

Parent Post Natal Stories

You are welcome to read stories submitted by our own members about their personal postnatal diagnosis experience. Do you have an interesting story to share? We'd like to hear it! Submit your story to the Holland Committee at hollandcommittee@ctdownsyndrome.org.

Enjoy!

At age 35 my husband and I found out we were going to have our 3rd child. Several weeks down the road much to our surprise an ultra sound showed us we were having our 3rd boy, how exciting! We did not care what the sex of our baby was going to be really, we just wanted a "healthy baby". Because of my age (oh, so old) and my 1st son having a kidney problem (which is not genetic) and he is fine now, we choose to have level 2 ultrasounds up at Uconn Medical Center. I did not have the 1st phase of testing that they are doing now as far as blood work goes, just the typical routine bloodwork at that time. Well, all the bloodwork checked out fine and our first level 2 ultrasounds came back great! Nothing looked out of the ordinary. Actually, they considered me "very low risk". We went back for a couple of level 2 ultrasounds after that and still everything looked great still "low risk". My numbers of having a child with Down syndrome were at the lowest! This pregnancy was as uneventful as the others. I felt great and measured up fine at every OB appointment.

On May 4th 2006 I woke up at 2am with feeling a surge of fluid trickle down. I thought to myself, this can't be happening Sam is not due until around June 12. Immediately I woke my husband and then called my mother (who is an OB Nurse). My mom advised me to call the Dr. to let him know. I called the Dr and he said....ok, go back to bed and come into the hospital around 9am. Great, I thought to myself, I really wanted a natural birth and was using Hypnobirthing so the longer at home the better. I had no contractions at the time at all so I went back to bed and rested a bit.

Once in the hospital, they checked me and I was about 3cms with no contractions but my water did break for sure. Having not yet had the test for Strep B they wanted to administer antibiotics so I let them do that intermittently so I can still move about the room. I had no I.V. fluids pumped into me just when I received the antibiotic for 20mins each time. The doctor wanted to give me pitocin (synthetic drug to speed up labor) and I refused. As long as the baby and me were ok I said absolutely NO. They asked me every hour or so to have pitocin and I kept refusing and told them I will let my baby and body do what it needs to in its own time.

At 12 noon my contractions started :) They came on strong and fast but I was in my Hypnobirthing mode and on the birthing ball in my dim room with the relaxation music on. I was on that birthing ball for about 3hrs completely relaxed having contractions. I felt the urge to get up and felt some pressure. I got up on the bed and said the baby is coming. At this point, the DR rushed in and said "wow, that was fast", since I was only 5cm when they check me last. Yes, my body moved quickly. Sam came to the world without any pushing or birth breathing out. My body had a contraction and there he was! This is called expulsive reflex by the way. Your body can expel a baby without any "pushing". It is so cool! When Sam was on my belly they did give him a little blow by oxygen for a couple minutes but then did fine. Not surprising for a preemie to need that.

Sam weighed 6lbs 2oz, not bad for a preemie 5.5 weeks early. He is so cute I said and immediately brought him to breast. He nursed like a champ immediately. After a few hours of bonding on me skin to skin I wrapped him up so tight and he met his Daddy in arms for the first time and then Grandma. He looked great and a spitting image of my first son.

Later that night one of the nurses said, "Do you notice something about Sam's arm?" I said "no, what". The nurse said, "hmm..." "he does not want to move it up like the other arm, see". I said, "oh yes, I do see that". The nurse then stated "oh...I am sure it will be fine it is probably how he was in utero, just keep your eye on it. So I thought, "hmm, ok and did not think again on that at all. I just focused on my baby...feeding him, diapering and watching him sleep.

On May 6th we were discharged from the hospital after a fight on what car seat to bring him home in. The one we had was not an infant seat but an infant to toddler convertible (not a bucket seat). That is what I had for my other boys and it was great but Sam was so small and a preemie they thought he should go home in a car bed? What, I thought is that? Where do you get it? Well, there seem to be no answers on why we needed it or where to get one. They finally let us go since we lived 2 blocks away they thought he would be fine in the car seat we had.

On May 7th we went to the Pediatrician for a weight and overall check since he was a preemie. Remember, other than him being early he was fine. My husband and I both went to this appointment. When we got into the room the DR came in said "Oh, he looks good, a little jaundice but not bad. However, I do have suspicions that Sam could have Down syndrome." I looked at my husband and he looked at me and then said to the DR, "Ok. well what do we do now? Where do we go from here?" The DR immediately sent us back to the hospital to have his heart checked out. Although, they did not hear any abnormalities they still wanted to check it. I called up my friend who is a Cardiologist and she met me there and did the echo cardiogram herself. After a review of everything all checked out fine with his heart.

So there you have it....normal pregnancy, false negatives on blood work and ultrasounds. At birth and in the hospital no one said a word (this was because my mother worked there on the maternity unit and they wanted genetic testing first before they said anything) which in a good way was nice because I had no worries in the hospital, I just enjoyed my baby as it should be. However, if I was told in the hospital that probably would have been fine too.

After the 1 week wait of genetic testing (and me searching the Internet trying to learn every inch of what Down syndrome is and what to do) the results where in....drum roll please. Sam has 21/21 Translocation which is a very rare way to get Down syndrome. Typically, this is because a parent is a carrier but in our case after being tested and neither my husband or I being carriers, this was just a random thing that happened. A piece of the 21st chromosome landed on top of the other 21 chromosome which gave him 3 - 21 chromosomes which is Down syndrome.

How did we deal with all this?? We just did and still do. Sam is our baby no matter what. Did we have some rough times? Sure we did and still do but it is nothing we can't handle. Our love from friends and family has helped us through some challenging times. The one thing I have learned and never forget is to treat Sam just like I do my other boys and he will do just fine. So far, he has the typical 2yr old attitude and is cuter than a button!

Rebecca is my 3rd child. I had decided not have the hormone blood test near the beginning of my pregnancy for several reasons. First, I knew I wanted my child no matter what the outcome of the tests. Second, we had had a false positive with my older daughter and I wasn't interested in creating worry when there shouldn't be any.

When I had my ultrasound (it was a girl!) the doctor found some hydronephrosis (water in the kidneys indicating a possible problem), and I was sent for a Level II exam. Based on the level II exam, the doctor gave me some number in 1 chance of having a child with Down syndrome. I was given another chance for a blood test and an amnio as well. I knew I did not want an amnio because I did not want to take the risk of losing the baby and a diagnosis for Down syndrome wouldn't change my decision to have the baby. Based on my previous experience with my other daughter, I decided I would have a happier pregnancy without the weight of "probabilities" on my mind from any blood tests.

With Rebecca, I had some challenges during my pregnancy. I had increased water (a marker for Down syndrome) and had to go into the doctor's office every week for stress tests. Because of the increased water, I had to have additional level II ultrasounds (I can't even remember how many I had, I only know that of all my kids, Rebecca was the most photographed in utero). The Level 2 ultrasounds showed shortened limbs and we also had a potential heart problem. When we did the fetal echo, the doctor determined that the heart defect was not there (in the end, Rebecca did have a heart defect, ASD and VSD (Atrial Septal Defect and Ventricular Septal Defect) — basically, holes in the heart that shouldn't be there).

Based on all of the various "markers" I had (shortened limbs, excess water that did not go down, funny look I got from one ultrasound tech, etc.), my husband and I realized that we had a good chance of having a child with Down syndrome. We weren't worried. I'm not sure why. Maybe it was because we believed whatever child we had, would be the perfect child for our family. That has definitely been true. Soon after Rebecca was born my husband said, "Rebecca completes our family" and that's the way we feel about her. She makes our family the family it ought to be.

Rebecca's labor was the fastest and easiest of all my kids. When we got to the hospital, Rebecca was ready to see the world. I am now glad the doctor didn't catch the ASD and VSD because I'm not sure I would have made it to any area hospital with a Level III NICU. (The nurse in the maternity ward said to me, "If you feel like pushing, don't. We've delivered babies before but we'd rather wait for the doctor.")

Once Rebecca was born (very soon after we got to the hospital), we quickly realized something was not quite right. Her oxygen saturation levels were less than 85 (they should be over 90). When they put her on me, she nursed a little and her levels went up temporarily but went back down again. Things happened very quickly after that. We were informed she had to be moved to University of Connecticut Hospital and by 11:30 AM, a transport team came, loaded Rebecca into this plastic bubble infant transport thing and left. My husband followed the ambulance and I was in this maternity hospital room without my baby nearby.

No one said "Down syndrome" to us until we met with the Geneticist, but after two kids, I knew immediately Rebecca had Down syndrome when I saw her. When they took her to the nursery, my husband said "I think Rebecca has Down syndrome" and I said "She clearly does." For me, it is a fact, not something to be sad about or mourn over. It's a fact like John has brown eyes and Jennifer has lighter hair than my other kids. It is part of who Rebecca is. It's not a disease or a disappointment. When I told a friend of mine that Rebecca had Down syndrome her first response was "I'm so sorry." My thought when she said that was "I'm not." Rebecca's Down syndrome is not something that I am sorry about. It's like her mischievous smile. It's not something good or bad but something that is part of her.

Many things happened after soon after Rebecca got to U-Conn. We had the cardiologist say in a very matter of fact way that our daughter had a hole the size of a dime in her heart. Considering the size of her heart, it was a big hole! The thing that we wanted most was for her to come home, but because of her heart, she couldn't eat as well. As a result, she had to have a nasal tube because she couldn't finish a bottle. 4 weeks into going to the hospital every day, we thought she was going to go home with us. We learned how to check to make sure her tube was in place, how to give her medicine, etc. The plan was to take her home on Friday but that week her eating levels plummeted. On that Wednesday, the doctor called (less than an hour after I had left the hospital I must say) and said the cardiologist had come and determined that we should not wait any longer for

Rebecca to grow any bigger. She should have her surgery as soon as possible.

So, the Friday she was supposed to come home with us, Rebecca was moved to CCMC (Connecticut Children's Medical Center) so that she could be ready for open heart surgery.

On September 4th, 2007 Rebecca had her surgery (a big a day as her birthday) and on September 15th, she came home. Once her surgery was done, she was a different baby. She was more alert, more active, and most of all able to eat with no problems. Looking back, the surgery was very traumatic. Open heart surgery for a little baby is pretty scary – more for the parents than for the baby. When she came out, she had 14 different things going in and out of her. It is shocking and frightening to see a little baby on that big bed with so many tubes and people surrounding her. She is fine now and remembers nothing of it.

Rebecca is a great joy to our family. She has a mischievous smile she has been using more and more recently (to my chagrin). She is developing wonderfully. She has had her challenges (nystagmus where her eye wiggles when it shouldn't, low thyroid, etc.) She is just starting to communicate (she can show me where my nose, mouth and eye are as well as sign “more” and “milk”). Each day we can see her grow and develop. She is not like my other children in many ways, but no child is the same and as my husband said, she completes our family. We are truly blessed to have her in our lives.

When

I was 25 years old, I found out I was pregnant with my third child. I had two daughters who were seven and two years old. I had an easy pregnancy and I went into labor February 5th, 2001, which was two weeks early. At 4:49a.m. on February 6th I had my first son, Donny. Later

that morning, the pediatrician came in to check on Donny and she told me she was concerned about a few things and she was going to have a specialist come in. I had no idea what any of this meant at the time, so I just waited. A short time later another doctor came to examine Donny. She said she was worried about his chest being too narrow, his arm bones being too short, his eyes being too close together. They wanted to run a blood test to check to see if he had Down Syndrome. The test results would take three days. Everytime the specialist came to my room, I would start crying. I had a lot of mixed emotions at that time. My mother-in-law even called me and said if I couldn't handle it, she would take and raise Donny.

The next few days were stressful. Donny couldn't hold his temperature and he had to be tube-fed because he wouldn't eat. He was in the special care nursery most of the time he was there. It was 4 days later when we got to bring him home.

Donny is almost 8 years old now and he is the sweetest little boy. Everyone at school loves him and helps him. I could not imagine my life without him, even through the health issues and some sleepless nights.

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