

## Brooke Birth Story

Contributed by Lauren Snyder  
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Hello!

While I've been lurking around for months and months now&hellip;I've been shy to post an intro.

First of all, I must express my gratitude for this list. I have learned a lot from you parents and have also learned to be grateful for what I do have, as opposed to what I don't have from reading posts of families struggling with things we don't struggle with. One of the life lessons I've learned from Brooke's birth is that life is so much about gratitude and perspective. I knew that before, but on a deeper level, "I get it". Those two things, along with my faith have really helped me cope.

Well here it goes:

My daughter, Brooke Isabelle was born on March 16, 2003 at officially 26wks5days weighing 2lbs 6oz. Although, in retrospect I was probably in labor from the night before, I didn't realize it until I had 3 contractions (the ones where you can't talk/try not to hold your breath and whince) in 15 minutes followed by my water breaking and minutes later the intense desire to push my baby out. I freaked of course when it hit me what was going on. Without pants on (just a blanket), we rushed to the local hospital's ER room where Brooke was delivered within 10 minutes. She was crowning in the car!

Given her delivery and her early gestation Brooke did remarkably well in the beginning. She was off the vent and onto the CPAP within days. Her brain scan was clear and she was given surfactant in the hospital as I was never given the steroids obviously. As the next couple weeks continued however, her alarms increased and blood was drawn regularly to check for infection, etc. Everything came back negative for infection her entire hospital stay. In a way, though it was bad news because she was deteriorating rapidly and no one knew why. One night, two weeks after her birth, she "crashed" (as I call it) and was removed from her isolette and returned to an open bed. We walked in that morning to find all the Dr.s hovering over her in the open bed. She was re-vented and sedated. Her body was grey, listless and swollen like a balloon as her body was shutting down and her kidneys were failing.

To make long story a little bit shorter, she was eventually diagnosed with Cardiomyopathy. A heart condition where the walls of the heart are too "thick", decreasing the interior blood volume. Essentially she didn't have enough blood in her heart to pump to all of her organs &ndash; so they were shutting down and failing. She was shunting blood to her heart and brain. That was the dark day of April 02, 2003. We were told that there is very little one can do to correct Cardiomyopathy. There is no surgery to correct anything. One more night (maybe two) like the one she had just experienced, and I was sure she wouldn't make it.

Miraculously, (and my husband and I believe that it was a miracle &ndash; a literal gift from God &ndash; we said a special prayer for her/blessing that day) on a follow up exam from the Cardiologist her heart was declared "Normal" and her Cardiologist recommended the Neos quit "treating her" (they were attempting to manage her fluids) for Cardiomyopathy. Two hours after that new declaration her kidneys started functioning again and I knew she would live. A follow up brain scan revealed again no brain bleeds even after all the trauma.

She remained vented for the next several weeks and weaning from the sedatives took nearly two months, but after that dark day it was pretty much "just" a matter of healing, getting stronger, feeding and gaining weight. She did have 12+ blood transfusions from 3 donors (and I fought hard to keep those to a minimum). And curiously developed or showed a grade I brain bleed just before discharge that resolved itself within a few weeks of being home. (by 40wks gestation) Brooke is now 9 months old, 6 months adjusted. She came home on oxygen and a monitor. She was weaned from her oxygen at 7 months actual. It's been two months without oxygen and I can't believe we were ever on it. We do keep a tank around for emergencies. We've been blessed with pretty much no feeding issues outside of constipation (except for the day I introduced peas &ndash; we had a little regression) and my inability to maintain my milk supply due to pumping/stress regarding her health. Today, she weighs a whopping 18 lbs! For some reason she doesn't role at all but is almost sitting unassisted. I'm still watching closely for behavioral, developmental and speech problems (or lack of). We do regular albuterol treatments for asthma. We've just had our first eye exam with a pediatric ophthalmologist which came back within normal range (slightly farsighted &ndash; which most kids are). She was pre-threshold for weeks and weeks, but in the end never did have surgery for ROP. Emotionally, I am just now coming out of the "stun gun" phase. I look back at the early pictures of me and think, I didn't LOOK as frazzled and freaked out as I felt. (Except for the 20-25lbs I've kept on &ndash; I'm usually a lean 120/125). You know, I've often thought: if someone were to have given me the choice between having a premature/disabled/sickly child or no child, I think I would have chosen no child. I feel like I've been learning

that's an ignorant choice. I would choose my daughter and all of our experiences together to date all over again, now that I know better. But I have to admit, it can be a slow lesson to learn. (Which gives me something to think about as I contemplate having another child and risking/fearing another premature child) I love the posts in particular that talk about their inability to cope or the fears they are unable to shake, because those are often the ones that give voice to the things I'm afraid to admit or face or think about. I admire the courage and honesty of so many people on this list. Thanks for reading. I can be wordy. Lauren (31yrs)  
Mom to Brooke (9mos actual; 6 months adjusted)