmly, methodically fell into the appropriate life-saving rhythm while my heart pounded in my ears and burned in my chest, like a steep drop in a roller coaster ride. My husband left to grab the phone. I was in too much shock to have an emotional reaction. My first thought was, “Why did she listen to his chest? I could have told her that he wasn’t breathing. He’s blue. Of course you’re only going to hear vent breaths.” I wished for a second to rewind the video of my life so I could be ready for the crisis when I hit “play” again. My mind entertained several “what if” or “had I only been awake with him” scenarios. But almost as instantly as those thoughts pervaded my consciousness, I shoved them to the outskirts, focusing on my immediate responsibility.

Six months ago I wouldn’t have known what an ambu bag was much less how to perform rescue CPR using one. But now I was somehow able to comfortably compress the ambu bag, forcing pressurized air through Mikan’s trach and into his underdeveloped lungs, while shaking his limbs and patting his face.

“Come on baby, wake up, take a breath,” I pleaded. With each breath I gave him, images of the last five months came flooding through my mind. Had we made an awful mistake? How did we get into this situation?

The Beginning

“You’re going to stay here till you deliver this baby.” I stared at the ER nurse, who revealed the crippling information to me that she probably told plenty of women each week, then I glanced at my husband, then back at the nurse. “You mean, tonight?” I asked, bug-eyed.

“You are definitely leaking amniotic fluid. You could deliver tonight, tomorrow, three months from now. We just don’t know. We’re going to watch you here in the hospital.” Jerking my gaze to the ceiling, my muscles tensed and I forced the back of my skull to make a shallow impression in the stiff hospital headrest. My sigh carried a more irritated than tragic tone. How was I supposed to work? My eyes closed, and I blacked out whatever words of comfort the nurse rattled off.

“Can I at least put my clothes back on? I feel fine.” At only twenty five and a half weeks pregnant with my first child, I hadn’t completely mentally prepared for delivering a baby, in fact signing up for Lamaze classes was on my list of things to do the next day. So you could deliver babies this early before their due dates? I had no idea. So your water could break and you could still avoid labor? I had no idea. No one told me that there was a possibility of leaking amniotic fluid in a hospital for an indefinite period of time before I delivered my baby. It was February 17, 2008. I was due May 28th. I lasted two and a half weeks on bed rest after which Mikan was born at exactly twenty-eight weeks gestation.

Congratulations

“Congratulations.” A nurse brought Mikan over to me swaddled in a blanket. Because he entered this world breathing on his own, I was immediately allowed to see him in the operating room. I knew he would be small, but seeing him for the first time was appalling. A tiny mouse-like face peeked out of a quicksand of blankets. The blanket ever so slightly rose and fell with his shallow breaths, hiding, then revealing his miniscule features. One pound twelve ounces, thirteen inches long.

A few hours later, yet another nurse wheeled me into the neonatal intensive care unit on a hospital bed after my emergency C-section. Groggy and weak, I turned my head when she pointed to Mikan’s bed. Surely this was a different baby. This baby, if that’s what you could call the small mass of bone and skin, was sprawled out on a warmer, with cardio and respiratory leads attached to his chest, an IV in the back of his hand, and tubes wrapped around his face like a boa constrictor, concealing everything but a tiny nose from view. His transparent skin made him look more like a baby bird than a human. He stretched a little bit bigger than my husband’s hand. I silently wept while the nurse at his bedside tried to explain what each of the wires and tubes meant. Although I would soon learn each of their functions, I couldn’t process anything she said about Mikan’s equipment that day. When I held

him, I held more machines than baby. At some point during those first few weeks, John and I discussed that if Mikan didn't make it, we would demand to hold him without his wires and tubes, just to see what that felt like. A mother wanting to hold her child without any machines attached. Is that unreasonable?

Help! We Have an Expensive Baby!

"You need to think about how you're going to take care of this baby. Look for all the help you can from the government." This from several family friends who knew a woman who knew a woman who had kind of been in a similar situation.

We were confident that our private insurance would pay for Mikan's incredibly expensive hospital stay. We had decent insurance, and had already met our out-of-pocket maximum for the year. The NICU social worker met with us near the beginning of our stay and gave us pamphlets on several government-run programs to help parents with the ongoing cost of a medically fragile child.

"Is there an income limit for these programs?" we asked. The social worker was never able to answer this question upfront and would scurry away, promising to do additional research and get back to us. Unfortunately, every program required our salaries to be slightly less than the teaching incomes we brought home.

Other family or friends suggested we try to sign Mikan up for Social Security's Temporary Disability Program. This effort ended up being a waste of an afternoon. After countless attempts to call and set up an appointment, waiting an hour at the office for my name to be called, and spending another half hour filling out information about our finances, I was told by the Social Security representative,

"The computer says you're denied. It looks like the primary reason is because you have over \$3,000 in assets. Honestly, you'd be better off if you blew your bank account on a new car." He smiled. "But if your finances change drastically in the next thirty days, you could reapply." Was he making a joke? Despite any deposits we'd made into the system, we couldn't tap into any of the \$62.5 billion that would be distributed by Social Security that year. I curtly thanked him and left, making a mental note to set-up another appointment with the social worker.

Teenagers

"So how old are you exactly, if you don't mind my asking?" The nurse who took care of Mikan on his three week birthday asked me this. Initially I wasn't offended. I've often been mistaken for a much younger age. As a teacher, I've been accidentally reprimanded by administrators for "roaming the halls" during class time while trying to make copies of tests. But I had lived at the NICU long enough to observe many parents, and after asked

the same question by another nurse, I realized that they had assumed Mikan's prematurity was due to my youth. There were two early births within a few weeks of Mikan to fifteen and sixteen-year-olds. I was twenty-four at the time and perfectly capable of healthily bearing children.

Fake Smiles and Polite Conversations

"So have you met a lot of other parents in the NICU?" I heard this question so often, and I always replied with the same conventional answer that the questioner anticipated, the one that would move the conversation along the smoothest. I usually didn't possess the energy to give the real answer as often as it was asked.

"Yea, there are a lot of parents here. It's nice to talk to people going through the same thing we are." But really, this was a lie. John and I were different. We didn't meet many people in our same situation. Sure there were a lot of other babies in the unit, but they were all there for different reasons. Perhaps there were a few families we might have befriended under different circumstances, had their stay lasted as long as ours. But the truth was that most babies came and went within a few weeks or a few months. Very few endured our length of stay. We were also unique as part of the 40% of premature births that have no known cause. When we asked my ob why my water broke early, he told us,

"If I knew the answer to that, I wouldn't be here. I'd be in Stockholm accepting the Nobel Prize."

Mikan wasn't born early because of an anatomical failure on my part, or because I experienced trauma, or was a diabetic, alcoholic, smoker, overweight, underweight, too old, or too young to have a child. On bed rest, my ob told me that I most likely had contracted an unknown infection that hurt the baby's amniotic sac, but left me unaffected. We didn't know how it happened. We don't know how to prevent it in the future. I loathed practicing my smile while passing other NICU parents smoking in the parking garage, another constant reminder of the unfairness of my situation. John and I would pass at least one or two smokers every day, some repeats, but it seemed that every few weeks brought a different population to the hospital.

(an excerpt)

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