

An Orange Socks Snapshot Story-
Dawn: Born Typical; A Misdiagnosis Of "Incompatible With Life"

It was December, and everyone was in the Christmas spirit except us. My heart was shattered. I had been to the doctor for my routine ultrasound. I was pregnant with my third child. My older boys were sick, so I instructed my hubby to stay home with them. I mean, what can go wrong? As I lay there, I knew. The technician called the doctor in, and I thought.....twins? He took my hand and said, "Dawn, we see some markings on the brain as well as what looks like a club hand and foot. His ears also are not the correct size, and I do believe there's a hole in his heart." I went numb. No, this can't be happening! The doctor said, Let's make an appointment for a few days from now to give your mind time to calm down." Calm down? That will not happen! I sat there numb and heartbroken.

I don't remember driving home, but when I pulled in my driveway, I had to pull it together for my older boys' sakes. My husband took one look at me and saw right through me. Having to tell him was one of the hardest things I've ever done. We went back to speak to the doctors the following week. They ordered a fancy ultrasound ("fancy" being the now normal 3D ones) and suggested an amniocentesis. They told us, "We believe your child has Trisomy 13. He does fit all the visual characteristics. There is no cure. In these cases, we suggest termination of pregnancy as the "fetus" typically passes away within the first few hours or days of life." I was again speechless. It felt as if the air was sucked out of my body. I looked at my husband and saw nothing but heartache. I was already entering my fifth month of pregnancy. They told me that if he did survive-and he will not- but if he did, he would not be able to run, walk, or crawl. He will be wheelchair dependent. He will need 24-7 care, which includes a feeding tube, and lifelong diapers, among other medical issues you will have to attend to. He will not know laughter or joy. He will know only suffering and pain. He will not be able to move his legs and arms. I told them that I could feel him kicking, but was told that wasn't him kicking.

As they told me all this, I kept feeling these little taps in my belly as if he was saying, "Don't listen to them" It was never a decision for me or my husband to choose termination, I was having my baby!

I think the worst part was all the things family and friends said and how some made it about themselves somehow.

When I tried to open up to some family members, it turned into how THEY couldn't sleep or eat over our decision to keep the pregnancy. I heard things like, "You're being totally selfish keeping this baby," "You are aborting, aren't you?" "At least you have two healthy kids so focus on that." "Is it fair to do THIS to your older boys? Dawn, stop thinking of yourself."

What nobody could get was, I preferred five minutes of holding and showing my child all my love than a lifetime of wondering and never being able to say, "I love you" to that little face.

We decided to go through with the amniocentesis so we would know what we may need, and how exactly to prepare our older boys. They explained that if we decided to terminate, depending on when the results came in, I'd probably have to go out of state for the termination.

The phone rang few weeks later: "Well, it seems he doesn't have what we said, but there are still complications." I was floored- Trisomy 13 was not present in the amniocentesis results. What if I had decided to terminate my pregnancy based on their recommendation? At that point, I was in touch with The Children's Hospital of Philadelphia. They found markings on his brain and a hole in his heart. Again, they told us to abort, we again declined, but I couldn't help but question if they were wrong on these "findings" as well.

I remember wanting to STAY pregnant with him I felt like in my belly, he was safe. In my belly, he was happy and felt no pain, and in my belly, I personally was keeping him safe. No words can describe the feeling when being told horrific things about your unborn child. It rocked our world. It puts life into perspective. The little things no longer exist.

As they wheeled me in for my third C-section, new emotions arose. My husband laid his head on my shoulder as tears rolled off my face onto his. The fear of the unknown is awful. My doctor said, "Here comes

baby! LOOK, LOOK!!!!!" Fear took over. I closed my eyes so tight as if the more I squeezed, the healthier he would be. Would he have any deformities? Would he even cry? Can his little injured heart handle the delivery? Will his little brain work? My husband yelled, "Dawn! open your eyes! OUR SON IS PERFECT!!" As I peered up, there hanging from the doctor's hands was my eight-and-a-half pound, 22-inch nugget of healthy perfection!

He was scanned after birth, and yes, he has what's called **Choroid plexus cysts** (CPCs) which are **cysts** that occur within the **choroid plexus** of the brain. The brain contains pockets or spaces called ventricles, with a spongy layer of cells and blood vessels called the **choroid plexus**. This is in the middle of the fetal brain. It doesn't cause water on the brain or anything. Most people don't even know they have them! He did have a very small hole in his heart, but was observed and it closed itself.

Now he's about to turn 15 and is healthy! He developed typically mentally and physically and has ZERO complications, conditions, or diagnoses. He's my toughest! Fifteen years later, here I stand and here he stands. Fifteen years later, tears still fall as those emotions come right back. They never leave. You never forget that.

Running has a different meaning to me. Talking has a different meaning to me. The way his arms move when swinging a bat -- these are all things that hold a different meaning to me. Every day I celebrate these things. I am proud of all my boys, but I'd be lying if I said Dean's abilities didn't pull at my heart a little more. I think to myself, "And they said you'd never be able to do this." No words can describe how I feel about choosing to NOT terminating the baby doctors said was "incompatible with life."

All these years, I felt almost selfish to share our story. How can I have the nerve to speak about my feelings when in the end, I had a Trisomy-free, perfectly healthy baby? I can say that in that moment, the moment you are told your unborn child has health issues, you get this flood of emotions. I've never wanted anyone or anything so badly in my life, with or without all the complications. All I knew was LOVE and all the love I had for this very special baby.

Every day I say a prayer for all the mommies and daddies who are walking in those horrible shoes we did for a few months. Every day I think about the mommies who didn't have the outcome that I did. I'm not an overly religious person, but I do ask God to give them strength and protect their hearts. They are the special mommies. "God only gives special babies to special people," my mother-in-law told me when I was pregnant with Dean. I have admiration for all the parents who deal every day with their child's health needs as they are the heroes.

In closing, I'd just like to say that today, tomorrow and every day after, I celebrate all our babies and kids, every milestone, even the blink of an eye can be a precious one. Listen to your mommy instincts, and don't ever hesitate to celebrate every little thing this life has to offer.