In Due Time...
Waiting on a possible diagnosis

As told by moms/ mums around the world

Compiled by Jennifer Jacob
2014

Waiting.

For some families, this was a conscious choice. For others, it did not become apparent that they had waited until their new little one had arrived. ‘Waiting it out’ is a term used by some to define parents who may have an increased risk of a chromosomal abnormality based on prenatal blood tests or ultrasounds, but then choose to not undergo any further testing for an official diagnosis. As a result of some tests, parents are given a risk assessment for some of the more common trisomies (13, 17 and 21, for example). Even with only a risk assessment to go on, many families grieve initially, very similar to those who have receive a confirmed prenatal diagnosis. There is an adjustment period that must take place. Eventually, grief subsides and hope is renewed as families begin to put things into perspective. For some, the wait can be torture. Waiting, wondering, not knowing, imagining how life could possibly change. Some may delve into research or join support groups and begin to prepare themselves for the birth and future life of a child with Down syndrome. For others, holding onto hope is enough for them to sail through the rest of their pregnancy with very little thought of the fact that they are, in fact, 'waiting it out.' Generally these families have come to peace with the idea of having a child with Down syndrome. The waiting game is hard, there is no way around it. Having so many unanswered questions, while at the same time experiencing the life of your unborn baby tossing and turning within your womb, can leave an expectant mother feeling overwhelmed and exhausted. Know, however, that when you finally give birth to your precious child, every second of the wait will have been worth it! To finally have answers ...

Our Stories

{Kayla}

At our 19 week ultrasound, we walked in feeling great. We were not planning on finding out the sex of our baby, so really this was just going to be a routine visit to count fingers and toes and make sure everything was developing properly. I walked into that room without a care in the world. It never even crossed my mind that they would find anything that would indicate there was something "wrong." Our little stinker was very cooperative; she kept her back to us, so even if we wanted to know the sex I don't think we would have been able to find out. The ultrasound technician spent what felt like forever going over every little organ and feature. This was our first child, so I had no clue how long these things were supposed to take. When she was finished, she called the doctor in. He matter-of-factly looked right at us and told us that our baby had dilated kidneys. By itself, this was really no big deal. But this, combined with our quad screen results (which were also news to us at the time) showing a 1 in 99 chance that our baby could have Down syndrome was a slight "concern." At this very moment, I just froze. And then the tears started to flow. I was not prepared to hear those words. I had never even considered something like this happening to us. Things like this happened to other people, but not us. Even writing this now, I realize how ridiculous this sounds.

The doctor immediately said we needed to discuss having an amnio to confirm if our baby did in fact have Down syndrome. My husband and I both looked at each other and

without hesitation declined. Even though it isn't huge, amnio carries a risk of miscarriage, and for us that was not a risk worth taking. I understand why people do it and I am not judging that decision at all, but for us, this was not an option.

I left this appointment in tears. I was terrified. I am pretty sure I cried for two straight days. Rich kept reassuring me that everything would work out the way it was supposed to, and that if this is what was meant for us, we would figure it out. A couple days later I finally stopped crying and moved on. Once I realized there was nothing I could do to change the circumstances, I let it go.

We had two subsequent ultrasounds to monitor the kidneys. In each ultrasound the kidneys kept looking better and were eventually within the normal range by our last ultrasound. The doctor's opinion was that we were, in his words, "good to go." Because we only had this one soft marker outside of the quad screen, I convinced myself that everything was going to be fine. A 1:99 chance is only a little more than one percent. I did continue to read the complications board on my *What to Expect When You're Expecting* app for anything related to dilated kidneys and Down syndrome for the rest of my pregnancy. I have no idea why. Maybe, I was curious or maybe I subconsciously knew. But I never did much research beyond that. I never even googled Down syndrome, other than the phrase "down syndrome and dilated kidneys." I never searched for pictures of babies with Down syndrome either. I still wonder about this. Was I protecting myself? Did I not believe that this was really going to happen to us? Did I not want to know and see what our possible future could look like? On June 5, 2012, I went to my weekly doctor's appointment. We decided to have my membranes stripped, which was one of the worst experiences of my life. I am pretty sure I will just let

things occur naturally next time. We were told that there was a 50 percent chance that I would go into labor that night, but I was convinced that it wouldn't happen. So I went about my business, working a full day from home because I had terrible sciatic nerve pain and it was a serious struggle to walk, especially up and down stairs. I worked the full day, and really didn't think anything more about my membrane-stripping earlier that morning. On my husband's way home from work, he stopped to get me dinner. I scarfed down the three tacos he brought me like it was my job and, within minutes, the contractions started.

My contractions were painful, but I am such a rule-follower, I waited until they were exactly five minutes apart before we called the doctor. My husband told them the situation and they told him to bring me in. That car ride was the longest car ride of my life! There was nowhere to turn or move my body when I was having a contraction, so it was miserable. We finally arrived at the hospital 20 minutes later, even though it felt like five hours!

They immediately checked me and said that I was already seven centimeters. No wonder I was in so much pain! I wanted the epidural. Honestly, it was never a question. I knew I wanted it. I knew I needed it. I quickly progressed to 10 centimeters dilated, but she was not ready to come yet. They also said that I was too numb and I needed to wait so I was able to feel the push, but at least at this point I was relaxed. Several hours passed, and then they had to give me Pitocin to start my contractions again. This whole series of events was a bit bizarre, but eventually the doctor announced that it was time to deliver. I was going to meet my baby soon. I started pushing and pushing and pushing. I think we tried every position imaginable. I pushed for over three hours. I

honestly didn't think I was going to be able to do it. I was convinced this baby must be at least 10 pounds, considering how difficult this was. I was also surprised that they eventually didn't say that I needed a Cesarean section because the whole thing was taking so long. They had more faith in me than I had in myself.

Finally, at 8:41 a.m. on June 6, 2012, our angel arrived. I was so exhausted from all of the pushing and crying, I couldn't even see my baby when they held her up. I just remember saying, “what is it? What is it? I can't see! I can't see!” My husband shouted through tears, “it's a girl! It's a girl!” I never knew how badly I wanted a baby girl until I heard those magical words. This was definitely a bonus for waiting to find out the sex. It was one of the most amazing experiences of my life. She was finally here, all 6 pounds, 7 ounces of her.

After I was told my baby was a girl, she was swept away to be checked out by the team of nurses. She did not cry right away and that worried me a little, but I was too exhausted to think much of it. I don't remember hearing a lot of talking or celebrating going on either. They finally handed me my baby so we could be skin to skin and it was the most amazing thing I have ever experienced. This little person was mine. God trusted *me* to be this perfect little angel's mother. She was very swollen, probably from all of the pushing. She also had a slight cone head from coming out sideways. People have asked me if I knew she had Down syndrome the first time I saw her, but I had no clue. Honestly, the thought never even crossed my mind for one second. She just looked like a perfect little swollen angel to me. Now of course when I look back at pictures, I wonder how could not have known.

My actual doctor didn't make it in time for our delivery, but he did make it a few minutes after, just in time to stitch me up. He was very quiet the whole time, which is not like him. He wasn't cheerful; I don't even know if he said congratulations. I am sure he did, but all I remember is a lot of silence. Looking back, I believe this was because the nurses told him their suspicions and he was probably sad for us.

At some point during this first day, the nurses informed my husband of their suspicions as well. I am still not quite sure why they didn't feel the need to wait and tell us together. They told him, because she was so swollen, there was a chance that they were wrong. He asked them to wait until some of the swelling went down to be sure before they told me. He didn't want me to get worked up for nothing. So I went along in my blissful state of new motherhood for another day before I had any clue.

On June 7, 2012, my world was forever changed. My husband came in the room with the doctor on duty. The doctor looked right at me, said hello and told me that she was pretty sure that my daughter had Down syndrome. At that moment, I just felt completely numb. I honestly don't even know if I replied. She kept talking, but everything she said sounded muffled. My mind was going in a million directions. I couldn't hear anything. I kept thinking that this was a dream, this could not be happening to us. Even days later, I still thought it was a dream. I do vaguely remember the doctor telling us that she too, had a daughter with Down syndrome and that, really, it was no big deal. At the time I was so distraught, that I remember thinking that it might not have been a big deal for her, but it was for me. I was not cut out for this sort of thing. And then the tears came, and they continued for a couple months.

Throughout our hospital stay, my husband was so strong. He's the type of person that can handle something like this, not me. I broke down crying every few minutes. I know now that most of my fears were all fears of the unknown. I really didn't know much about Down syndrome. Of course now I was kicking myself for not doing more research when I was pregnant. My husband kept reassuring me that we could do this and everything was going to be ok. Of course, I didn't believe him at the time.

The next couple of months were filled with many tears and many breakdowns, to the point where my husband thought I needed to seek help. I just couldn't keep it together. One minute I would be perfectly fine and then the next I would be on the floor crying. My mom even came back to stay with us to try to help keep me sane.

As I sit here now, staring at my beautiful daughter, I realize how ridiculous I acted. I wish so badly that I could go back and tell my old self, just how "ok" life was going to be. In fact it would be so much better than "ok," better than I could ever imagine. However, I wouldn't change a thing. I feel like I had to experience those emotions to get to where I am now.

Now I am in a place of complete amazement that this is my life. That God trusted me to take care of this awesome little girl, who just turned one. This year has been filled with many ups and downs, but definitely more ups. I feel truly blessed. I look back and almost laugh at the things I was worried about. I do want Kayla to know this. Through all of the sadness and tears, it was never about you as a person. I loved you with every ounce of love I had. I was scared of the unknown, about your future. But my love for you never wavered, not for one second. I just wanted to protect you from all of the evil in this world.

This year Kayla has taught me so much about myself and about life. She has made me see the good and beauty in all people. She has taught me that every single life is precious and we should not spend one day on this Earth wasting it. She has given me a renewed relationship with God. I truly believe that this was my plan all along. When I was going on and on about how I couldn't do this and this sort of thing didn't happen to people like me, God knew better. He knew that this was the exact type of thing that happened to people like me, and I was one of the lucky ones. It may have taken me a little while to accept this new life. But now that I am here, I would not trade it for the world. Kayla has always been exactly the person she is supposed to be: the beautiful, fun-loving, sassy little angel that is absolutely amazing. I am not saying that I will not have hard days; there will be days when I worry about her future and days that I absolutely hate Down syndrome. But I accept this life and any challenges it brings, because this life brought me the most unbelievable gift: my sweet girl. Kayla, thank you for being you. I am so excited to watch you grow and see what you do with this one amazing life you have been given.

~ Amber, Kayla's mom; 33; Ohio, United States

{Angus}

I had fallen pregnant for the first time and I was thrilled at the honour of finally becoming a mum. I made an appointment to see my General Practitioner for confirmation; she said that due to my age, I should have first trimester blood screening. I knew no better so went ahead and had them done at 10 weeks. A few days later I arrived home message from my GP stating that I should call her back about my results. The worry set in as I wondered what the problem could be. When I called her, she told me that my baby had a 1:17 chance of being born with Down syndrome. She asked if I wanted a copy of these results and provided for me information on genetic counselling. I had also received a call from my newly-appointed obstetrician; at this point I felt like I had done something wrong! I wanted everyone to leave me alone let me enjoy my pregnancy. I wanted to put my hands over my ears and sing “La La La La La La La.” My husband and I had discussed the procedures that had been offered to confirm diagnosis and we did not want to have these invasive tests done. If our child had Down syndrome then he/she would be welcomed into our loving home just like any child. But my head and heart were fighting a vicious battle. My head was saying no, your baby doesn’t have Down syndrome. Everything will be OK. Since it was my first pregnancy, I felt like this couldn’t be happening. “Why me?” I would ask through tears. Then the voice of reason would come in and remind me that I was going to be a beautiful mum to this child no matter the outcome. He/she would be a blessing and bring us much love.

Then it was time for our 12-week scan. There was the little blessing on the screen before me: strong heart, all organs good. Bub looked healthy and strong, so we carried on…

16 weeks through the pregnancy, we were on a plane to Paris. This trip was organised before we knew we were pregnant, but I was glad to get away for a few weeks. I remember visiting Notre Dame Cathedral and, despite the crowds, it filled me with a sense of peace. I believe in synchronicity and the universal laws and sometimes, a person just needs to let go. I lit a candle in the cathedral, sending a prayer to the spirits, ancestors, angels, or whoever wanted to listen to please let my baby be healthy and arrive safely. I purchased a small sculptured token of mother and child, a symbol I held onto throughout my pregnancy. On our return back to the Land of Oz, we had our 20-week scan booked for the next day. My husband and I started calling the radiologist "Dr. Charisma," as he truly lacked people skills. He measured the fluid behind the neck, which was within normal range, and said that while our baby was small, everything seemed fine. The only soft marker was his little finger; the middle joint was missing, a condition known as clinodactyly. I was still hopeful that my prayer had been heard. Yes he/she was healthy, small, and had a bent little finger, but that didn't mean that anything was out of the ordinary. I spent the rest of my pregnancy watching the disk of the scan and looking at the beautiful little being. When you are told there is a possibility of having a baby with Trisomy 21, you start looking for things that are wrong, because people put it into your head that something is wrong. Back at the obstetrician's office we discussed that the baby was measuring small and that there was a possibility of aneuploidy, or chromosomal anomaly. Once again, I was asked if I wanted to have an amnio and I declined. "What if the baby has Down syndrome?" they asked. "Would you continue the pregnancy?" The answer was simple: YES.

I cried many times in the obstetrician's office. I always felt like there was something incredibly wrong with the baby due to the way medical staff would talk. I never thought

for a second about terminating, as I felt this child deserves a full life, regardless of the perception everyone else had. Yes, my child may have Down syndrome, but he/she was a perfect combination of me and my husband's DNA. Shouldn't he/she be seen as an individual, just like a child with 46 chromosomes?

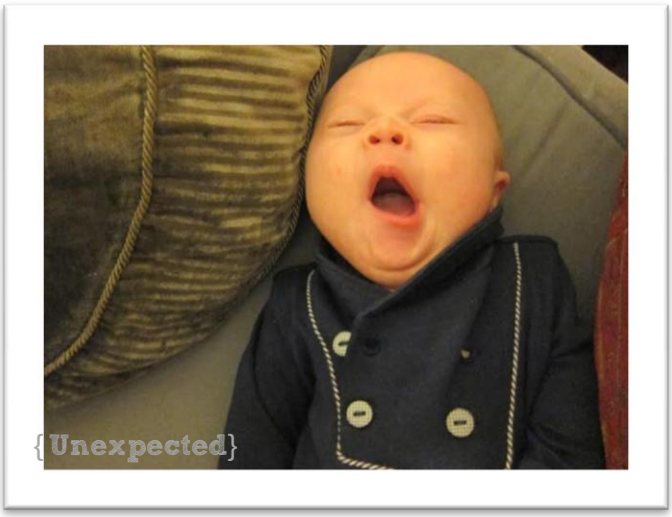
Weeks 33 and 34 I had weekly ultrasounds, as my obstetrician wanted to keep a close eye on growth, so we journeyed back to "Dr. Charisma" to learn that baby had not grown much. He told my husband and I to expect the worst, which upset me. "The worst" for me would be the death of my baby. I was also going into the hospital twice a week to have Cardiotocography monitoring, which was fine. My obstetrician wanted to transfer me to a larger hospital due to the slow growth and possibility of aneuploidy. We had an ultrasound, this time with a lovely woman who genuinely was concerned for the baby's well-being. She stated that this baby needed to come out, which left me truly worried and, yes, crying. Again.

We had a planned caesarean section at 36 weeks. When our beautiful baby boy finally came into the world, I immediately knew he had Down syndrome, but he was perfect. The Paediatrician noted a few markers, such as the single line across his left palm, the inward curve of his little finger, and the gap between his big and second toe. That evening the concerned Paediatrician told us the interim chromosome report stated that Angus had Trisomy 21. Of course, I cried. I was totally exhausted. But regardless of this outcome, what I had been holding in my heart was true: I loved this beautiful child, no matter the number of chromosomes.

~ Angus's mum; 39; Australia

{Henry}

I was 31 years old when I found out I was finally going to be a mom. I had just married my significant other of ten years, and within two months, we were excitedly moving forward with our life together and starting our family. Shortly after our first ultrasound to confirm the pregnancy, I fell ill with the flu, including a severe fever. I was so worried about my little baby being affected by it, all I wanted was to hear that heartbeat again, to make sure everything was ok. We hadn't even chosen a care provider yet, as we were in the process of interviewing midwives for our planned home birth. I told one of the midwives that I was particularly concerned about the baby, so she offered to fax a referral for me to have another ultrasound.



I was just shy of 13 weeks when I went in for my appointment. I noticed it was a perinatologist office, but I didn't know what that meant. I was just focused on seeing and hearing my baby again so I could stop worrying. The nurse who performed my scan was very thorough and didn't say much. The time was long and the room was quiet. It didn't strike me as odd, though, I was simply happy to see my baby squirming up on the screen in front of me. Afterwards, she put me in a room and told me the doctor wanted to go over the results with me, and that he would be right in. I was mildly annoyed as I sat there waiting for well over 30 minutes. He came in and had a terribly morose look on his face, like someone had died. My heart sunk and my ears started to get hot. I heard

him explain that my baby had a very large NT measurement, nearly 6mm, including a cystic hygroma, and that he didn't even need to do bloodwork. He had been "doing this for years" and could tell me with confidence that my baby had Down syndrome, if not some other guaranteed chromosomal anomaly. He looked at me with pity in his eyes and remarked, "not every pregnancy can be perfect and these things unfortunately do happen." He did not leave me with any literature or further recourse, other than to say, "you have a lot to discuss with your husband."

I felt like I had been punched in the stomach as I walked out to the car alone, ignoring my husband's text asking me how it all went. I was more worried about how I would be able to tell *him* when he got home from work. Would I be able to remember all the technical jargon? Would I be able to stay strong for him and not cry? From what I could piece together that day, they had performed a high level ultrasound on me because that's just what they do there at perinatologist offices. I had unknowingly and by chance walked into a high-risk office, only to find out that I was indeed, myself, a high-risk pregnancy. Google became my best friend and most hated enemy as I ravenously read about Down syndrome, cystic hygroma, and nuchal translucency measurements.

I grieved, my eyestrain giving way to sobbing and tears. Each day following was an eternity of obsessing at the computer. I kept staring at the little ultrasound profile, trying to discern if the doctor was correct. I kept a smile on my face to friends and family, but inside I was crushed.

I asked myself some very dark questions. Surely this was punishment for any number of sins I had committed in my lifetime. 'Why us?' was often echoed by an even lonelier call, 'Why *me*?' My husband and I each experienced a deep and personal struggle, but

we also went through it and came through together, hands held. We knew we would move ahead with the pregnancy, forgoing the amnio, and just treating the pregnancy as if we knew for sure our baby had Down syndrome, as this was just prior to the breakthrough diagnostic tests now currently offered to expectant moms that carry no risk. I channelled my grief into research and educating myself. Intellectually I forged ahead, while emotionally I struggled, stagnated in anger. My own mother made it worse, upsetting me with her attempts to pray away the quasi-diagnosis. Any shred of lingering religious faith I had left as a young adult was obliterated with this experience, and it was an insult to me that she would unwittingly infer that my baby was in need of fixing. I told her that what I needed was *acceptance.*

Well, it was official; my pregnancy would not be rainbows and unicorns. I was now an outsider, a role that I actually felt pretty comfortable with in other contexts. All the same, it was hard to see other pregnant moms walking around without a care in the world when I had to wake up everyday and wonder whether my baby had Down syndrome or not, and if so, what other myriad of health issues would accompany it? It felt like never feeling the sun on my face for six months. I was walking in the dark. I wallowed in pity, lamenting that the joy of my first pregnancy had been stolen from me. My privately complicated pregnancy was made even more complicated because of my pre-existing mistrust of doctors and nurses.

I won't mince words, I detest the American medical system. Always have. I think it's a corrupt institution, right alongside the insurance companies they partner with. I have never believed [in] MDs, yet found myself feeling utterly at their mercy because of my high-risk pregnancy. I grieved the loss of my planned home birth just as hard if not more

so than the actual diagnosis of my unborn child. You see, I did not yet know for certain my unborn child had Down syndrome, but I *did* know about the AVSD heart defect. We found out about it the same day we learned our son was a son. A guaranteed open heart surgery was our child's fate, and we hadn't even met him yet.

My husband and the midwife we had chosen together remained my rock as we navigated the uncertain course ahead. I "played both sides" so to speak, my midwife fully aware of the possible Down syndrome and confirmed heart defect, and my perinatologist aware that I was still seeing my midwife for prenatal care. We were told I would have to deliver at a hospital with a level III NICU or higher, as this is the standard protocol. As I filled out the registration paperwork, it felt as if I were being forced by another hand to sign a lifelong lease with the roommate from hell. The prospect of having to deal with doctors and nurses on an ongoing basis was honestly a living nightmare for me. I have since come to embrace it as my life's most ironically enticing challenge.

My son's prenatal echocardiograms were encouraging despite the hole in his heart, a beacon of hope to me already. I didn't know much about him, but I could tell he was strong, a fighter and defier of odds. When my water broke spontaneously at 37 weeks, I was rather caught off guard, but had a long labor in which to wrap my head around the fact that I was going to be a parent. I had focused so much on the potential special needs part, that I forgot I was going to be *just a mom*. Period. Hello and holy $&@#!

My son was born a healthy eight pounds with no signs of distress, my midwife and my husband by my side. I remember when my son was placed on my chest, I immediately tried to get a good look at his hands. I was looking for the simian crease. I couldn't get

his palms open, because he was clutching my own fingers so tightly. I then gazed upon his face, finally meeting him, recognizing that he did have Down syndrome. It didn't upset me though, because I was completely overwhelmed with love for him. It was that simple. All the wondering and worrying that had been building up all those months sort of faded from my mind and became background noise; the loud crescendo of unconditional love struck my heart, as my son finally became real, something I could know and hold. I knew then that I was just like any other mom falling in love with her baby, and if there *were* differences that would reveal themselves with time, they could only challenge my character in the best possible ways.

His karyotype of Trisomy 21 was confirmed shortly thereafter in the hospital NICU, where he would ultimately stay for 20 days. It was the longest 20 days I have ever endured, and even more difficult than when I had lost my own father a decade earlier. The NICU ironically decided the cascade of minor setbacks that would keep him there: the usual jaundice due to being separated from me and not nursing those first critical hours, followed by low oxygen and then the beloved feeding challenges. I was helpless to fix the problems they created and forced to follow someone else's say-so regarding my child. It was awful.

Being discharged from that hospital after giving birth and having to drive home without my baby was excruciating. As if the postpartum period isn't hard enough on a new mom, I had to grieve all over again with the confirmed diagnosis and then go home without my child. That nasty sterile hospital would become our second home for a month as we drove back and forth in the Las Vegas heat every few hours to pump milk for him and hopefully get to hold him and love on him.

It was so heartbreaking to see him in that incubator, attached to monitors, alone beneath the bilirubin lights. I wanted to snuggle him so badly. Every cell in my body cried out to be able to do what mommies do. My son's own cardiologist had cleared him to go home when he was just two days old, but that evil NICU insisted he stay anyway. It was ridiculous. He looked like a giant diapered Buddha, ready to bust out of that plastic rectangle, sticking out like a sore thumb amongst all the itty bitty preemies surrounding him. They were not satisfied with the amount of milk he was ingesting, even though he lost very little weight, and was making consistent gains. His suckle was weak, so he was fed breast milk through a tube in his nose. As day followed day, I came to understand the archetype of "momma bear" much better.

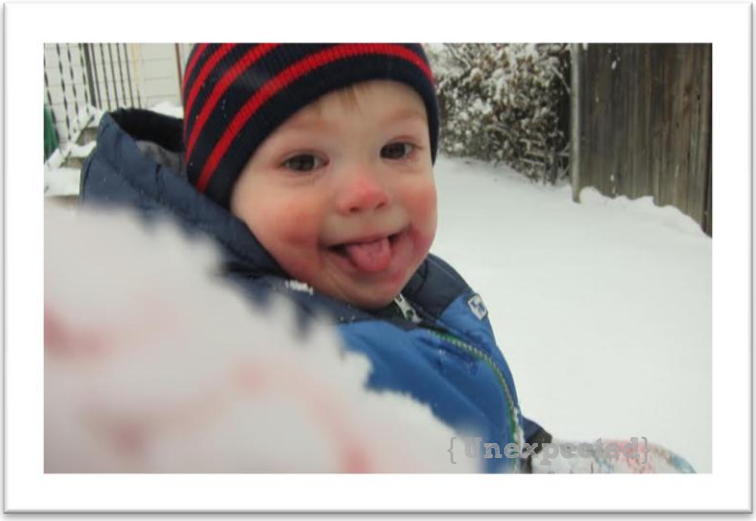
At my friend's suggestion, I eventually sought assistance from the hospital's patient advocate, because I was not happy (gross understatement) with how long it was taking for my baby to be released to come home. Every hospital has someone with this job title, and they are there to help **you**, the paying customer.

Recalling it all stirs up the residual frustration of something I am so glad to be on the other side of. Going through that experience made me fully aware of the deep well of strength I had within myself, which was the silver lining of my son's NICU stay. I still have to deal with the medical concerns in my son's life as they come along, and will continue to do so within his best interests, but it's in much smaller, more tolerable doses now compared to those early months.

When our little man turned 10 months, we found out he was going to be a big brother (Gulp!). We had been going back and forth with the cardiologist about when his surgery would be scheduled, because what they originally believed to be a complete AVSD was

indeed a partial AV Canal, and did not require imminent surgery after all, which was great news. We could have waited another year or more to have his repair done, but we all decided it was best, emotions aside, to move ahead preemptively, because doing it with a new baby in tow would've been much harder logistically.

He had the hole in his heart repaired when he was 15 months old, which was very stressful, but it was stunning to witness just how resilient our little ones are! He charmed all the nurses during his recovery, and was back home in less than a week's time, completely unfazed. He was right back to cruising the furniture and had no setbacks in his development. He was doing great before his procedure, but we could tell he was doing even better afterwards in terms of growth! He is truly an amazing little guy, and I was very humbled by the swift success of his open heart surgery. I even caught myself liking his surgeon! Just a little bit…



My son is nearly two years old now, and our life is very "normal," whatever that means. I chase him around and try to keep him from incessantly sticking his fingers in baby brother's mouth! We didn't do any prenatal testing with our subsequent pregnancy either, because I wasn't scared of the possibility of more Down syndrome. It's all we knew until just recently and we feel very blessed. Not chosen. Not burdened. Not special. Just blessed.

~Leah, Henry's mom; 31; Nevada, United States

{Emily}

We chose to not do any genetic testing, as it wouldn't have changed the end result for us. We first learned that that something was amiss at our 20-week ultrasound; the doctor reported that Emily had a large kidney and we would need to have at least one more ultrasound to monitor the situation. We were told that this is common and it usually goes away before they are born; we assumed there was nothing to worry about. I had my repeat ultrasound right after Christmas, around one month before my due date.

After the ultrasound, I went to the exam room as usual, but I remember it taking a long time for the doctor to come in. I thought she must be busy with other patients or delivering a baby, but instead she was reviewing my ultrasound report. The doctor finally came into the exam room and starting discussing the ultrasound. It's hard to recollect everything as the moment was such a blur, but I remember that the doctor told me she had a "double bubble," or a duodenal atresia, a common occurrence in babies with Down syndrome.

I was an emotional mess, as my baby was sick. I still can't believe I was able to pull myself together and return to work. I was given a great book and received much support from the doctors in Bismarck. Now, after hearing several horrid doctor/patient stories, I feel very fortunate that I had a supportive medical team. I was also told that I would need to move to Minnesota immediately so I could be closely monitored by

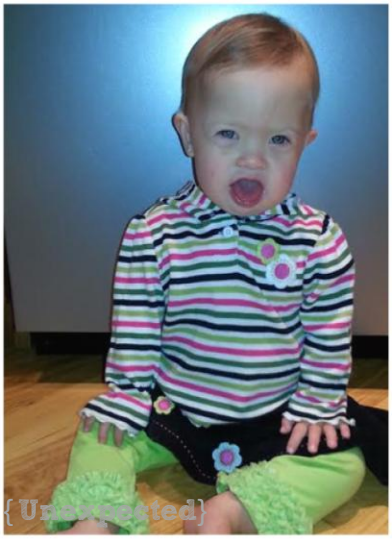
specialists, as Emily would need immediate surgery to fix the duodenal atresia. I would deliver her there since there are no pediatric Gastroenterological surgeons in North Dakota and I certainly would not want to be 430 miles away from my baby girl.

I moved to Minnesota a week after receiving this news, leaving behind my husband and three-year-old son. I am very fortunate that I was raised in Minnesota and all my family is there; they were incredibly supportive and went with me to many Maternal Fetal Medicine appointments and ultrasounds. They found over four markers that indicated Down syndrome. I remember looking at her ultrasound pictures and seeing if we could "see" evidence of an enhanced chromosome. I was offered an amniocentesis to confirm the diagnosis, but in reality, why? We were faced with pretty good odds due to all the markers. We did meet with a genetic counselor, who took notes on our family history and gave us a folder with information from the local support group in Minnesota. I thought the hardest thing was going to be telling my family, but to my surprise everyone was supportive and there was never a negative comment. Emily was officially diagnosed with Down syndrome one week after she was born.

I was initially shocked, upset, and fearful of the suspicion that my baby would be born with Down syndrome, mainly because of the unknown future. How was this going to change our lives? I often asked myself whether or not I was capable of taking care of a child with special needs. After getting over the initial shock, reality hit me and I decided that there was a reason why I was given this gift. She's going to make me a better person and it makes me happy to imagine how many people she will positively affect in her life. Granted, there are going to be hurdles, disagreements, and setbacks, but life is short, so we need to stay strong and be positive. I need to enjoy my extra-special gift

and take every day as it comes, even if we don't know where this bumpy road is going to take us.

~Ranee, Emily's mom; 35; Minnesota, United States



{Ellie}

I would assume that very few individuals ever imagine themselves raising a child with Down syndrome. Even though I had been fortunate enough to both grow up with a wonderful friend who has Down syndrome and been blessed to work as a pediatric nurse caring for children with special needs, never had I envisioned my life as a parent of a child with special needs. This was a thought that had never crossed my mind.

It was a warm, sunny day in September of 2011 when I got the call - the call that would forever change the course of our lives. I was 16 weeks along in my first pregnancy and my husband and I were counting the days until our 18-week ultrasound when we would hopefully learn the baby's gender. It was about noon and I was just sitting down for lunch when the phone rang. It was my doctor's office: "Your quad screen has indicated that your baby is at an increased risk for having Down syndrome. Based on your age (I was 28 at the time), there is a 1:25 chance. We would like for you to go for further testing and have a level-II ultrasound done."

In that moment I was panicked, shocked, and devastated. Quite honestly, those are the only words that I remember; the rest was just a blur. Immediately upon hanging up with the nurse, I burst into tears. I realized that I needed to call my husband. I thought to myself, how will I tell him the news? How will he handle it? Will he be able to continue his work day?

I quickly dialed the phone and told him through tears, "Honey, I just got a call from the OB's office, they said that there is a very good chance that the baby may have Down syndrome ... something about there being a 1:25 risk." I was totally not prepared for the response that I would receive. "And you're calling me emergently at work why?" he said. "This is not a big deal. If the baby has Down syndrome we will still love him/her either way. Don't worry! I've got to go - I'll call you when I'm on my way home." I hung up even more upset than before I had called. What did he mean, "no big deal"!?

After four rounds of oral fertility meds, three IVF cycles, an early miscarriage the year before, and three years of waiting on God's timing, I couldn't wrap my brain around the news that we had just heard. I wondered why, after all that we had been through, this would happen to us. I cried out to God and asked for the testing be wrong. I pleaded for a perfect level-II ultrasound in the coming weeks and for us to be blessed with a "normal" baby. I immediately called my two best friends, my sister, and my mother to tell them the news. That evening, I wrote an email to our closest friends and family asking for them to pray with us. I stood by as my husband called his parents and told them what we had learned. Instantly, there was an overabundance of love and support from everyone with whom we had shared our news.

Days later, after some much needed processing, I realized that our sweet angel baby was a gift. I truly believed that we had been chosen to love and nurture this little person because God knew that we would be the perfect parents for him/her. I finally understood what my husband understood all along - this really wasn't a big deal! What fear I had quickly diminished as I became an advocate for this tiny little person growing inside of me. The focus of my prayers shifted, as I asked God to bring us a healthy baby with or

without Down syndrome. Down syndrome would be the least of our worries, so long as our baby was healthy. By the grace of God, I had found peace and acceptance.

Two weeks after the quad screen, we went in for our level-II ultrasound and learned that our baby girl (Yes, GIRL!) had a condition called ventriculomegaly, where the ventricles in her brain were dilated. Additionally, we learned that the long bones in her arms and legs were behind on growth. Both findings were markers for Down syndrome, bringing our risk from a 1:25 chance to 1:4. Given our new risk assessment, we decided to not pursue further testing. We had come to terms with the fact that she would likely have Down syndrome. From this point forward, we dove head first into researching Trisomy 21 and learning all that would could to best prepare for our girl. For nearly another 18 weeks, we would "wait it out," not knowing for sure if our baby would be born with Down syndrome. Further ultrasounds would reveal additional markers for Down syndrome including a heart defect, hydrocephalus, and increased nuchal fold measurement, among other findings. Our risk assessment was eventually adjusted to a 1:2 risk.

Our angel baby entered the world at 37 weeks, on a snowy day in mid-January. On that day, all of our fears vanished as excitement took over. The baby that we fervently prayed over had finally arrived and was miraculously healthy! There was no need for an immediate shunt placement for hydrocephalus, nor was there a need for immediate open-heart surgery. Our girl was thriving! It was about 24 hours after her birth that we finally received the diagnosis that we had been waiting for and it was confirmed that our sweet angel did, in fact, have Down syndrome. We literally high-fived (yes, high-fived) the geneticist when she told us the news. After all that we had been through and after all of the concerns we had with regards to our baby's health, a Down syndrome

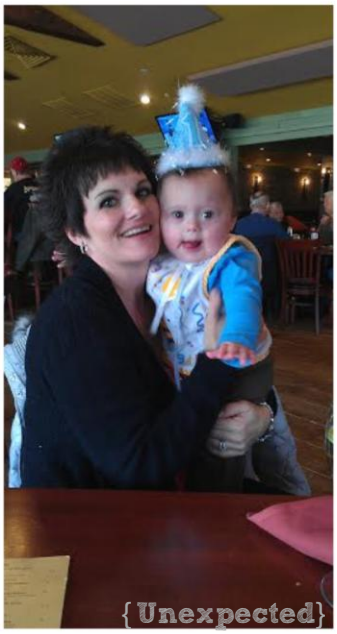
diagnosis was truly the least of our worries. Knowing that our girl could have been born with a different disorder or anomaly, some of which may not have even been compatible with life, we knew that Down syndrome really was the best case scenario. Finally, we were at peace and could totally, wholeheartedly move on with our life, with our newest addition now a part of it.

Today, Ellie is 19 months old. She is happy, healthy, smart, vibrant, and full of personality. She has been walking for two months now and is into everything - such a typical toddler. She is an excellent communicator and knows over 100 signs. Lately, she has also been a bit of a chatterbox, pointing to and trying to say everything that she knows within her environment. Some of her favorite activities include swimming, playing at the playground, rocking and feeding her baby dolls, dancing, reading books, and spending lots of time with family and friends, Despite our doom and gloom pregnancy, Ellie never needed brain or heart surgery, as we anticipated. Though she wears glasses because she is farsighted, Ellie has been discharged from all other specialists. She is an absolutely incredible little girl and is our greatest blessing. She is changing minds and hearts every day, and we couldn't be more proud to call her our own.

~Lauren, Ellie's mom; 28; Virginia, United States

{Matthew}

On Labor Day weekend of 2011, the phone rang and I heard the words, “your triple screen came back 1:5. You can call Tuesday to speak with the doctor and make an amnio appointment.” 1:5? What does that mean? And I’m left hanging over a holiday weekend? The following week I spoke to the doctor, who said I need to have an amniocentesis because there was a high risk for Down syndrome. I declined the amnio. She proceeded to tell me that I had no idea what I was doing or what I could be getting myself into. That’s when I decided it was time for a new doctor.



My new OBGYN was wonderful! They completely supported my decision to avoid invasive testing. I wasn’t willing to risk losing my baby and wouldn’t terminate in the face of unexpected results, so I just wanted someone who would take the best possible care of me and baby and allow me to enjoy the pregnancy. I was already considered high risk due to my age (43), so I was being monitored very closely anyway. Our level II ultrasound showed no markers and the fetal echocardiogram showed no issues , so we felt like we were good to go.

Fast forward to February 20, 2012 at 3:16 a.m. I got up for my potty break and felt trickling. By 4:30 a.m., my water broke! It was my birthday and I had a pedicure and dinner planned, but I was off to the hospital instead. I had to wait around for a few hours since I had to have a cesarean section, and at 12:37 p.m. my beautiful Matthew was

whisked into the world. I asked question after question in those next few moments: “Is he OK?” Yes. “Is he breathing?” He answered me with a scream! “Does he have hair?”

“Happy Birthday, Mommy. He’s beautiful!” they said as this gorgeous little baby was placed into my arms. “Happy Birthday to US!” I corrected them.

The next day his doctor came to see me after checking him out. She told me he was beautiful and was pleased to know he was nursing well. Then she said, “if you don’t mind, I’d like our geneticist to come take a look at him. He has a few markers that lead me to believe he may have Down syndrome.” I stared at her and it was like my head was suddenly in a tunnel; I wasn’t hearing right. She also told me that he would have to be placed under the bilirubin lights that night because he was slightly jaundiced. So not only would he be away from me, but he might also have Down Syndrome? I couldn’t breathe; all I wanted at that moment was to be alone and cry. I felt like a truck was just dropped onto my chest! But for the next few hours I had to put on my happy face for our visitors and my little girl, who kept telling me she loved her new baby brother so much she just wanted to cry!

I had read up on so much during my pregnancy that I knew I didn’t care that he had Down syndrome deep down, but I was so scared at the same time. I knew he had no complications in utero, and had checked out fine so far, but the fear of uncertainty had its hold on me. Finally everyone left and I had a chance to sob uncontrollably. My friend called me that night and I could barely get the words out. “They want to check him for Down syndrome,” I said. Beyond that, I couldn’t speak. I just kept crying. What will this mean to our family? Will he be able to go to school? Will other kids accept him? Will

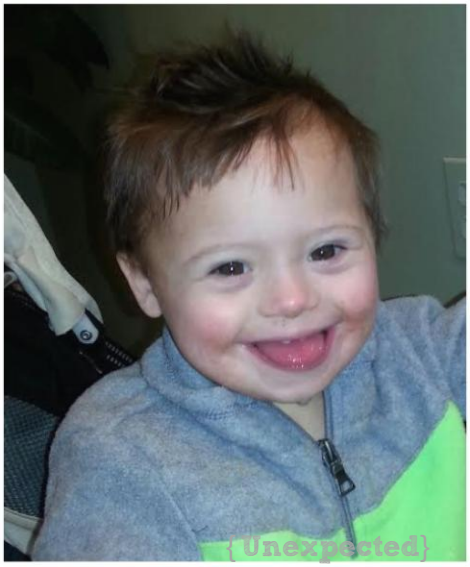
they tease Zoe about her brother? All of this was running through my mind as I cried. I had to go sit with my baby and hold his hand.

The next day the geneticist (who had NO bedside manner) examined Matthew. She agreed that she thought he had Down syndrome and we needed to run a blood test. I sat with Matthew clutched to my chest as she rattled off all of the horrible things a child with Down syndrome could have. *Gee lady*, I thought, *have you noticed how healthy he is? Is there anything positive you can say?* I told her to run the test and we would talk about everything once we had results. At that moment, NO ONE was going to take away my joy of giving birth to this precious, healthy baby! Matthew had no health issues, so we were discharged on February 24th.

We had a check up on March 1st. All was well and there was still no news on the labs. But no sooner did I walk in the house from our appointment when the nurse called and asked if I could please come back, as the doctor needed to speak with me about our labs. I was just there, so I knew what the results were if I had to go back. I felt my whole chest tighten up. We got in the car and I couldn't speak, so I turned the music up. The words "what doesn't kill you makes you stronger" came blaring from the radio and I started to laugh, hard. I saw it as a sign that I would make it through this.

When I heard the words, "Yes, he does have Down syndrome," I cried, but only for a minute. I had already shed enough tears. Now I had to be strong for my son. He failed his initial hearing test, so my only concern was if he could hear and communicate with me. I got my list of all of the doctors I needed to see immediately and took it from there.

16 months later, he passed his hearing test, his ASD has almost closed, he has seven spoken words, four signs, and eats like a piggy! His smile lights up a room and his giggles leave me in hysterics! He has his sister's stubbornness (maybe a bit of that came from me, too), and all is just as it should be!



~Melissa, Matthew's mom; 43, New Jersey, United States

{Connor}

I had my first child when I was 29, and it was the biggest , most positive thing that had happened in my life in a number of years. My first born son also just happened to have Down syndrome. Connor's diagnosis was officially confirmed in January of 2005, just after he was born. We didn't need a blood test to confirm what I had known in my heart for a long time. And I was ok with that, but we were still scared.

We had been married at the end of 2001, and after going through the death of my father-in-law and my grandmother, and losing my first two pregnancies to miscarriages, Connor was a welcome addition to our family. We didn't need to grieve, as we had already been through that process after it was confirmed that the second child I miscarried had Down syndrome as well. I felt terrible knowing that a 28-year-old could have a baby with Down syndrome (how wrong I was in my lack of knowledge), and I grieved for that child a great deal. I think the worst thing was knowing that the baby had been a little girl.

I lost my first pregnancy at 11.5 weeks and my second at 12 weeks. I'm terrible at being pregnant, so after finding out of our so-called “genetic abnormality” in our second pregnancy, we had felt like we had to find out if we were genetic carriers of Trisomy 21 and were so relieved to find out that we were not.

So with a change of towns we decided to try for our much-longed-for baby. I spotted through the beginning of this pregnancy as well, and I was petrified. Things settled down and we made it to the 12-week mark, when we also had a nuchal testing. In our

small town, the regional expert in this test coincidentally happened to be working on the day of our scan. He picked up on some markers that increased our chances of having a child with Down syndrome. Add that to our history and we weren't surprised to find out we had a 1:2 chance of having a child with Down syndrome. We decided that we wouldn't have any invasive tests (even though we had made a pact before we got pregnant to have a CVS) and mentally prepared ourselves that our child would be born with Down syndrome.

That night I had a heavy bleed and we were petrified that we would lose another baby. I had had half an aspirin a day with my second and third pregnancy, and stopped it when I had my heavy bleeds. After my next ultrasound showed that there was still a heartbeat, I stayed in my chair in the lounge room and didn't move for weeks. I had terrible morning sickness and could hardly eat anything, and was threatened to be put on a drip if I didn't improve. I think I was terribly nervous about every little thing.

After I hit the 20-week mark, it all settled down for me. We had a couple weeks of a perfect pregnancy without stress until my General Practitioner said he needed to be sure our baby didn't have any heart conditions or else he couldn't deliver for us. The ultrasounds were awful and showed a number of problems, so we travelled to Brisbane and saw more specialists. My parents and my mother-in-law came with us. The doctors and nurses couldn't believe that we hadn't had an amnio, and they kept saying that we had two weeks to decide if we wanted to keep our baby, as the option for a medical termination ended at 24 weeks. We were incredibly stressed and out of our depths. Since we refused invasive testing, we kept the ultrasound on me for over half an hour to see if our baby would unclench his/her hands, as this is an indicator of Trisomy 13 and Trisomy 18, neither of which are compatible with life. After what seemed like forever,

our baby unclenched, and we were ecstatic.

We made an appointment with a heart specialist for the next day and, in the heat wave in October 2004, we travelled our three hours home and prepared to do the trip again the next day. That night was terrible for us. I was gutted as I was pretty sure I had seen boy bits floating around, and I didn't want to know the sex of my baby. We even decided to have an amniocentesis if the heart specialist had terrible news, just to prepare ourselves. But he said he didn't know what the other scanner saw, as our baby's heart was great. He saw some holes, but they weren't anything to stress about. On the way home from that appointment we bought a baby's cot and hid it in our spare room; we thought we could finally start to prepare for the reality of having a baby.

My General Practitioner was happy to deliver our baby and I laboured on my own all night. We went to the hospital at 5:30 a.m. and had our son at 6:36 a.m.; he was 2.7 kilograms and 2.5 weeks early. I stayed in hospital for 10 days, as it was a small country town and I didn't feel confident enough to go home. We struggled with a very sleepy baby and he wouldn't feed very well, so I breastfed him every two hours during the day, then pumped to try to increase my milk flow. I demand-fed him every three or four hours at night. I had read that breastfeeding was the best thing for speech therapy so I did that exclusively for nine weeks. In hindsight, I should have stopped at seven weeks; the community health nurse was visiting often almost labeled him “failure to thrive.” We were petrified.

Connor, on the advise of our paediatrician at the time, started solids at 12 weeks. Being bottle fed, and starting the solids definitely helped him gain weight. We woke him up for a dream feed every night at nine, and eventually he started to sleep thru the night at 12 weeks. My weeks were full of appointments, early intervention, and mother’s groups.

Despite this busy schedule, I clearly remember someone telling me shortly after Connor's birth that we were very unlucky to have two babies with Down syndrome in a row, and that I might have a fault in my ovaries. But we certainly don't think of ourselves as unlucky at all. We finally got what we wanted: a baby.

Connor is eight years old now and I've since had two other children. Hayley, who is six, had the same due date as Connor, so they are almost exactly two years apart. Jeremy, who is three, was our "surprise" baby. Connor has mild to moderate hearing loss, so every year he goes under anaesthetic for a check on his ears since his canals are so tiny, and grommets are inserted if necessary. This year he has had his ears checked and five baby teeth were also removed in that surgery, as his teeth were overcrowded and they baby ones were wedged in. He has had a testicle pulled down, and next week the surgeon is pulling the other one down, so this year has been huge for him. Generally he is healthy and his lack of speech is our only concern. He loves our semi-rural life, especially the tractors and cows.

~ Shannon, Connor's mum, 29, New South Wales, Australia.

{Beatrice}

Our official diagnosis for Beatrice did not come until she was three days old. It was January 21, 2011, and honestly it was more of a technicality than anything else. At that point, acceptance had already started to set in. But five months prior, during my 13-week ultrasound we were shocked to receive our first hint that something might be "wrong."

It was August 2010 and I was extremely nervous for our first trimester screening ultrasound and lab work. I was 36 years old and knew that risks were higher for my age. Having been pregnant three times before, I also had a gut feeling that with this pregnancy, something was different. The technician took some measurements and, knowing that the nuchal fold reading should be a fairly low number (< 2.0-2.5mm), I was shocked when it measured at 3.5mm, 4.0mm, and 3.8mm, over and over and over. I work in the healthcare field, and I asked the nurse if I could to talk to the doctor right away, since I knew what these measurements could indicate. I wanted some reassurance and a simple explanation of what problems we might need to be concerned about. I knew that the test results would take several days and I dreaded the thought of waiting without any information. They told me that the doctor didn't have time. The nurse came in and drew my blood and seemed very jumpy and nervous. A long, five days later, the office called. Yes, my lab work was abnormal. Yes, the nuchal fold was

high. My chances of having a child with Down Syndrome went from 1 in 300 (according to my age), to 1 in 5.

I was at the local zoo with my 3 boys when they called. I tried to hold it together, but I cried and cried in my van. I was fearful of what the future would hold. I wished my husband was nearby. I wished my boys weren't with me to witness my pain. I wished the doctor could have met with me right after the ultrasound to discuss the findings with me then. Maybe then this information over the phone, in front of my children, wouldn't have hit me so hard. Maybe I could have been more prepared. The office wanted us to come in as soon as possible and advised me to "bring a support person" with me.

Later that day, the perinatologist pushed for CVS or amniocentesis, saying "we didn't have much time." My husband and I insisted the result would NOT change a thing. She replied, "That's what everyone says. No one knows how they will ultimately respond until they know the truth." We immediately switched perinatologists. Our personal OBGYNs were phenomenal. They were nothing but supportive and caring. They called to check on me. They encouraged me. They listened to me. They supported whatever our decision was--to wait it out or to ease the anxiety of the unknown and have an amniocentesis. They reassured us that we could choose to have the amniocentesis at any time for the rest of the pregnancy if the waiting became too unbearable. They were with us every step of the way. They made us feel that no matter the outcome, life would be wonderful.

After many long discussions, my husband and I decided to wait it out. We did not want to risk miscarriage just to know whether or not our child would have a chromosomal

abnormality and relieve our personal anxiety of the unknown. It did not change anything for us. We would love our first daughter (after three boys!) no matter what.

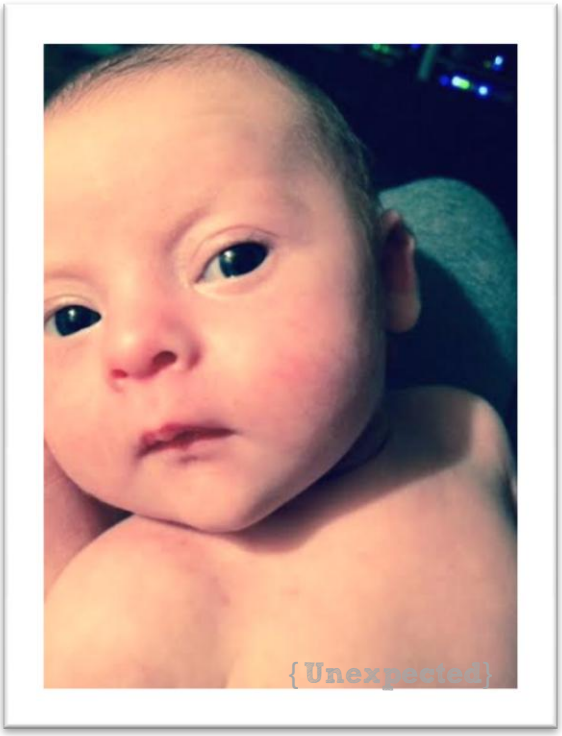
Yes, the waiting was hard. But in the end, I know we made the right decision for us. Once Beatrice arrived and we received confirmation of her Trisomy 21 diagnosis, the best medicine for me was simply taking care of my baby: feeding her, burping her, bathing her, changing her diaper, swaddling her, and rocking her. These things helped me to focus on Beatrice, the baby, my daughter, our princess. She is the light of our lives!

Beatrice is now 2.5 years old. She is just learning to walk, starting to say a few words, and soaks up signs more quickly than I can learn them and show them to her. Yes, the milestones take longer to reach, but she is still a daddy's girl, a sweet little sister, and an irreplaceable member of our growing family. We look forward to seeing what she will accomplish in life!

~ Tracy, Beatrice's mom; 36; Iowa, United States

{Ryan}

My water broke around 8 a.m. on a Tuesday, September 4th, the day I was returning to work after a much-needed, long holiday weekend. I was minutes from leaving my apartment to hop on the hot, smelly, crowded subway for a 30-minute commute to Penn Station. Not fun or comfortable for a 37-week pregnant lady.



I contemplated what to do. My husband was out with the dog and I certainly didn't want to be the one to cry wolf. Finally, I decided to text my doctor after persuasion from my mom. He was pretty certain that indeed, it was time to welcome our baby into the world. I was quite calm, which came as a surprise to me. I was TERRIFIED of giving birth. I would have panic attacks just thinking about it. But when it came to crunch time, I delivered (literally)! We followed the instructions that we learned in class - try to remain home as long as possible. And so we did. It was 5 p.m. when I finally called my brother and told him it was time to go. He had been on standby all day to take me to the hospital. That ride up the West Side Highway was brutal. By this time, contractions were very frequent, and starting to get a little uncomfortable. Why I waited until rush hour on a rainy day, I will still never figure out.

Once at the hospital, it was confirmed: I was 7cm dilated. I was so proud of myself! We were instantly whisked to a room, and so it began. The birth was relatively easy; really the whole pregnancy was. I was one of the "lucky ones," with no horrible symptoms

besides occasional heartburn and a craving for ice cream (actually the craving is a lie. I just capitalized on it as an excuse to eat ice cream every day). The only minor incident we had was when our doctor called us after our 12-week ultrasound to tell us we were at an elevated risk of having a baby with Trisomy 21 due to my age and some soft markers they found. We were offered additional tests, but my husband and I both agreed there was no need. These things don't happen to us. And even if they *did*, what was the point of another test?

Everything had been perfect. And at 11:04 that evening, our Little King, Ryan, was born. He was gorgeous. He was placed on my chest, and I was in love. Instantly. It's really something you can't put into words. We celebrated, called our friends and family, cried, and laughed. We were so happy. Everything was still perfect!

At some point early the next morning, the pediatrician came around to check in on Ryan. I can remember her saying, "His ears look a little smushed, don't they?" I wasn't really sure what to say in response to that. I'm sure I gave her a blank stare. Of course instantly, my mind raced. But when she said, "it's probably just from the birth," I went on my merry way of basking in the glow of new motherhood. That afternoon when they took him for his circumcision, she came back and pulled up a chair. My heart instantly dropped. And from that point on, everything is very fuzzy. I heard a lot of "Wha wha wha…Down syndrome…wha wha wha….soft markers….wha wha…Down syndrome…."

She left, and I cried like I have never cried before. My husband held me tight, but I kept sobbing uncontrollably. How could this happen to us? These things don't happen to us. Next thing I know, we had another visitor. He introduced himself as a Geneticist. He was there to tell us that yes "Wha wha wha…markers for Trisomy

21…wha wha wha….test….wha wha…tomorrow….Wha wha…Don't Google it…" And again, more uncontrollable sobbing from me. My husband held me tighter.

My mom arrived that afternoon. I told my husband that I would put on a brave face and tell her the news, but as soon as she walked through the door, the uncontrollable sobbing started again. I literally could not get the words out of my mouth. It's like I was paralyzed, and all I could do was cry. I didn't want to cry, and I wasn't exactly sure why I was crying. I didn't know anything about Down syndrome. Was it because I was afraid of the unknown? Was it because I was afraid of what he would look like? Was it because I was afraid he wouldn't be able to play with his cousin? Was I feeling guilty for thinking these things? Was I just so in love with him that I couldn't control my sobbing? Was I embarrassed because I was crying? Was it pregnancy hormones? I'm still not sure. All I knew was that definitely, without any doubt in my mind, I loved this little man more than anything in the world. And I would do anything in my power to protect him.

Next up, another visitor. She introduced herself as a cardiologist. Again, I heard a lot of "Wha wha wha" as she was drawing something. It was a diagram of the heart, and she drew where Ryan's 4 holes were located. What? Holes in his heart? We were just told that not only does our precious baby have Down syndrome, but he also has congenital heart defects that would require open heart surgery most likely before he was 2 years old.

This is where is gets even more fuzzy. There are a few things I can remember from our hospital stay: my husband telling me that "We aren't taking Park Avenue, we are taking Madison instead;" my mom and husband holding me tight constantly, and being the

ones who listened to the doctors when discussing his conditions; sobbing into my brother's arms after we told him the news; being angry at the nurse who abandoned me and Ryan after she said she would be back to assist with nursing.

We were released from the hospital after 2 days. My emotions were still unstable, to put it mildly, and remained that way for months. My husband and my family were amazing. I am so lucky that Ryan has a Daddy who can put everything in perspective, take care of his emotionally-unstable wife, rock a swaddle, and love unconditionally. On the drive home, I remember telling my Mom, "I now know how much you love me." I knew deep down everything was going to be ok. I had my baby, my husband, my family. Everything was still…perfect. And so was Ryan.

~ Mandy, Ryan's mom; 37; New York, United States