

Bringing Sophie Home

I look as my youngest daughter balances precariously then takes several deliberate, careful steps. Each one in defiance of physics, gravity, and grace. She was born six weeks early, premature, a preemie. Premies' bodies don't grow like other babies, something no one bothers to tell you. Their heads tend to grow much faster, so while her height is only in the 8th percentile, her head is in the 65th. Sometimes, when she rolls onto her back she gets stuck, like a turtle, and must be helped over. At her last checkup her weight percentile had actually doubled from 10th to 20th. I'm fairly certain most of that is head.



I think back to a year ago when instead of struggling to walk, she was struggling to eat without choking and maintain her body temperature. I remember the lights of the NICU, always blue-tinged, with rows of acrylic incubators and white, metal bassinets lined up neatly and close, a precise sense of order amidst the chaos. And the wires. God, the wires. Babies festooned in wires like they were some kind of marionettes made from skin as wrinkled as tree bark. If only there had ever been some music for them to dance to.

Instead, there were the constant sounds: the soft whoosh of machines, light pings of mechanical observation, hushed conversations, sometimes light, sometimes serious. Inevitably a monitor would go off, followed by a rush of footsteps. A pause. The whisper-quick click of computer keys. Usually a few buttons were pressed and the pattern would resume. Occasionally another nurse or two were needed to address whatever crisis in miniature was occurring, but these also settled fairly swiftly. A few times a doctor was called over and a baby was rushed from the room. Every single time I

thought, 'Better someone else's baby than mine.' Horrible. But even now I don't regret it.

Babies' birth weights were listed on the outside of whatever container they resided in. My daughter's was 4 lb 4oz, and by no means she was the smallest. That honor went to a little girl who weighed just 1 lb 2 oz. She was hidden in a separate room with a glass wall, all by herself. Not even the peripheral presence of other humans, just isolation. I never found out what condition required such extreme clostration.

Sophie's biggest problem was eating. Almost everyday she'd start choking, at least once, and then the machines would start shrilling, screaming at everyone that her heart was skipping beats and her breathing had paused, as though her body couldn't handle so many complicated functions at once: suck, swallow, breath, heartbeat.

The advanced medical treatment for this was to sit her upright and pound her back a bit. Her heart and her breathing would resume their normal measures and we would begin the cycle all over again. There was one time when I was feeding her where she just couldn't do it. She just couldn't get manage to get a single swallow down without choking. She looked at me with such a small, delicate face of misery that it made me feel shattered; a helpless, defeated ache. Like I had failed her, failed her in every possible way. Why couldn't my body hold on to her? Why did it have to be such a breakable garden?



Eventually, she began to improve. We brought her little outfits I ordered online, made especially for preemies. Made to allow the wires to fit snugly under while providing easy access. I also bought her little headbands with flowers on them so she could look pretty, their soft, pastel colors contrasting with her dark hair. It was

the only thing I was able to do for her, other than provide her with milk. I couldn't take care of her any other way.

When circumstances allowed I would hold her, skin to skin, taking the burden of maintaining her temperature off of her body by offering her my own. She was surprisingly warm, a tiny bundle of heat I wore over my heart for brief moments. Even today her head is still remarkably warm and soft. We all love to stroke it. Sometimes her oldest sister thaws her chilled hands on it when she thinks I'm not looking.

Finally, she was down to a choking incident every other day or so. By this point my husband and I had become quite proficient at sitting her up, briskly slapping her back, then continuing her feeding. We were no longer fazed by the situation. At some point it had stopped being terrifying and had become ordinary. Not to the doctor in charge, however. He was dire and dour and refused to let her go.

He held my baby hostage, intoning predictions and enumerations of all the things that could go wrong. I wasn't satisfied. He spoke down to me on the phone, verging on belittling me. He felt like a bully. I never wanted to punch anyone in the face as much as I wanted to punch him. I almost spat out that he was speaking to a Georgetown educated biochemist, so he could get off his goddamned high horse, but I didn't, because I felt I shouldn't have to. I shouldn't have to use the privilege of my education to bring my daughter home. I felt my words should carry weight because they were true and my logic sound, not because he had respect for my profession.

Instead, I hung up the phone and thought, trying to figure out what to do. I rummaged through my purse, located my insurance card, and called my insurer. I tried to get them to stop payment to the NICU by telling them continued treatment was unnecessary. They informed me they always go with the doctor's assessment. I asked if there was anything I could do to challenge the doctor's opinion. Their answer was basically, no. I almost succumbed to despair but I decided I wasn't going to stop fighting for my daughter to

come home. I would never stop fighting. I knew she was ready, and if that doctor had an ounce of real intelligence then he should know that too.

So I rifled through a pile of papers until I found the number of the hospital social worker and called her, pleading my case. Soon enough we had an appointment with the doctor and the social worker and we all sat in a tight, badly decorated room, where my anger felt too constrained to hide. But I had to bite it down deep inside because this man, this arrogant ass, stood between my daughter and me. This man who was educated enough to be a doctor, but not confident enough to look at the entire situation instead of relying solely on what some machine was saying.

In science, you never rely on the results of one type of experiment. You approach a problem from various angles, assays, and tests, and only if they all concur do you draw a definitive conclusion. You might run a Western blot, qRT-PCR, and a FISH before you'd say you knew what was happening for certain. Only after all that. You'd never rely on just one of them, like this doctor was relying on the results of one machine. Sophie never had a full episode where she either quit breathing or her heart stopped. She never needed to be aspirated. These episodes were brief and usually resolved in under a minute. She was able to keep most of the milk down, able to regulate her temperature, and was gaining weight and growing. But this doctor didn't see all that. He only saw a machine that periodically indicated that there might be a problem.

But I sat there while he talked down to me once again, my nails biting into my palms, my face stretched into politeness while my mind contemplated sending him ground coffee laced with sodium dodecyl sulfate. Drink it down and get a good whiff, asshole, I smiled at him with my eyes. He



had all the power in the situation. There was no way I could take her home against medical advice; no way to just walk into her room and take her. I felt the desperation that all mothers do when unwillingly separated from their children. There is no hatred like the hatred you feel for someone who won't let you claim your baby. It is a hatred expressed in crimson, ash, and hard purple hues, razor sharp, and visceral, vicious. I hated this man. I still hate this man.

There was a sudden flurry of standing, we were all standing, and I wasn't quite sure what was going on, and then the doctor was saying we could take her home today, if, *if*, we agreed to bring her home on a monitor, got monitor training, and she passed the car seat test. Just like that. I had won. I had won!

Quicker than it even seemed possible everything was in motion, and our daughter was sitting impossibly small in the center of a car seat that looked like it was meant for a child three times her size. She was hooked to her monitor, and we were to see a specialist in two weeks time to assess her condition, but we were allowed to take her home. Before we left one of the nurses patted me on the back and whispered, "Good for you." She didn't care for that doctor, either.

33 days. Sophie was in the NICU for 33 days, at least seven of them unnecessarily. I thought that once we were all home I would feel elated, relieved. No more 30-minute drives to the hospital. No more half-life for our family, where we had a baby, but we didn't have the baby. But I didn't feel relieved or elated. I felt exhausted. Drained.

For the most part the monitor was a nuisance, but no big deal. Except the few times it went off and catapulted us out of bed, our hearts crazy and wild, our hands shaking. But there was never anything wrong; it was always a false alarm. When we went in to see the specialist she plugged it in to her computer, studied the read out, and pronounced, "Everything's fine. She hasn't had a single incident since she's been home." I faced my husband in triumph. "See, I told you she was fine! I told you that doctor was wrong and didn't know what he was talking about." I felt the sweet thrill of vindication. The doctor

would receive a report. He would know I had been right all along. My mother-wisdom was proven. I was satisfied.

It's been not quite a year since then. In a few weeks it will be my oldest daughter's birthday, the same day, coincidentally, that our youngest was finally able to come home. It's also the day my husband asked to kiss me the first time, seven years ago. That day of the year is a good day.

Sophie is my baby of ease, the one who is almost no trouble at all. She is the one who rarely cries, and if she does it is usually brief and gentle. She is happy to play by herself as long as someone is near. She is not demanding the way her older sisters are. She also doesn't quite have their exuberance, but she is sweet. She always smiles when she wakes up, smiles even bigger when she sees you're there. She can't laugh properly; it doesn't come from her throat in quite the right form. It has a harsh, guttural quality. We say it sounds like she's pooping out her laughter. It's endearing and strange. And when she's tired she will crawl over to you and rest her enormous, warm head on your chest.

This past winter was my first with both a toddler and an infant. It was also one of the coldest, snowiest that we've had as well, so the three of us have been holed up inside most days. The monotony has created a gossamer lacuna that some days swallows me whole. I feel worn down by the rub of monotony, all my edges smooth and free of features. They say Spring is coming soon, but I don't believe it. When I was outside earlier today the breath of the world was still cold, and the sky smelled like snow. The ground around our home is still wrapped in a white, crinkled crust; frozen-unfrozen-frozen.

Inside, the three of us, Sophie, Fiora, and me, crawl under the piano and lay on our backs. We've learned that if we raise our voices into high pitches they resonate and vibrate the strings before fading away. We do this until it is time for them to take a nap. Fiora is first, and she unexpectedly drops off immediately instead of fighting her way into exhaustion.

Next, I tuck up Sophie in her crib, her eyes already drifting before fluttering back open, as if sleep can be held back by force of will alone. She pulls the bottle from her mouth briefly, smiling up at me as if I'm the most amazing thing she's ever seen and just for a second everything feels whole and new. This is what so much of parenthood is made up of: these tiny little moments of perfection spread throughout the day; the ones we will gather and hold to us and remember when they've grown and left us, the shadow of their smallness still heavy in our hands.

