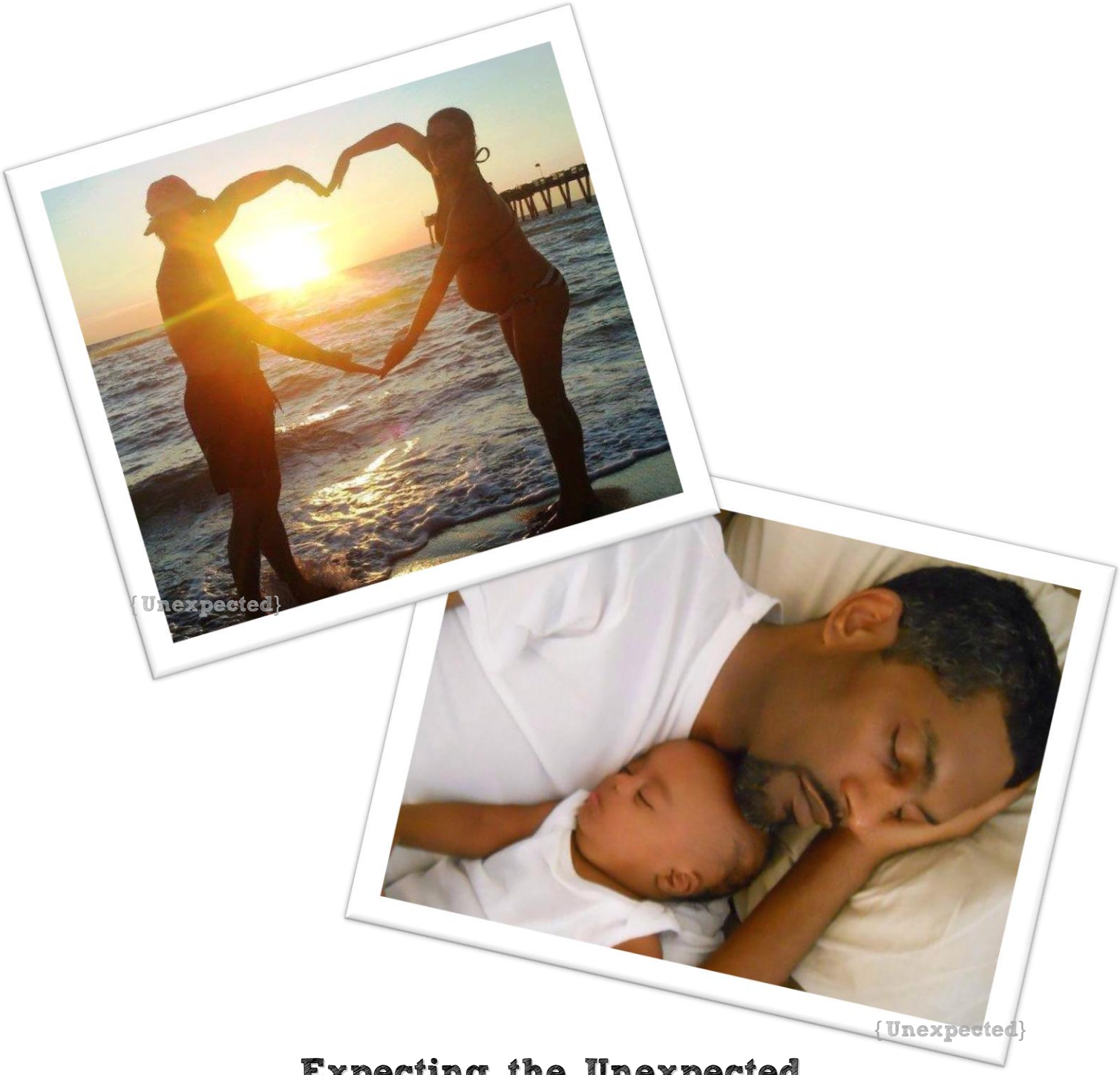


Expecting the Unexpected...

Receiving a Prenatal Diagnosis
As told by moms/ mums around the world

Compiled by Jennifer Jacob
2014

Words that a parent is never prepared to hear from a medical professional: We have reason to believe that your child may have Down syndrome.

Receiving a prenatal diagnosis for Trisomy 21 (Down syndrome) can leave you feeling a range of emotions. Confused. Scared. Isolated. Terrified. Angry. Anxious. Love. Many feelings are similar to those faced in the grieving process. The dream of the baby imagined is now replaced by a new child surrounded by so much uncertainty and, perhaps, fear. All of these feelings are valid and normal.

Prenatal testing has come to the forefront in the headlines recently, although parents may not understand the depth of the ramifications involved. Perhaps you did the prenatal testing without a second thought based on the doctor's recommendation.

Perhaps you went for the ultrasound scan just to could catch a glimpse of your baby, never imagining there would be anything wrong. Perhaps you requested the testing based on your pregnancy history. Regardless of the exact path of diagnosis, life changed in a moment with one extra chromosome.

For many mothers, there is a lot of time spent processing the diagnosis, analyzing it inside out. Some mothers report feeling that they get to a point in the pregnancy where nothing more can be processed until meeting the baby at birth. At this point, there is generally a feeling of acceptance. There is excitement, as you realize that your baby is going to be very loved and will require just the same amount of care as any other baby. This renewed sense of hope at what was initially perceived as doom and gloom is worth holding on to. Once that baby is placed in your arms, all those undesirable feelings will disappear and be replaced ten-fold with love.

Every mother's journey along the prenatal path is different, yet the similarities are undeniable. It is our hope that as you read these stories you will find your own feelings validated and know that you are not alone.

Our Stories

Our stories (continued)

{Natalie}

My first pregnancy and the first few months of my son's life were tumultuous. We had an early miscarriage scare, and then there was a thickened nuchal fold (which turned out to only signify a minor heart defect that resolved on its own), long-lasting morning sickness, cord issues, a two-day induction, a NICU stay, and weight gain and milk supply issues. It was an exhausting and stressful year. So when I found out that I was pregnant again in October 2011, I was determined to have a happy, healthy pregnancy, pop the baby out with no intervention, and exclusively breastfeed my baby who would get fat and happy. After everything I had been through, I deserved it, I said.

But at my nuchal translucency scan, about 12 weeks into my pregnancy, I knew something was wrong immediately. The nuchal fold was large again, larger than it had been with my son. The doctor came in and gave us the rundown. We already knew it all: chromosomal issues, heart problems, high rate of fatality. They told us that they could do a CVS (chorionic villi sampling) right away, and we accepted. My husband could not come in with me because our son had come to the hospital with us, so the genetic counselor held my hand during the test. I went home and wept, because I knew no matter what the outcome, I had been branded. My pregnancy was "high-risk", a title I so desperately had convinced myself I would escape this time.

For the next 10 days, I told myself that everything would be fine. The genetic counselor had said that she believed our baby would probably have the same kind of heart defect our son had... no big deal. But I think that despite what I told myself, I knew the news wasn't going to be what I wanted. When I considered the worst case scenarios, Down syndrome was always scarier in my head than the fatal trisomies. Maybe because I'm a terrible person, maybe God just has a sense of humor, but I had always had issues knowing how to talk with people who had intellectual disabilities. I could never look them in the eye, always felt uncomfortable around them. Having a child like that, I thought, would be the end of my world.

The genetic counselor called a week before Christmas, around 11:00 in the morning. "It's a good thing we did the test, because your baby has Trisomy 21, Down syndrome," she said. I held it together long enough to ask if it was a boy or a girl. She didn't want to tell me, but I told her I wanted to know. A girl. A girl, like I had wanted, just with an extra chromosome.

I fell down. I screamed and cried and begged God for it to be a mistake or to take it away. My son almost cried when he saw my distress, but then in classic toddler style decided to take advantage of the situation by obtaining the forbidden remote control. When I finally looked up from the floor he was one click away from ordering "Cowboys and Aliens" on Pay Per View. First I called my husband, and without even telling him the news, begged him to come home right away. Then I called my parents, who managed to hold me together for the next 30 minutes while I waited for my husband, each in their own ways. My dad shared my sorrow and prayed. My mom expressed her joy at a new baby girl. The two totally different responses were both exactly what I needed right then.

I spent the next few weeks over the holidays in a deep darkness. Every once in a while I would see a glimmer of light. Emails from friends that said, "Congratulations on your baby girl!" and "We can't wait to meet her!", along with uplifting blogs or online videos, like the one that talked about the statistics showing how overwhelmingly happy people with Down syndrome and their families are, helped me start thinking about how what I thought was an end to my life could actually be the start of a new, better one. But mostly there was sadness and crying and wishing that it would all go away. There were days when I would stand at the top of our steps with a laundry basket in my arms wondering if I could make myself fall and somehow end the pregnancy without hurting myself too badly.

God's grace was enough to keep me from falling, literally or otherwise. Before the diagnosis we had told the genetic counselor there was nothing that would make us consider termination. But then a few hours after she had delivered the news and we called her back for more information, she asked what we were thinking about keeping our baby. I kept putting her off, trying to think of another question to ask. Honestly, I wanted to end it. I did not think I wanted this baby anymore, and the only thing that kept me from telling her that was fear of committing a deep sin. Eventually I managed to get out the words that we would not terminate. I wanted to call her back, I prayed for a miscarriage, I even got a little hopeful when I would have Braxton Hicks contractions that they would result in pre-term labor. These words are true, but they cause heart to ache now. Over time I adopted a "not my will but thine" attitude. I could believe that God had given us this baby for a reason: a test or trial or maybe a punishment even. It was something we would accept and overcome. I could not believe that this baby herself was a gift.

Finally on Valentine's Day we had our first moment of joy since the diagnosis. We went back to Johns Hopkins for a scan of Baby Girl's heart. After an incredibly long ultrasound in a very hot room followed by a lecture from the doctor on the many heart conditions that babies with Down syndrome could have, she said, "But your baby doesn't have any of these". She was healthy! At that point I was probably more relieved for myself, thankful to escape living in a hospital for a few weeks after surgery and scores of cardiologist appointments. But I marked the occasion by buying her a dress; or rather, letting my mom buy her a dress. And we finally named her: Natalie.

It's funny how a tiny pink dress and a name changed so much for me. All of a sudden, I was excited. I was ready to decorate a nursery and buy some more clothes and figure out logistics. I decided to devote my time to these endeavors and "gave up Down Syndrome" -- that is, the obsessive research I had been doing on it -- for Lent. After Easter, we were getting close, and I went on planning, preparing, but still taking Benedryl almost every night to avoid the fears and worries that would otherwise come in the early morning hours. Breastfeeding was something that was incredibly important to me, so I found an online lecture on how to succeed in breastfeeding a baby with low muscle tone. I started a binder and jotted down the phone number for Infants and Toddlers in our county so I could call them as soon as we were home from the hospital and settled. And I went to the doctor, a lot. My doctor wanted me to have two non-stress tests a week. Natalie was pretty lazy, so these tests were often long and, despite their name, pretty stressful. I would sit there for over an hour while the nurse prodded my belly and encouraged me to drink juice and eat crackers. Natalie would usually wake up and start kicking like crazy right as the maternal fetal medicine staff started talking about sending me to Labor and Delivery.

On June 15, 2012 we headed into the hospital for an external version. Natalie was breech, though it was a bit unclear exactly what part was where. We only knew she definitely wasn't ready for launch, and I had held off my doctors to 39 weeks so that she could grow. I desperately wanted to avoid a C-section but after 45 minutes of my OB trying to push on my belly to make her turn, I conceded. A nurse in the operating room exclaimed, "Let's have a birthday party!" The C-section was... unpleasant, mostly thanks to an incorrectly placed spinal. My feet were very numb, but my midsection, not so much. Eventually the OB pulled out Natalie who still had her legs crossed and her back arched like they had found her inside me. "Take a picture dad!" the OB exclaimed. "I'm not feeling so good", my husband said. And then he blacked out and fell to the floor. "Someone get his camera," was my only comment. The nurses did what I asked and took some pictures, and then after my husband came to and then passed out again, they wheeled him out of the OR and set him up with some cookies and a drink while I got sewed back together under partial anesthesia.

My husband's failure to stay upright did result in something positive besides giving me a permanent way to shame him. After Natalie was checked out by the NICU doctors and deemed 'OK' she was rolled into the recovery room with him, and he got to spend a few moments alone with her before I could join them. He was smitten. I hadn't really talked to my husband very much about how he felt in the previous six months. I was so wrapped up in my own grief that I couldn't bring myself to ask how he was dealing with it. But then I saw him holding our sweet little girl, and I knew we would make it.

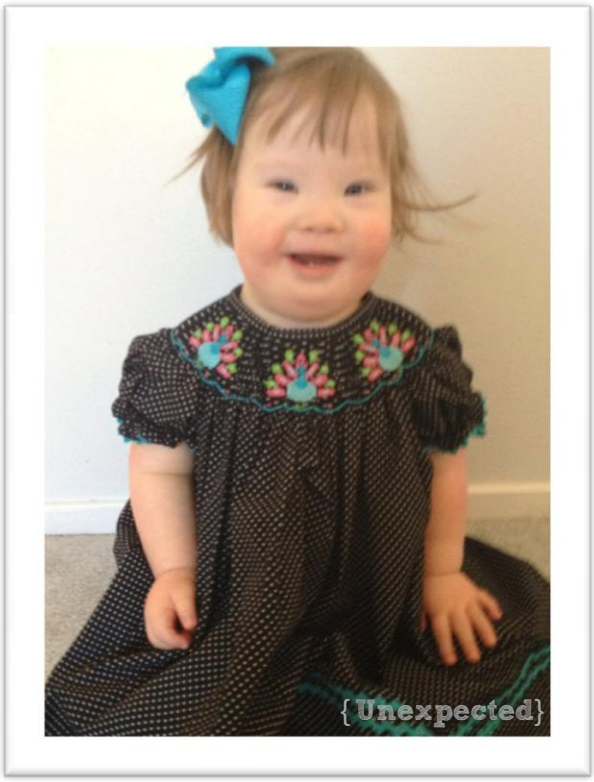
Later that day, the hospital lactation consultant came in with what seemed like 50 ways to feed our baby. She had several types of bottles, a supplemental nursing system, nursing shields, and more. She told us that babies with Down syndrome could often

learn to breastfeed, but sometimes it took a while for them to catch on. I had prayed and prayed that nursing would work out for us. I had gone through weeks of pumping, supplementing, and taking all sorts of disgusting herbs to be successful in exclusively breastfeeding my first baby. I knew with two kids at home I would not have the time to do much, but I desperately wanted to nurse. God answered that prayer. Natalie latched on and nursed perfectly. My milk came in before I left the hospital, and she was back at birth weight within a few days. She is definitely fat and happy like I had hoped. This answer to my small prayer was a huge blessing for me. Nursing my baby has given me time to sit, reflect, relax, and love her. And love her I have.

When I was pregnant, I never spent any time thinking about what type of person I had growing inside of me. Most of my time was occupied with thinking about her health, her future, and how I might be inconvenienced. Natalie started to show us her personality early. By two months I had dubbed her "Princess Indignation". She tolerates most things, but when we cross the line to what she will not tolerate she immediately transitions from pleasant smiles to bloodcurdling screams. She is fiesty, determined, cuddly, and sensitive. Best of all, she adores her brother. Brother (or, "bruddah") was her first recognizable word. She is always happy to see him and will cry when he is upset, but she also will not hesitate to shriek at the top of her lungs when he takes a toy from her, or grab his hair and pull hard when he is too close for her liking. Just like every sibling relationship at these ages, it is full of love and loyalty mixed with a little bit of resentment and wariness. It is so normal, and I love it.

Life with Natalie all around is normal, actually. We have been very lucky that Natalie has been healthy. She spent a few days in the hospital when she was around seven weeks old for a urinary tract infection, but we have had no major concerns. Life has been

completely chaotic and fun, just as we expected it would be with two children. At 14 months, she does have some developmental delays, mostly in the realm of gross motor skills. In other facets of her life, she is developing right on par with other children her age. We spend a little extra time with Natalie trying to help her reach milestones, and she gets physical and occupational therapy each twice a month. To me, it's just another way I spend time and play with her.



Natalie is perfect. She brings us so much happiness and amazement every day. There are still many days I'm sad that she has Down syndrome. I wonder what it would be like to have a typical toddler at this stage, a running baby instead of a rolling one. I worry about her health, affording everything she will need, and what will happen to her when we are too old to take care of her. But the sadness, fear, and insecurity I've faced since the diagnosis, I am coming to realize, are all mine. They are my issues, not hers. The unknown baby/child/adult with Down syndrome in my head, I think, will continue to haunt me through my life. But the Natalie playing on my floor, eating in my kitchen, and sleeping on my chest has and will only be a source of joy and light. She is a beautiful gift from God.

~Anna, Natalie's mom; age 31; Maryland, United States

{Nicholas}

Minutes after we received the news that our third baby had a confirmed diagnosis of Down syndrome, 18 weeks into our pregnancy, there was a thunderous downpour of rain. It was quite appropriate, really, dramatically drawing a distinct line between before and after the moment where our lives changed forever.

Early into the pregnancy, we were rather surprised by the discovery we were expecting our littlest love, and it took four pregnancy tests to convince me that our third child was in progress. Coming from a family of seven children, I knew in my heart my family wasn't quite complete after having our two boys, but I'm not sure I'd really come around to the thought of being pregnant again quite yet. But we were happy, albeit slightly terrified, about having three children under four years old. We shared our good news with close family and friends, and planned to keep any public announcements until after our 12 week scan. But that's when things got a bit rocky.

On September 12, my husband Ben and I went along to our 12 week nuchal translucency scan where we saw our tiny baby, looking very healthy and 'structurally good' according to the sonographer. We gave a sigh of relief. We then met with the consulting doctor who put all the numbers in the boxes and waited for the computer to process our 'risk result' for Trisomy 21. The answer was 1:14. I remember the doctor

talking about what the next steps could be in terms of further testing, but I felt like I was having an out of body experience.

We stopped at a park on our way home. I cried, and we began Difficult Conversation Number One of what would be many. While I don't consider myself particularly religious, I felt as though I heard God say, "Just trust me." While comforted by that, I didn't get the sense that He meant "Trust me, I'm going to make this easy"... more like "Trust me. This might be a cracker of a journey, but I'm here with you." I think in hindsight I had a sixth sense that this pregnancy was different.

The next few weeks were difficult, to say the least, and I fluctuated between feeling completely lost, and hoping that it would turn out I was just being a drama queen. Ben and I talked about our fears, thoughts, possible action plans, and then had times where we just couldn't talk about the baby anymore. I would love to say that we were immediately unified in our decision to keep this baby, but we come from different families with different beliefs, and we didn't know if we were up to the task of raising a child with a disability. Most of all, we were afraid. We both considered all options. The turning point for me came when we were sitting on the couch one night, and I was researching on the iPad. I began reading posts on a forum where women were discussing their regrets after having a 'termination for medical reasons', which was difficult enough. I then read about the physical process of terminating a pregnancy, and it broke me. I cried so hard I could barely breathe. I had felt this baby kicking inside my belly since 12 weeks into the pregnancy, and he was already so much a part of me. While challenged and terrified by a potential positive diagnosis, we came to the decision that we would have this baby regardless of his chromosome count. We made decisions

based on the assumption the diagnosis would be positive, but we still clung desperately to that 7% chance everything would be okay.

The next question we needed to address was whether we could ‘wait it out’ for a diagnosis at birth, and the answer was that not knowing was killing us. After much research and discussion, we booked an amniocentesis, which couldn’t be performed until after 16 weeks into the pregnancy, and settled in for the next wait.

The amnio was the easy bit. I wasn’t exactly looking forward to the process of having a needle inserted in my belly, and was almost ready to pack up and go home when the sonographer couldn’t see any of the usual ‘markers’ for T21 on our very healthy baby. But I stayed. I felt confident in the hands of the doctor we’d chosen, and the procedure went really well, with little, if any, pain. We were due to receive the results by phone call, from either our obstetrician or the doctor who performed the procedure, within 48 hours.

On day one post-procedure, I settled in at home, enjoying the peace and quiet of being temporarily child free, and put the thoughts of getting an early phone call out of my mind. On Day Two, my stomach churned from the second I woke up. Mid-morning, my mobile rang, and my OB’s phone number came up on screen. "This is it," I said to Ben. Deep breath. It was the receptionist from our OB’s office, completely unaware of our current situation and innocently calling to rearrange our next appointment. False alarm. By lunchtime, I am sure I could have been diagnosed clinically insane. At 3pm, I told Ben we needed to call them, but we were only able to leave messages. More waiting.

By the time we got the call at 4pm, I was beside myself. I couldn’t answer the phone and didn’t want to hear the news on speaker phone. In my heart, I knew what the answer would be. I watched Ben’s face as he listened to our obstetrician on the other

end of the line. He just nodded, "It's positive. Baby has Down's." We cried and hugged each other. The rain came down so heavily we could barely hear ourselves think. Then Ben went to pick up our eldest son from daycare. I sent a text to the loved ones who were waiting in the wings for news. The world kept turning, and life had to go on.

We each went through the various stages of grief over the next few months, but never at the same time, it felt. While we had made the decision to keep our baby after the nuchal test result, a confirmed diagnosis made it all so real that it was difficult not to re-question our beliefs. Initially after the amniocentesis, I was really careful about any heavy lifting and potential risks to the baby as a result of the amnio – but then we received the T21 diagnosis, and I wondered whether it would be easier if this baby did just pass away, if all these difficult decisions were taken out of our hands. We chose to see counsellors both together and separately as we talked through all our options. There was much anger and sadness, and oh so much silence between us as we each stumbled our own way through the darkness. I participated in online forums and read lots of information. Ben spoke to a few close friends and decided to do his information gathering once he could meet our baby in person. We just had to lean in and love each other through the pain and trust that it would all be okay.

Over time, we started sharing the news of our baby's diagnosis with friends and extended family, and usually via email. It was really important for me to be able to share our news in a positive way (and without me being a visible, blubbering mess), to let everyone know we were okay, that we were excited about meeting our beautiful baby, and that we wanted them to be, too. I wanted other people to be able to process the news and grieve in their own way without being worried about how they may react, and I am grateful for the many beautiful, heartfelt and honest responses we received. While

no one else could walk in our shoes, we knew we were well supported in this journey, that our baby already had a strong network waiting to love him. A few weeks after the diagnosis, we went to a detailed ultrasound to check on our baby's health. After feeling as though we had been greeted with bad news at every recent turn, we waited expectantly for more challenges – but were thankful to discover that Baby Love seemed to be growing and developing beautifully, with no apparent health concerns. I was comforted by how active he was in utero – always such a busy baby. As the pregnancy progressed, we continued to have regular ultrasounds and breathed a little easier each time, hearing that our baby appeared healthy and well. The specialist we consulted at each appointment often commented that, without the amnio results, we never would have known about the T21 diagnosis until birth. With each prenatal scan and appointment, we tried to avoid finding out our baby's gender and let him reveal at least one surprise at birth.

Some days I felt invincible, facing our new future with strength and peace. Other days, the roller coaster of emotions dipped and turned with such ferocity, I just couldn't put on another brave face, and it was easier to stay inside and hide from the world. Some days, trying to put on the façade that I had it all together was just plain exhausting. I expected the emotional recovery to improve day by day, but in all honesty, there were good days and bad days. However, having an almost-two and almost-four year old afforded me little time for self-pity.

My two big boys were very excited about meeting their new baby brother or sister, and especially our eldest son who was now old enough to understand the concept of a new family member. As the weeks went by, I began to feel a glimmer of excitement at welcoming our new baby too. There were so many unknowns, but we were ready to

hold that squishy new baby in our arms, to get to know him, and just face any challenges as they presented. I was also quite looking forward to being able to bend over again. A few days before reaching 40 weeks gestation, I went along to a scheduled appointment with my obstetrician one Monday afternoon, and had a strong inkling that we would soon be meeting our baby. I went home, tucked our boys into bed, tidied up loose ends, added the last bits and pieces to my hospital bag, and went to bed, but was woken by a very strong contraction at about 11.40pm. Within two hours and 55 minutes, after a smooth and speedy delivery, we met our very beautiful and perfectly healthy third son, who we named Nicholas.

As Nicholas was delivered onto my chest, I did a quick glance at his almond-shaped eyes, silently confirming the T21 diagnosis, and then soaked in every inch of my new little 3.8 kilogram bundle. He had his first breastfeed within 15 minutes of being born, continued to be a champion feeder, and was back to his birth weight by the time we went home four days later. I can honestly say that our grief and sadness became part of history the moment we laid eyes on our youngest

baby boy, and he continues to bring joy into each day that we are blessed to spend with him. As difficult as it was, I would go through those months of heartache again in a flash in order to have him in our lives.

Nicholas has white blonde hair, with a big curl that stands up on the top of his head like something out of Dr. Seuss, and big, sparkly blue eyes. He is loved – by us, our wide network of friends, his grandparents, his 16 cousins, his uncles and aunties, and most especially, by his two big brothers. He may take a little longer to do the things that kids of his age are doing, but it's not a competition. Nicholas is writing his own story. Every day that I get to snuggle his little body, see his big beaming smile, see how loved he is, I am thankful for the journey that guided us to this place. Ironically, we received Nicholas' Trisomy 21 diagnosis in October, which is Down Syndrome Awareness Month, and he arrived into the world on March 20, the day before World Down Syndrome Day. I think he was always meant to be part of our love story.

Nicholas is 17 months old. He has been really healthy from birth, and is a fun, happy, engaged, playful little boy with white blonde hair and amazing blue eyes. He has just started moving from his tummy up to sitting position, loves to roll pretty much everywhere, and he can pull himself up to stand. His favourite words are dad and hello, and he loves music, especially doing the actions to his favourite songs. He is happy to eat anything, but loves fruit, and was breastfed up until very recently. Nicholas is adored by his extended family and wide circle of friends, but most especially by his mum, dad and two big brothers. We can't imagine our life without this gorgeous boy in it.

~Annie, Nicholas' mom; 33; Brisbane, Australia

Blogging @ http://www.mummalove.wordpress.com

{Josee}

We had two beautiful healthy children when I felt the need to extend our family just one last time. This yearning for a third child began at the ripe old age of thirty two, and went on for about a year. In that time I had many lengthy discussions with my closest girlfriends and my husband about what to do. I had a real sense of now or never, and when I visited my local family doctor, he too gave me the now or never lecture, which I thought surely must be a sign I needed to make a decision sooner than later.

I decided to go off the pill, and that same month I fell pregnant. My husband wasn't happy; I think he wanted a few more months to practice! I had a great first few weeks, and felt fantastic, but I just couldn't shake the feeling that something wasn't right. Ever since those little lines early on my pregnancy test announced very boldly that I was pregnant, I had an inkling that something was up.

Our 12 week ultrasound was booked for the Wednesday afternoon, with the plan being that we could announce it to friends and work on the Friday before breaking up for the school holidays. I met my husband at the radiology clinic, and sent my kids off with a friend to go and have some afternoon tea whilst they waited. They were very excited to hear how the baby was.

As the technician began, she showed us an ultrasound image of what a foetus with an enlarged nuchal fold looks like. I nodded, as we had both been through this scan before, but at the same time also thought to myself, "That's interesting, no one has actually explained that to us before." I took note of the image of what an enlarged fold looked like.

As our baby came onto the screen, I breathed a sigh of relief. It was there, I could see it moving, there was a heartbeat. Phew! All the worry that I had that something had been wrong was unfounded. When she showed us the full length image I briefly glanced to where the nuchal fold was and thought to myself momentarily, "That kind of looks like what she showed us in the picture beforehand." But then I thought that it was probably hard to tell anyway, and pushed the thought aside. The technician began her measurements and my husband and I marvelled at this new life.

My husband left after about thirty minutes as he had to go back to work, believing all was ok. The technician finished up her measurements, she had become quieter and edgier the longer she went on. She turned the equipment off and looked at me to explain that before I had the ultrasound my chance of having a baby with Trisomy 21 was 1:350, based on my age. She then went on and said but your chances after having the nuchal fold, coupled with your bloods puts your chance at 1:2. I could barely breathe, and I could hear blood pumping through my ears.

"You're kidding," I said. I felt like someone had just dropped a bomb. She explained that she had seen babies with a higher fold that had gone on to have typical chromosomes. But it was in vain, I just knew. The rest of what she said was a blur as I was numb, and felt physically ill.

She went out of the room to see if there was a Doctor that could come and speak to us. In that time I messaged a few friends and said the scan wasn't looking good. I also messaged my friend who had my children, and told her to prepare for some bad news.

As she came back in I could barely hold back tears. I felt like I had been delivered a death sentence. I could barely speak, barely think, and I just wanted to turn back time to when I wasn't pregnant.

I rang my husband in tears, saying, "They think the baby might have Down syndrome, I'm sorry, I'm so sorry." I repeated my apologies over and over. He made his way back to the clinic and told me to stop apologising. My friend who was minding my children brought them back to me, and through tears, I broke the news that their sibling may have Down syndrome. In the midst of the chaos I had forgotten that my children went to school with a child who has Down syndrome. My eldest child looked at me and said, "But Mummy, why are you crying? We love him, why are you so sad?" Her reaction really made me stop in my tracks as I tried to explain why I was upset. From that moment I tried to be brave and put on a front for my children, but on the inside I was breaking.

We organised a second opinion scan to be conducted the next week, hoping that the first scan was wrong. In those six days from the first scan to the second scan I was like a zombie, functioning on auto pilot. The only reason I managed to hold it together was for the sake of my children and the fact that I was on holidays from work.

At the next ultrasound we were confronted with even further bad news. The nuchal fold, which was already enlarged, had doubled in size, with the fluid now going up and over the back of the baby's head. There was also fluid noted in the baby's chest cavity and

all under the skin. We were given the grave news that our baby had hydrops and was in heart failure. We were advised to go ahead with a CVS in two days time, so that we knew what was going on, but were solemnly told that the baby would most likely pass away within 24-48 hours of the CVS. We sadly made the appointment for the CVS and two days later, with heavy hearts, we headed into the hospital for what was a cold and clinical procedure. I could barely look at that tiny little body fighting for its life on the screen. Watching the biopsy needle come onto the ultrasound screen within centimetres of our baby was an image that I couldn't handle.

Once the biopsy was complete I rested for ten minutes. The Doctor then turned the ultrasound machine back on to check our baby. As the screen flickered on we could see our little fighter, kicking and moving about, oblivious to the world outside. We took what we thought was one last look at our baby on the ultrasound after the CVS and went home to wait for a miscarriage, but began praying for a miracle.

This grave diagnosis certainly put our initial fears in perspective. We initially thought there was nothing worse than a diagnosis of Down syndrome, but to be told that your child would not survive was definitely the worst news. We decided that we would enjoy every day that we had left with our child, and began to purposely find joy in each day. A deep sense of peace washed over my body as I knew that, no matter what, this child was loved and wanted.

We were called into the hospital four days after the CVS for the FISH results. We had already decided to love this child no matter what, and when the Doctor gave us the diagnosis that our baby had Trisomy 21, we just smiled and said thank you. We asked the gender, and were told it was a little girl. We were overjoyed! The doctor began to

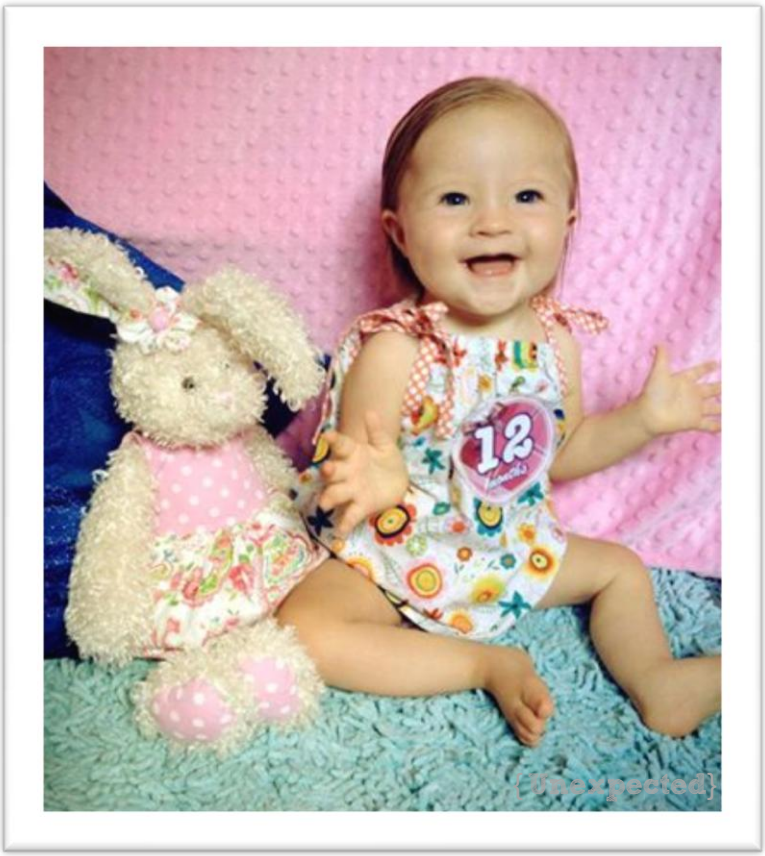
explain all the downfalls of our diagnosis and the multitudes of illnesses and challenges our baby would face in her lifetime. It fell on deaf ears. We had read so much in the short time from the scan to diagnosis that nothing we heard was new nor valued. This was our child, and to have their lifetime mapped out in doom and gloom was not something any parent would want to hear. The doctor then went on to discuss termination and that one could quickly be arranged. We said no, and then listened to him discuss what we could do if we changed our minds. We thanked him for his time and left.

Out in the hospital corridors, we went to our children, where we had left them in a little sunny nook overlooking the city. They jumped us as we approached them, and we gave them a cuddle as we told them they were having a sister. We all smiled and did a big family hug just as the doctor who gave us the diagnosis walked past. The look on his face was almost amusing... I think he thought we hadn't understood the bad news of the diagnosis!

My husband and I named our little girl that day with the name we had both liked early on in the pregnancy: Josee, which means "God will add". We thought it was fitting, as God had chosen to add to our family. My husband had a giggle as he said her name had a whole new meaning now, because God had also added an extra chromosome!

We went home that day, and tried to get on with life as we awaited our next scan. Each day we were grateful that our baby was alive, and I began to feel her move inside of me. We talked a lot to our children about finding joy in the every day, ordinary things in life. Already this little girl was changing our lives, perspectives and attitudes.

It was a long wait until our next scan, and when the day arrived we set off to hospital with apprehension, anxious to see if she was still alive and whether the fluid had increased. As the screen came on we saw our beautiful girl kicking around. My goodness, she had grown! Immediately my husband and I began scanning her body for signs of fluid, which show up as black spaces on the scan. A miracle had occurred! Our little girl's fluid had not only diminished, but disappeared, and she was growing beautifully! We were amazed, overjoyed and ever so thankful.



The rest of my pregnancy was reasonably uneventful. I was monitored well with a few extra scans here and there. Josee continued to grow, and all of her heart and gastrointestinal testing appeared fine. Having such a poor prognosis early on made me very anxious and fearful throughout the remainder of my pregnancy. I found it difficult to accept that she was ours to keep, and unfortunately, many doctors liked to remind me of the gloomy fact that 30% of babies with Trisomy 21 miscarry or are stillborn.

We prepared for our baby to come early, as so much of what we read talked about premature birth. For weeks on end we waited and waited. In the end I was induced after being ten days overdue. This baby was in no hurry.

As the contractions began, I suddenly became extremely irrational and overly anxious. It was as if the culmination of all the worry and fear in my pregnancy came to a head. I was so fearful of meeting Josee, but at the same time, I was desperate for her to be in this world. I was made to stay on the bed whilst I was constantly monitored, and I found this to be a complete contrast to my other children's active water births. The whole time my husband kept reassuring me that her heart rate was ok, and that she was doing fine. The labour was intense and quick, and she arrived naturally within a couple of hours. As soon as she was born my husband reassured me she was ok. I couldn't believe it! She was here and she was ok, what a Godsend!

My first cuddle with Josee Hope was the most magical moment of my life. I was so utterly amazed that she had made it into the world, and she was just beautiful and big! She nuzzled at my breast without feeding as the paediatrician wanted to check her digestive tract before she fed. We were given a short amount of time together where we just cuddled her and had skin-to-skin contact. I was, and still am, so thankful that the hospital staff allowed this.

Josee Hope spent two days in special care for observation and to monitor breast feeding. She came home five days after birth, and was initially slow to gain weight due to her low tone. She required top up feeds of pumped breast milk via a bottle after breast feeds for the first few months. Josee Hope continues to grow beautifully and has no medical issues. Today she is a gorgeous, social, and lovable baby with a smile that melts your heart. She is a true miracle and a blessing to our lives.

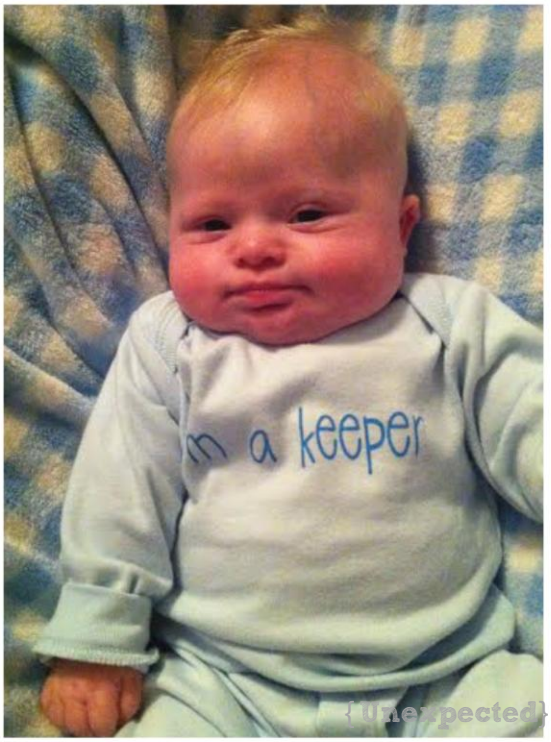
Josee Hope has just tuned 7 months, and is the light of our little family. She is extremely social and demands to be smiled at and talked to -- don't walk past her without

acknowledging her! Her big brother and sister are in love; they are her biggest advocates and protectors, they relish in every moment with her. Josee Hope began rolling early on but at the moment spends most of the time on her tummy wanting to move forward, flapping those little arms and legs determinedly! She prop sits, and loves to stand up in our laps whilst we sing and talk to her. What I imagined my life would be like a year ago with our prenatal diagnosis, and what our life is actually like, are polar opposites. Her health is great, she breast feeds and eats food beautifully, and has such a little personality. She has enriched our lives, and we are so grateful for all the little things in life. No prenatal diagnosis can predict this kind of happiness!

~Joelle, Josee's mum; 33, Queensland, Australia

{Benjamen}

Chris and I were blessed with a wonderful surprise in January of 2012. We found out that we were expecting Blessing Number Three! Logan, our second blessing, came after years of infertility and was considered a miracle baby, so you can only imagine our surprise. Brittany, my first blessing, started her second year of college in the fall, so we had literally just started with diapers and bottles all over again. It was somewhat overwhelming to find out about my pregnancy with Benjamen, but we got over it, and got on to being excited!

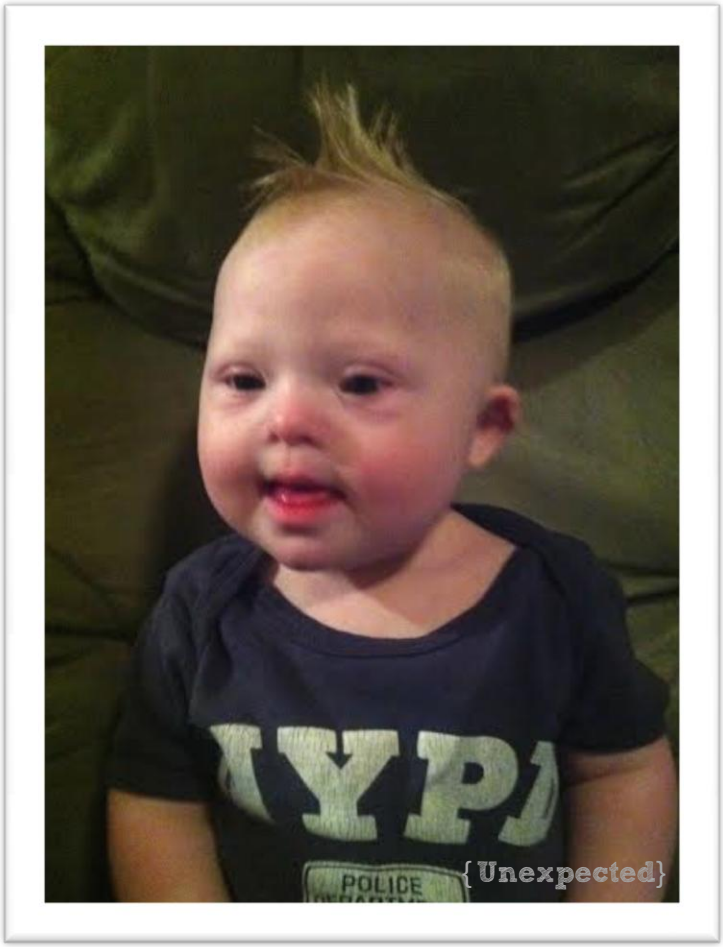


On April 16th, Chris and I decided to have an amnio done because our penta screen came back positive for Down syndrome. Our doctor assured us that the test often had false positives, and did not really recommend an amnio unless we just had to know for sure. I knew with all my heart that it would not make one difference to me either way, but felt a pull to know. In fact, I felt a special little surge of love just at the thought of it being confirmed -- my favorite Uncle Tommy had Down syndrome, and was adored by our entire family until he passed in his 60s. But by nature, I'm a list maker, a planner, and a researcher. I needed to know, because if it were really true, I had a lot of work to do to get Benji's little world ready to greet him.

On April 27th, we found out that the amnio also came back positive. I ended up being told over the phone by my doctor while I was at work. Sitting at the nurses station in front of God and everybody, he said, "I'm sorry Stef, but the amnio came back positive. Your baby has Down's." It was true. All the thinking about it before was so abstract. Now it was real. I went completely numb. I remember being in the middle of something and just putting the phone down and walking away. Without a word, I walked down the hall, down the stairs, out the door, and into the parking lot. I honestly think I held my breath that entire time. And then I cried and cried -- not because I was having a child with Down syndrome. But I had researched, as I always do, and there was more than just the joy of the personality that I remember of my Uncle Tom in the little bundle that I would be bringing home. There were so many potential health complications. I had not planned this! The vast amounts of information available at your fingertips had done me in. I was suddenly scared for him. And what did I know about having a child with special needs? I had doubts about myself; would I be a good enough mother for him? I went through literally every range of emotion in what felt like a second: happy, sad, joyful, fearful. But mostly, I was fiercely protective, from the second the doctor confirmed the diagnosis. I was hesitant to tell people because I didn't want to see a look of pity, or get an "I'm so sorry". I didn't trust myself at first to react kindly to what I knew were well intended comments. I looked back painfully, and realized that I myself had made them to others before, with no clue how badly they had likely stung. I wanted people to be joyful, to see the beauty of Ben, regardless of the number of chromosome he had. Ben's now godmother was one of the first people that I told. I blurted it out and watched, waiting for her reaction. Her eyes lit up, and she hugged me and told me "Congratulations! He will be just perfect!" And I cried again to have had such a loving reaction, the opposite of what I feared. And slowly but surely I started opening up to

others. And most were wonderful reactions. Others were well intended. I perfected the response, giving them a smile and replying, "No need to be sorry, he is perfect, and we are so excited for him to get here!"

It was time to let go of my fears and start working on figuring out what I could start doing to make sure we had every option available for a safe pregnancy and healthy delivery. A dear friend of mine sent me an email after hearing about the positive penta screen with the story "Welcome to Holland". It's a beautiful analogy to learning your child has any disability. I'm very thankful to have read that before we had our official diagnosis; it helped me summarize my feelings, and also realize that we were not alone.



Benjamen is now 12 months old and thriving after open heart surgery at 3 months for complete AVSD and PDA repair. He sits up beautifully, pulls to stand, and jabbers all day long. He has no problems telling us what he does and does not want to do! He is the light of our life. He is an inspiration and a blessing every single day. I cannot imagine our lives without him - he completes us!

~Stefanie, Benjamen's mom; 38; Florida, United States

{Cade}

In July 2012, we found out to our utter shock that we were expecting baby number three. Why was I so shocked? First, because I'm the ultimate planner. Nothing happens without me planning every last detail. Second, it took three years to conceive our older son. We had medical interventions, lots of tests, months of temping and taking ovulation tests. I honestly never thought that we'd get pregnant without these interventions. But despite all of that, here we were.

It took me a long time to get used to being pregnant again. It didn't help that I was sick for 18 weeks. Just as I was feeling better, I had some routine blood tests. A few days later my doctor called. "Your tests show a high risk for Down syndrome. We want to do an ultrasound and some more testing," they told me. Normal risk for any pregnancy is 1:700. Normal risk for a 36 year old woman is about 1:300. My risk after this blood test was 1:28.

No problem, I thought, those tests are never accurate anyway. We scheduled a Level II ultrasound with a specialist, and were excited to find out the gender of our little bundle.

But not so fast. During the ultrasound, they found two markers for Down syndrome. Our risk was now a life-altering 1:3.

We held it together in the doctor's office. Afterwards, we went for a quiet dinner before picking up our kids. Neither of us ate much, and I fought tears for most of the dinner. Down syndrome? Really? That night I lay awake long into the wee hours, pleading with God to make our baby be okay. Just make him healthy, I begged.

We went back to the specialist for a blood test called MaterniT21. At the time of our test, MaterniT21 was fairly new, but it was accurate enough to be a great alternative to amniocentesis. After the blood draw, the wait began.

We had Thanksgiving, where we bravely went ahead with my plans to do a gender reveal pumpkin pie. I cried as I made the cheesecake with a hidden blue layer, and was solemn as I later cut it in front of my husband's entire family. A few days after that, as we waited impatiently, everyone in our family came down with the stomach flu. It was miserable, but it took my mind off of the wait. Finally, two weeks after the blood draw, the genetics counselor called.

"The test is positive for Trisomy 21. Your baby has Down syndrome."

I would like to say I took the news stoically. I did not. I cried and cried. My husband was home at the time, but missed hearing the phone call. He came out to where I had been working in the garage and asked a question about something work-related. But one look at me stopped him mid-sentence. He got down on his knees and hugged me tight. We stayed that way for several minutes. Eventually, he said something about it

being okay, that we'd be okay. The baby was perfect the way he was. We'd love him just as we love our other two.

The next days are a little blurry in my mind. We met again with the genetics counselor, who politely offered to tell us about our options for termination or adoption. We met with our regular OB, and with our new specialist OB. We scheduled an echocardiogram to look at our baby's heart, and stumbled through those first two weeks after the diagnosis. I read a lot on Down syndrome, I joined the local support group, and we secretly Googled pictures of babies with Down syndrome when we thought no one else was looking. And gradually, it was okay. We told our families, we started telling our friends, and the more we talked about Down syndrome, the more okay it was.

After those first few weeks, I gradually began to enjoy my pregnancy, and take joy in the new life forming inside me. We looked forward to our son's birth with the same happy anticipation that we awaited the births of our first two children. The day before Easter in 2013, our son was born. Yes, he has Down syndrome. But, just as I'd asked from God, he was also born perfect and healthy.

Cade is nearly five months old and doing great! So far, he's a very typical baby who loves to laugh, snuggle with his older sister and brother, and look at himself in the mirror. He has no health issues whatsoever. Everyone he meets falls in love with him, and he charms them all with gummy smiles.

~ Heather, Cade's mom; 36; Oregon, United States
Blogging @ www.321mama.com

{Wyatt}

My son was only six months old when my husband and I found out I was pregnant again. We were shocked, but happy. Having our children so close together certainly hadn't been part of our plan, but we would soon find out that very little about this pregnancy would go according to plan.

Right away, we knew that the timing wasn't great. Matt, an active duty Marine, was scheduled to deploy soon. He was already going through his pre-deployment work-ups, which meant that he was away for training and preparations for weeks at a time. And he would not be home for the birth of this child. We were disappointed, but being a military family, we had always known this might happen one day and just prepared to deal with it. Meanwhile, I made my prenatal appointments.

As with my first son, I agreed to a first trimester screening test called the nuchal translucency screening. I had never thought much about it beyond knowing that it meant I would get an ultrasound that I wouldn't otherwise get, and who wouldn't want to see their baby if they could? The test consists of an ultrasound and a blood test, and those two combined give you a risk factor for Down syndrome.

In the week before the ultrasound, I couldn't shake this feeling of dread I had. I kept thinking that something would be wrong. I just knew it, deep down. So when the

ultrasound screen came up and the heart was beating and everything looked good to me, I was immensely relieved. But that relief was short-lived. I soon found out that the screening came back positive -- I had a high risk factor for carrying a baby with Down syndrome, with odds of 1:6. For a 26-year-old woman, this was especially unusual. I felt numb and confused, and agreed to a referral for a maternal-fetal medicine specialist, where they would do a higher-level ultrasound to try and find some soft markers.

This would be the last appointment my husband came to. For the most part, everything looked fine aside from a buildup of fluid behind the baby's neck. The doctor gently told us that this could be indicative of a heart defect, which could potentially lead to stillbirth. He cautioned us not to get too worried though, as it could go away and mean nothing at all. He also told us that now was the time to decide whether or not we wanted to get an amniocentesis done and find out for sure if the baby had Down syndrome. We agreed to get the amnio done, and I cried the entire way home.

Within a week, Matt deployed to Afghanistan, with lingering questions and fears left in the air. And I would have to get this test done, which I was somewhat scared to do, alone.

During the test, another wife from my husband's unit came with me to hold my hand. We noticed during the test how very active this baby was: kicking, moving, working out those little arms and legs. We gushed over the adorable little nose and thought how very perfect he looked. It turned out I didn't need to stress much about the amnio; it ended up being much less painful than I thought, and it was over in less than a minute.

Now, all we had to do was wait. The doctor told me I would have the results in a few days.

Three days later, on a Friday around 6:00 in the evening, my phone rang. It was my doctor's assistant, asking if I could hold for the doctor. I knew right then it was bad news. I knew the test came back positive. Sure enough, he got on the phone and informed me that the results had come back as a male, positive for Trisomy 21, or Down syndrome. I tried to remain calm on the phone while he asked if I had any other questions. I said no, made my next appointment, and hung up as soon as I could. And then I immediately burst into tears.

The first person I called was my mother, who I had kept up-to-date on what was going on with my pregnancy. We talked for about 45 minutes, and I unloaded all of my fears and heartache onto her. Would he be accepted? Would he have friends, go to school, get married? What kind of life would he have? Would he live with us forever? Could he work? I felt scared, trapped, and resigned to a life of misery and fear. My mother remained calm on the phone, but she told me much later that once we hung up, she cried. She had wanted to remain strong for me, and it wasn't the diagnosis she was crying over -- it was my anguish.

Luckily, my husband was able to call that night from Afghanistan, and I told him that our son had Down syndrome. His response? "OK." To him, it was a non-issue. I wished I had more of his strength and acceptance. I spent the next three days crying pretty much non-stop. And I didn't even know why. I just knew that this was devastating to me, and the fact that it was just made me feel even worse. Abortion had never been, and would never be, an option for us, but all the same -- I couldn't help but

wonder what kind of mother felt this way about her child? Was I some kind of shallow, prejudiced person who hated people who were different? What was the big deal? It was just an extra chromosome. But that extra chromosome sent my world into a tailspin. Every time I thought about the baby, I cried again.

Over the next few weeks, I was on an emotional roller coaster. I had brief moments of acceptance, and then plunged back into despair again. Matt and I had discussed naming our son Wyatt, after a good friend. I liked that name because I had read somewhere that it meant "little warrior". Now it felt stupid, because how could a baby with Down syndrome be a warrior? He would be weak and helpless, someone who I would need to take care of forever. He wasn't my little warrior anymore.

Then, as I slowly started researching Down syndrome, I found an interesting fact. Babies who have a chromosomal abnormality are overwhelmingly likely to end up as a miscarriage or stillbirth. This happens about 80% of the time. Evidently, many times when a woman has a miscarriage and the remains are tested, it is found that the baby had Down syndrome or a similar chromosomal defect, like Trisomy 18. And suddenly, I was looking at my baby in a whole new light.

No longer did I see him as someone who was helpless and fragile, someone who I would have to nurture forever. This baby was a fighter, a survivor. This was a baby who had already beaten the odds, just by surviving this long. I realized that this was my little warrior, and together, we would fight and forge a new path together. There may be rough patches, but we could take them on -- together.

Now that we had an official diagnosis of Down syndrome, it meant that I would have twice as many doctors appointments to go to. I would have to continue seeing my

regular obstetrician, who would monitor me, as well as continue to see the maternal-fetal medicine specialist, who would monitor Wyatt. This meant driving for an hour at least once a month, and as I got further into the pregnancy, once every other week. I actually didn't mind that much. Seeing the high-risk doctor meant that I got an ultrasound at every single appointment, and I knew that Wyatt was being well taken care of.

One thing that was incredibly frustrating to me was the stigma surrounding prenatal testing. I constantly was asked by people if I found out while I was still pregnant because I had considered termination. The answer is a resounding no, but it came up all the time. I found it very unfortunate, because it gives women the idea that prenatal testing is done solely so that they can abort the pregnancy. This attitude doesn't let anyone know how valuable it is, medically speaking, to know in advance. It also gave me time to process the diagnosis and accept it. It took a little while, but eventually, I could be happy about the pregnancy, and look forward to his birth. I couldn't even imagine what it would be like to get a surprise diagnosis, and feel all of the things I felt -- which I continue to feel a measure of guilt over -- while I was holding my son.

Medically, I was astounded at how much I was able to learn about Down syndrome from my specialist. From what I have heard since, many high-risk doctors are not very knowledgeable about Down syndrome, or up-to-date on what kind of lives people with Down syndrome are able to lead. I was thrilled to know that not only did my doctor know a lot about the medical aspects of Down syndrome, he was also free of the outdated stereotypes and negativity that I myself had even fallen into. He was able to explain why we would have multiple fetal echocardiograms, to check his heart, as well as what risks there were with other organs. He knew that the placenta, being formed from the baby's

DNA, also contained the extra chromosome, and therefore was at a higher risk of failing early. As we got later into the pregnancy, this meant constant monitoring. I had two non-stress tests a week, as well as a weekly ultrasound. This was solely to make sure that the placenta was still functioning as it should be. It got a little bit old, to be honest, but I was still grateful. If there was even the slightest hint that the placenta was failing, they were ready.

Thankfully, Wyatt appeared to have no health problems whatsoever. His heart appeared to be fine in all of the fetal echocardiograms, and all of his other organs were growing and developing normally. All the same, knowing in advance once again proved to be beneficial. My doctors had a plan for my delivery, and then a back-up plan, and then another back-up plan on top of that. If Wyatt decided to surprise us after birth with any surprise health issues, they were prepared. I appreciated that, because it allowed me to go into the delivery with no anxiety. I had a great medical team standing by, who was ready for whatever might happen.

Because I had an emergency c-section with my first baby, I had a second c-section with Wyatt. The surgery went well, and out Wyatt came. He was big and pink and crying loudly. He was healthy, and we were all excited and relieved. My husband was able to Skype into the operating room from Afghanistan. Everyone also knew that I already knew about the diagnosis, so no one was tiptoeing around our room. No one offered their sympathy or acted sad. All of the staff treated the birth as the joyous event that it was. It was wonderful. Wyatt had some physical features of Down syndrome, but that didn't matter to me or anyone else, because he was still so stinking adorable.

After the birth, we still had to do follow-up echocardiograms. Wyatt turned out to have three minor heart defects: two tiny holes, and a PDA, which is when the ductus arteriosis in the heart doesn't close after birth like it is supposed to. None of these ended up being bad enough to prevent us from going home after a few days. We followed up with a cardiologist for the next few months, and slowly, we saw all of his heart defects resolve themselves completely on their own. Since then, Wyatt has been the picture of health. I had braced myself for a million complications and health problems, but he has had none.

The hardest thing about raising Wyatt has been the developmental delays. Day-to-day, I don't usually notice them. He's just a baby. He cries, he eats, he poops. He also gives me huge, excited grins when I get him up in the morning, and he loves being cuddled and bouncing on my lap. Down syndrome doesn't really affect our regular life much. But every now and then, I can't help but notice how far behind other babies he is, and it is disheartening. Babies with Down syndrome typically take about twice as long to reach milestones, which describes Wyatt to a T. So I know that this is completely normal and nothing to be worried about. But it can still be frustrating, knowing that at 15 months old, he still can't crawl, can't pull himself to standing, and can only sit on his own if he's propped there first. I have to just try to remind myself that he will get there in time, and in five years, it won't matter when he started sitting or crawling or walking. The important thing is that he will get there.

I don't know what our future holds, but I no longer have the anxiety about it that I did in the beginning. Life with Down syndrome may have its challenges, but overall, it really isn't that bad. I have two adorable sons who love me, their father, and each other. An extra chromosome doesn't change any of that. Life is still good.

Wyatt is 15 months old today. We have been very lucky to have no health issues to worry about. He likes to cuddle, loves hearing his mommy sing, and can also be pretty stubborn when he wants to be. He's able to sit on his own if placed into position, and can rock back and forth on his hands and knees. He can eat Stage 3 baby food. He is a much-loved member of our family and makes our lives better every day!

~ Cassy, Wyatt's mom; 27; North Carolina, United States
Facebook contact: https://www.facebook.com/cassy.chesser

{Quinn}

I knew I was pregnant the moment I conceived. Call it a woman's intuition or a case of mother-knows-best, but I knew. As the weeks went on and I could finally take a pregnancy test and receive reliable results, my husband Brian and I stared at the giant plus sign and I said, "I told you so." As things progressed, I also knew I was having another boy. Friends and family members would wink and say, "Oooh, what if it's a girl this time?" And I would smile and nod and join in the what-ifs, but I always knew deep down that our oldest, Atticus, would be getting a little brother. And when our doctor confirmed this at 16 weeks, I just shrugged at my own intuitive nature.

So when I got the news at 24 weeks about our son, I was shocked that I didn't already know.

It all started at our 20-week ultrasound. It's supposed to be a fun glimpse at the life growing inside, a check of basic anatomy, and a reassurance that all is well. For most moms it is. Our doctor found that our little guy had slightly dilated kidneys, but she wasn't worried about it too much. Even so, she sent us off for a level II ultrasound the following week, just to make sure that it wasn't anything serious.

I did a little research into what dilated kidneys could mean, and learned that it could be anything from a temporary fluid build-up that corrects itself before birth, to a marker for

Down syndrome. As I was lying on the table with the unbearably cold ultrasound jelly smeared over my abdomen, it became clear to me that the ultrasound tech was looking for other signs of Down syndrome. She measured the heart, the level of fluid behind the neck, the length of the arms and legs, and the shape of the pinky finger. It turned out that in addition to the dilated kidneys, the baby also had an echogenic intracardiac focus. This is a calcification on the heart muscle that usually, like the kidneys, clears up on its own and isn't a cause for alarm. But it's also another marker for Down syndrome, and coupled with the kidneys, was therefore a cause for concern.

A genetic counselor came to talk with me and recommended that I have a new test called MaterniT21 that can definitively say whether or not the baby had a chromosomal anomaly. She stressed that there was still less than a 1% chance that anything would be wrong, and the test was merely a tool to give me peace of mind. The results would take a few weeks and she'd call me when they came in.

Enter the longest weeks of my life. I must have googled every variation of the words "soft markers for Down syndrome" a thousand times. Sometimes the results made me feel better, but more often than not they sent me into a tailspin of worry. It was a dark time. And then I got the call that would forever change my life.

Our second child would be born with Down syndrome.

The news was mind-shatteringly, heart-wrenchingly painful. I managed to cycle through a wide series of emotions in the matter of minutes. I grieved for the "normal" child I expected. I cursed whatever higher power would place this on our shoulders. I stared dumbfounded at the wall thinking that if I remained still long enough, the room would stop spinning.

We were suddenly faced with a multitude of choices. According to recent statistics, 90% of prenatal Trisomy 21 diagnoses end in termination of the pregnancy. I can't judge women who take this path when faced with such severe news, even when they are as far along as I am. The emotional, financial, and physical implications of raising a child with Down syndrome were mind-boggling to me at the time. But for us, at 24 weeks along, this wasn't a choice we could make. Our baby was no longer a clump of cells. I'd been feeling him roll and tumble in my stomach for weeks. We gave him a name. We gave him an identity. Termination was not an option for us.

Apparently, there are waiting lists for infants with Down syndrome, so the option of placing him up for adoption seemed a legitimate choice. Despite all that I had said about this child at this point in my pregnancy, he was still an abstract idea. He wasn't anyone I had met yet, and our bond had not developed. I only had attachments to what this child could become, and now my expectations had changed. Nevertheless, we decided we couldn't let someone else raise our child. And despite my surprise at this new challenge when my intuition into every other aspect of my pregnancy seemed so strong, I did know for certain that I would love him no matter what when he arrived.

Because of the diagnosis, my pregnancy was closely monitored. I went in for weekly ultrasounds, and each visit seemed to reveal possible worst-case scenarios. His kidneys remained dilated and now, in addition to the calcification on his heart, more calcification was showing up on his liver and stomach. The doctors told us it could be a manifestation of the Down syndrome itself, or a sign of something more serious, like a life-threatening infection. But the scariest finding by far was when we went in for the fetal echocardiogram to check for heart problems, and the doctor found a pleural effusion, which was fluid in the chest cavity near the heart and lungs. If it grew, it would

likely kill him. But with each subsequent appointment, we saw that it remained small enough to be asymptomatic, and we crossed our fingers that it would stay that way. The doctors told us our best hope for his well-being was for me to deliver as close to full-term as possible. Since my first was two weeks early, our medical team put me on modified bed rest to prevent pre-term labor. I could go to work and handle basic tasks at home, but was advised to put my feet up as often as possible. As a teacher with a rambunctious two-year-old at home, this was easier said than done.

But one night just shy of 35 weeks, I woke up at around 2:00 in the morning with a pretty intense, but short-lived contraction. I knew that this tends to happen toward the end of pregnancy, so I ignored it and fell back asleep, but it continued for most of the morning. At around 5:00, I decided to start timing the duration and frequency of the contractions. They hurt, but there was absolutely no pattern to them at all. Most labor and delivery rooms have a strict policy that laboring women are not admitted until their contractions are four to five minutes apart and at least 60 seconds long. I was nowhere near there, so I decided to head into work. I needed to help my students prepare for their final exams, and after laboring with my first for 19 hours before any real progress was made, I felt like I had time even if this was the real thing. But I nevertheless put in a call to my doctor and she confirmed what I was suspecting: it was likely prodromal, or false labor. Still, she wanted me to come in and be monitored to make sure that the baby and I weren't in any distress. I figured I'd be slapped with an order for true bedrest and a prescription to assist with the pain. I called in for a substitute, hopped in the car, and drove to the hospital to see my doctor, texting my husband along the way to let him know what was going on.

When I made it to the doctor's office, the contractions became pretty frequent and painful. My OB/GYN wasn't in the office that day, but another doctor in the practice came in to check on me. The look she gave me was one I'll never forget: it was a mixture of shock, urgency, and a how-the-hell-did-you-not-realize-you-were-in-labor? I was almost fully dilated, and the baby was coming. Soon. They ordered a wheelchair to send me downstairs to labor and delivery, and told me to call my husband and order him to hurry or he would miss it. When we got downstairs, the delivery room was already packed with a whole team, including the delivery doctor. Within the hour my husband arrived, I pushed a few times, and Quinton Robert Emil Mennes was born at just 35 weeks, over a month early

Weighing in at a healthy 6lbs, 13oz and over 18 inches long, we spent most of the day in shock. How did this happen so quickly? How was he so healthy for being born so early, especially after such a terrifying pregnancy? How the hell did I manage to teach three classes that morning, drive myself to the hospital, and deliver a baby before lunch? We asked and attempted to answer these questions for hours, telling and retelling the story to anyone who would listen. Had I decided to stay and teach my fourth period, like I really wanted to, I probably would have delivered this baby in an ambulance or

along the side of the road. It turns out our little dude was in a hurry to meet us. He spent a week in the NICU for jaundice and some minor breathing issues, but was released to us the day before Christmas Eve.

Now, 8 months later, he is doing remarkably well. We've been blessed that he is healthy and happy and have numerous resources available to help us navigate the unknown waters of special needs parenting. We know we'll face some challenges ahead, but we've fallen so deeply in love with this sweet boy that we're willing to take on the world to give him what he needs.

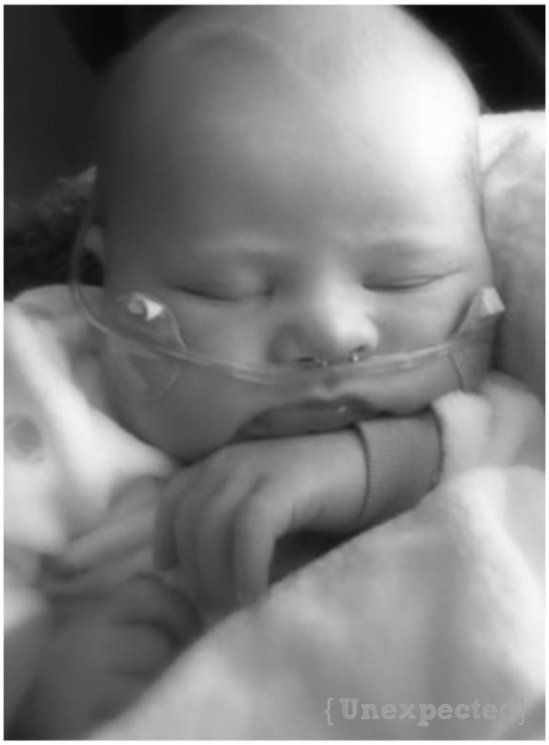
Parenting is the hardest job I will ever have. This would be true even if my son did not have Down syndrome. But he does. And we love him not in spite of it or even because of it. We love him because he is our son, our Quinn, and he just happens to have Down syndrome. It does not define him, it only enhances him. And it makes me so appreciative of everything I have in this life, especially my children.

~Megan, Quinn's mom; 30; Houston, United States

Blogging @ "Define Crazy": www.meganmennes.blogspot.com

{Owen}

This being baby number four and not having major issues, I didn't reschedule my 20 week anatomy scan when I found out my husband couldn't join me that morning. I had already waited two extra weeks to schedule once the kids were in school, and we were seasoned parents. I skipped off to my appointment, anxious to see the little one moving and grooving around.



The tech was wonderful as she measured and checked all the pieces and parts of the baby. She talked to me as she worked and printed out many photos for me to bring home. I was on cloud nine knowing that all the parts were there, and breathed a huge sigh of relief.

I waited to meet the doctor, and continue to plan for the rest of the pregnancy. I waited much longer than I believed I would, and my stomach dropped a bit when I met the doctor's eyes as he walked in. He asked me a few questions, and then asked me to join him sitting down. I won't soon forget his words. "These are difficult ultrasounds to go over and share," he said. At that moment I felt like I was watching myself from afar or on television. I felt like I was listening in on the conversation as a third party. The doctor continued to show me the images from the ultrasound and assured me that all the baby's functions looked good and is healthy. Then he stopped when he got to the baby's face and profile pics. He talked about the baby missing a nasal bone, and how

this was a marker for Down syndrome. He assured me the tech was quite qualified and usually saw things clearly. I remembered back to the scan as she struggled to get a good profile picture, and had to make me move around a bit. I never noticed anything off, but it was odd that she looked for a long time. He went on to show how everything else looked just fine; there were no other markers.

As he finished, his other comment still remains in my heart. "You will need to talk with your husband and decide what to do." I listened as he talked about a referral to a perinatalogist for a level two ultrasound and possible amniocentesis for a diagnosis. I left the office and cried on the way out to the car. I was so worried about all of the medical and social ramifications of what I had just heard. I had planned to go to the store and pick up a cute gender-specific outfit to share the news with daddy. Now I just wanted him to hold me. I drove, crying, the 30 minutes to his office, praying he wasn't on a job site and called him to come out to my car.

I felt such a heavy heart as I shared with Brian that our baby may or may not be "perfect." My emotions overwhelmed me, and my husband comforted me. He reminded me that our baby would be our baby no matter what. If I wanted more information, schedule an appointment. He was a rock of strength and his faith was unfaltering.

I decided at that moment leaving his office, that we indeed would be just fine. This baby was meant for our family in whatever form it took, and we would welcome it just as we had the other babies. A little retail therapy was called for, and after buying a few cute outfits, I was ready to face what was headed our way. Don't get me wrong, I had a billion questions and doubts, but I also felt a sense of calm that we would all be ok.

I called that afternoon and scheduled an appointment with the specialist. It would be two weeks of waiting and Googling and reading and researching. The nasal bone was a new marker to look for in scans, and it was often hard to detect. I was sure that this was the case and that our follow-up would show a nasal bone, and I could go back to worrying about my cervix as usual. Although I was anxious to go, I was more looking forward to some answers and moving forward from there.

We walked in ready for anything. The tech doing the ultrasound was very detailed, and talked us through much of what she was doing and seeing. Parts and pieces were all still measuring on track, so we were pleased about that. She took a very long time looking at the heart. I kept giving Brian the "oh no!" look, and we waited while she went to got get the doctor. We did get to see baby in 3D, too, which is always incredible to me!

When the doctor came in, they spent some time together looking at the heart and discussing quietly what they did or did not see. The tech was unsure whether there was tissue between two of the heart chambers, but the doctor believed that he did see tissue, so he said that was nothing to worry about. Phew! We knew from our research that heart defects can also be more common in babies that have Down syndrome.

The doctor then showed us the areas of concern. They still did not see a nasal bone, which was the strongest marker. In addition, they saw a bit of fluid around the heart and a dilated kidney. The last two markers, he said, would not be of any concern typically -- in an ultrasound he wouldn't even mention them -- however, they are both soft markers for Down syndrome. Together, the puzzle was coming together. He let us

know that these are just screenings. An amnio would give us a definitive answer, but we were unwilling to take that risk and lose the baby.

Our other option was a blood test. They were newer on the scene, but would tell us with 99% accuracy whether there were issues with the top four chromosal abnormalities. The test we were offered was called Verifi. It was non-invasive, just a blood draw for me. We would know results in eight days. We decided to go ahead with this test, so that I could have peace of mind for the remainder of the pregnancy.

Eight days. Eight days can be a flash or an eternity. For me, it was a mix of both, somehow.

I truly believe I already knew the answer we would be getting. There were several signs sent our way that week that may have seemed coincidental; however, I believe it was all there to confirm my thoughts so that we could continue on this journey.

The hardest part of this time was how to deal with it. I am a talker. My husband, thankfully, understands this and was fabulous, especially during this wait. We didn't really want to share what was going on with anyone, but did tell a few people. I didn't want people to worry. I didn't want to have them drawn into this craziness until we knew for sure. I didn't want looks of pity or sympathy, depending on the outcome. This was our baby, either way, and we never considered otherwise. I spent many sleepless nights that week. I found support online. I searched and searched about absent nasal bones. The more I looked, the more confident I felt that our little one would have "designer" genes, as one mom put it.

The call came exactly eight days after drawing blood. The genetic counselor asked whether I wanted to talk about the results in person or on the phone. I had a sense of calm as I verified my information so we could talk over the phone. I knew what I was about to hear, and prolonging the inevitable was not going to change anything. She explained that the test results were indeed positive for Trisomy 21. That would indicate our baby has Down syndrome with 99% probability. She explained about the test, and what this would mean for our pregnancy and life. She offered a meeting to go over things, so we set a time for the following week.

As I got off the phone, I let out a long, slow breath. I dialed Brian at work, and the tears began... although this time, they were from the relief and contentment of knowing, rather than from fear or worry. I am sure Brian loved having this conversation on the phone, but I could not hold the information in. I had to let it out and let it be real.

Next, we called our moms to let them know, as they had been patiently waiting with us. Their love and responses were so crucial in the process of acceptance. They were with us. This was their family too, and they were more ready to meet the new little arrival.

I found it interesting that two days later, just before my 24th week, my OB called to see how I was doing with everything. I found it interesting that he called me; that was not his bedside manner in my experience. In retrospect, I know that he called because in Iowa, medical terminations can be done until the 24th week of pregnancy. He called to check in; but he really called to see if I wanted to abort my son.

After receiving the official diagnosis, I decided to switch hospitals for delivery, which also meant finding a new OB. In our area, there are two health systems, and my kids

and I were not in the same one. We had a bad experience with one of the pediatric specialists in my system, hence the change for the kids, and I didn't want our new baby to be seen by that doctor either, if needed. So, with an already labeled high-risk pregnancy due to advanced maternal age and history of preterm labor, I was off to find a new doctor. It didn't take much time to find a perfect fit, and I was seen at the new office within the week. We created a plan and scheduled appointments with the maternal fetal medicine (MFM) office to evaluate our son further.

The rest of my pregnancy was quite uneventful. I went to appointments each week. The MFM completed an echocardiogram and determined his heart was structurally sound, although he had a thickened heart wall and pericardial effusion: fluid around the heart. I alternated seeing the MFM and my new OB. As the time got closer, I had appointments twice a week for a BioPhysical Profile (BPP) and a non-stress test (NST). Both were fairly quick, and baby boy was doing great.

Otherwise, it was Iowa in the winter. A week before we had him, we lost power for a full 24 hours. I was grateful to get through that storm without having to worry about digging out or, worse yet, delivering at home. But as the days grew closer, I became a bit more nervous about having him here. I was currently protecting him and sheltering him from whatever would be. Once he was born, that would become more difficult. I worked past my worries and was ready to meet him soon.

Christmas passed, and we went for a check up to the MFM. During the ultrasound and BPP that day, it was determined that the fluid around his heart was increasing. The MFM sat to meet with us, and consulted with our OB on the phone. They concluded that it was best to deliver the little squirt, and we agreed. We could head over the hospital

after lunch, or wait until the next morning. Always the planner, I asked for the next day. I like the birthday of December 28th, and I really longed to have one more night with my kids at home as a family of five. We left with an induction scheduled for the morning and I savored the evening with my family.

The next day I had three worries: baby's heart, what/who he would look like and what we would name him. Within hours all my fears were put at ease.

I have been blessed with quick labors with my children. Number three was interesting. My water broke at midnight, we arrived at the hospital at 1:00 am, and delivered him at 2:00 am. That experience was very empowering, because I delivered without any medication. So this time around, my goal was to try to go without again. My water was broken a bit after 10:00 am, and within a few hours it was a go. Grateful for not needing Pitocin, I waited out other pain meds. By noon, I was progressing, and needed something to take the edge off. I was given a dose of Fentanyl, and told subsequent doses would be less effective. Thankfully, it helped enough to ease me through, and one dose later, I was ready to meet the little guy. My OB made it just in time to catch him as he arrived into the world at 1:04. Nothing in the world is like welcoming a new child. He cried, and I was able to relax a bit as we saw him, and watched the NICU team check him over.

Everyone said how great he looked, and I was able to nurse him a bit before they took him to the nursery while we switched rooms. Owen Henry was born at 38 weeks, 5 days. We welcomed our precious son on December 28, 2012. He was seven pounds, seven ounces and 19 ¼ inches long. And he was perfect.

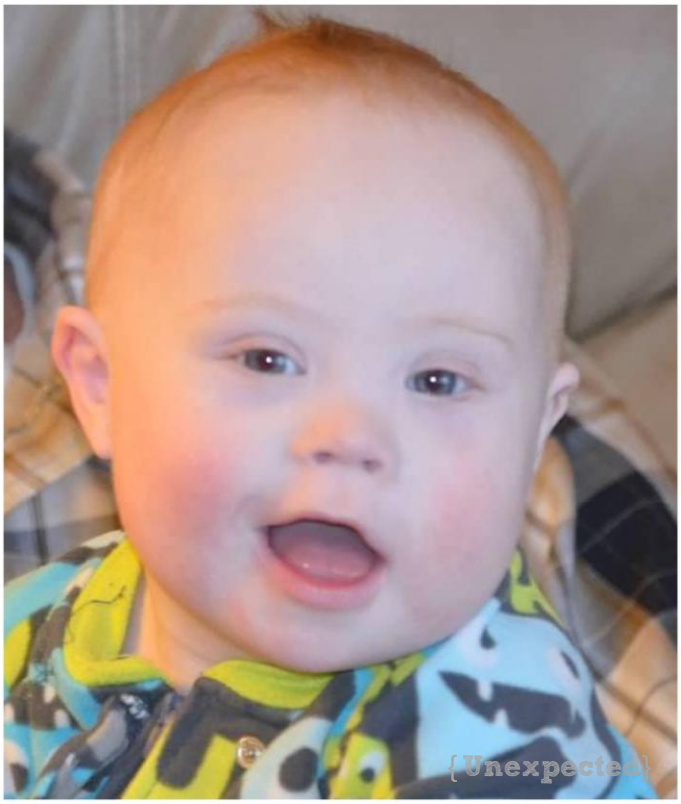
After a while, the doctor came in to explain that his oxygen levels were not great, and that they were going to transfer him to the NICU. I was so disappointed, but I knew that we should go with it. I was a wreck worrying about his heart, but a short time later, the cardiologist performed an echocardiogram and found no concerns at all. What an answered prayer! That night, though, it was determined that his hemoglobin numbers were off. They believed he had extra hemoglobin in his blood, which was thickening it, so it was harder for him to get it moving around his body, especially his extremities. So they did a procedure to exchange out some blood for saline to dilute his blood, essentially. It worked, and he was resting comfortably that evening and stable. He was also on billi lights for a bit to help stay ahead of jaundice issues, and also received a low flow of oxygen. Pulmonary hypertension was the diagnosis, and the doctors were convinced it was just something that would take time to resolve as his body worked to stabilize.

In the NICU, there were ups and downs, but he progressed nicely and fed wonderfully. I had a huge worry about eating, but he nursed well and took bottles well. After going through a 30 day NICU stay with our oldest 7 years earlier, we decided to pump breastmilk and bottle feed to work on getting home. He did great and after 5 days, the team decided he could go home the next day. It was wonderful to take him home and have our family of six under the same roof.

The next weeks were filled with appointments and checkups to monitor the little guy: a pulmonologist, an audiologist, an ENT, and a pediatrician. Dealing with the oxygen and monitor was frustrating at home, with lots of tubing and waking to the pulse ox monitor several time a night. After visiting with the pulmonologist two weeks later, the oxygen was discontinued. Owen continued to sleep relatively well, although he did breathe quite

loudly and wake himself several times a night. But over time, this lessened. We had scheduled a sleep study to look into the possibility of sleep apnea, but a bit before, he developed an ear infection and during the antibiotic treatment, his sleeping quieted and his breathing calmed.

Hearing concerns remained throughout his first months, as he did not pass any of the screens at the hospital or afterwards. His ear canals were tiny, and that was believed to be part of the problem, along with fluid in the inner ear. Owen's first ABR showed mild to moderate hearing loss, and after a few appointments with the ENT and audiologist, we prepared for hearing aids. We visited the ENT one day before our hearing aid were to be picked up and we had progress; he could see his ear drums! This was great news, until he shared that he did not see any evidence of fluid. This led the ENT to believe that Owen's loss was most likely permanent hearing loss. It wasn't the news we were hoping for, but we were grateful that there were supports in place to help.



At the audiologist the following day, she wanted to run the screens one more time while we prepared to learn about the world of hearing aids. She ran all three screens and he passed every single one. We were in awe and so happy to know that this would not be another hurdle in the Owen's journey.

With the hearing and oxygen issues resolved, Owen became one boring baby. Our appointments decreased dramatically. His lower tone was evident, but he was still keeping on track developmentally. Physically, he consistently measured near the 50th percentile on the typical charts. Boring has never been so wonderful and appreciated!

Today, Owen is 14 months old. He has been very healthy and we are working towards milestones like standing and walking. He crawls like crazy and loves to torment his older siblings by climbing on them and pulling their hair. He loves to eat mashed potatoes and carrots. Our three older children love him to pieces and love to make him smile! It has been over a year since our diagnosis, and although it has been a roller coaster at times, we are so grateful he is here and well!

~ Jenny, Owen's mom; 35; Iowa, United States

{Jude}

Everything with Jude seemed okay at first. I opted for early testing which involved an ultrasound. Piper, my third child, came with me and we laughed at Skippy's, Piper's nickname for the fetus', antics. She was rolling around, standing on her head, and just being super active. I felt her rolling around very early on, and was reassured by her energy.

Then we got the call. My results from the first trimester blood test had come back with a 1:5 odds of the baby having Down syndrome. I was devastated. I sobbed and cried. I got really angry at God, at the universe, at the world. I felt like I was being punished for wanting too much. I mean, come on. I already four children, and this is what happened when I pushed for five. I knew this was not a diagnostic test, but I was convinced that it was, and lived my life with that conviction. I had this feeling for months now. I had even debated with a friend, because I had said I would not terminate for Down syndrome. As much as I am not woo woo, I felt that I had known about Jude for a long time.

For two days, I cried. I researched tons of information and tried to bolster myself with some hope. Her nuchal neck count was two mm, which was normal. The doctor had not mentioned anything about her nasal bone, and I scanned her ultrasound pictures,

hoping I could find the bone. But deep down I was convinced she had Down syndrome. My husband and I decided to go ahead and get an amniocentesis done. I felt that I had to know, that I couldn't bear to live in this half space of not knowing.

A week before the amnio, I stopped feeling Jude move. Because I was also at risk for Trisomy 18, I believed she had this much more severe chromosomal disorder, and that she was dead. I had suffered a miscarriage months before conceiving Jude, and I was scared it was happening again. At this point, there was a small shift in my feelings. Down syndrome was by far better than having a dead baby.

My mom came down Sunday, and on Monday accompanied me to my appointment. I wrapped my white rosary around my wrist, and brought a Mary card with The Memorare on the back. During the hour I waited, I prayed that prayer about ten times. Mary was a mother, and she had lost her son. I felt very close to her as I sat there waiting for them to jam a giant needle into my womb. I wavered, even then, over whether or not I should have even the test.

When we were finally called back, I was near panic with fear. And then there was the baby, moving around, heart beating perfectly, and I started to sob. The baby was alive. Suddenly, Trisomy 21 didn't seem like the worst option possible. What mattered in those few seconds was that the baby was kicking, swallowing, pumping blood through her tiny heart. The tech was very thorough, but acted impatient with me, and kept saying "This is all really hard to see at 16 weeks. We usually do these tests at 20 weeks," and then, "If you choose to do the amniocentesis... " It was clear that she had no idea why I was there. I finally said "Um... we are here for the amniocentesis." And then my mom said something about not aborting for Down syndrome, and the woman again began acting

very annoyed, and said, "Well, you have two soft makers. She has no nasal bone and her bladder looks bright, but we'll have to ask the doctor what he thinks." And then she left. I cried and texted my husband the news. I told him the baby was a girl first, because I knew he was hoping for another girl. I softened up for the blow... not just high risk, but two soft markers. He wrote back, "So?" The doctor came in, and performed a careful but really long amniocentesis. He refused to speculate on the soft markers, but the lack of a nasal bone confirmed what I had accepted three weeks ago. I knew deep down that this baby, now Jude -- I had made a promise to St. Jude that if she was alive I'd name her Jude -- had Down syndrome.

We got the call two days later. Jude had Down syndrome. Initially, I just felt relief from knowing. I cried a lot at how kind my friends were. And when I started to reach out to the Down syndrome community, I was drawn right in and welcomed, which made me cry. But really, I was also crying because Jude was not perfect. I was crying because I was not going to have a "typical" baby. I was crying because I was terrified of the future. I was crying because I was worried about how her care would effect the rest of my family. But then, I didn't dare express those feelings. My husband and my mom were so positive and supportive. My husband already loved Jude with the fierce passion that he shows for all our children. I loved her, but that love was overshadowed by grief and fear.

For the rest of my pregnancy, I'd swing between despair and hope. It helped that Jude was showing no health problems and that my pregnancy was going well. Usually at night when I was alone, I'd cry a lot about her future. I worried that she would never read, go to college, have an independent life. I wasn't sure how she was going to fit into our homeschooled, eccentric family. On other days, I felt that there was no better place for her. But what carried me is that I loved her no matter what.

Jude was born quickly in the midst of a rain storm in mid-December. I didn't even have time to get into a hospital gown before I started to push. Even with the furious rush of her coming, she was born into a quiet and calm space. The young midwife who caught her was still in awe of this miracle as were we despite this being the fifth time. And then they put Jude on my chest and she, the first of all my children to do so, lifted her tiny face towards mine. Our eyes meet, and there was a lot resting in that look she gave me. We knew Jude had Down syndrome. And I thought I was prepared. When I looked at her all I could see was the Down syndrome, and it was a shock. It was a crack in my expectations of how I would react. Of course it was not the shock, a woman feels with a post natal diagnosis but I wasn't expecting it to be a shock at all. I didn't feel like I didn't love her, or that she wasn't mine....I just felt this distance. I am aware that this could be from the shock of such a quick birth (I thought we had at least a few hours to go) but I'm honest enough to admit that some of it was the shock of seeing those features, and sadly my inability to see Jude. But as the night wore down, and my husband finally handed her over to me (he was in love right from the start), I was able to just be with her. I first noticed that when she was sleeping she pursed her lips into a little kiss just like my three year old daughter used to as a newborn. When she was getting ready to squawk, her face got all red and crinkly like my third child's face. The shape of her lips were similar to my second child and her tiny size reminded me of my sweet first born. And as the night turned into the day after, the light did come in, and suddenly Jude wasn't the face of Down syndrome. She was Jude. The baby who completed our family. She was what we needed and were waiting for even though we did not know it.

Jude does have Down syndrome but that is not her only qualifying characteristic to being human. She, like the other children, will surprise us with her own expectations of herself and her world. Her light, shining through my cracked bottles, will join with the light that we already have let into our family. She will have different, sometimes harder, challenges of course. We are not naive. But we are hopeful, and we all feel pretty lucky that this sweet baby has graced us with her life. I hope that we're worthy of such grace.

~Ginger, Jude's mom; 40; Georgia, United States

Blogging @ www.greenteaginger.blogspot.com

{Ada}

Taking the first trimester screening test was just a checkbox for us. We hardly gave it a second thought, because it came back with very low risk with my first, and we thought it would with our second also. They measured the nuchal translucency (NT), and it was small just like my son's. She took the largest measurement, which was 1.5mm. A week later, I got a phone call on a Friday afternoon from the OB nurse. You never want to get a phone call -- it seems they always have bad news. She said the risk of our baby having Trisomy 21 was 1:92. I tried to tell myself that a 1% chance of having a baby with Down syndrome was still very unlikely. Somehow, I still just had a feeling. My husband thought the risk was so low that we didn't even need to research or talk about it, but I still started researching on my own.

It seemed like forever -- it was actually a week and a half -- before we could get in to see the genetic counselor. By the time we met with the genetics counselor, I was 13 weeks pregnant, and I had researched all the new blood tests. The genetic counselor explained to us that my PAPP-A was low (0.2 MOM), and that was the reason our risk was elevated. She offered me the MaterniT21 blood test, and we had the blood draw done right away. However, two weeks later, she called to tell me that the blood tests came back inconclusive. We could either redraw, or I could proceed with the amniocentesis. Waiting had been agony, and I didn't want to go through two more weeks just to be told the results were inconclusive again. We scheduled the amnio. We had to wait almost two more weeks, and it was beginning to look like we would have to wait through our second weekend without the amnio results. Then, my OB called just before 4:00 pm on Friday, six weeks after the first phone call. They always like to call on Friday, it seems. My husband was on the way home, so I was alone with my 15 month

old son. She congratulated me on having a baby girl. Just what we wanted - one of each! However, she proceeded to tell me that my daughter had Trisomy 21. At that point, I could feel myself breaking down. She gave me the cell phone number of the genetic counselor, and said I could call her right away if I wanted. Right after I got off the phone with the OB, my husband called, and there was no way I could keep the tears and fear out of my voice. I broke down the second I answered, and told him everything while he drove home.

That weekend, we spent most of our time reading about Down syndrome. We mostly read stories about adults. We were concerned that our daughter would suffer, that our family would suffer. Would my son get everything he needed if we were in and out of hospitals for our daughter? By the time we met with the genetic counselor, we were leaning heavily towards termination. I even wrote a letter to my unborn daughter apologizing for not being able to raise her and care for her. I placed the letter in a box with the only thing I had bought, hoping for a baby girl. It was a bib that said "My big brother is pooh-rific!" We discussed all of the options with the genetic counselor. She scheduled for us to have a fetal echocardiogram right away. The fetal echocardiogram didn't show any heart defects and the ultrasound technician couldn't find anything else either. We were told that if we hadn't had an amnio already, then they wouldn't have thought she had Trisomy 21. We tried to go ahead and schedule our termination, thinking we would schedule it for a couple weeks away, and think about it until then. But she said that she wouldn't schedule the termination until we were certain, and we had a few weeks to think about it since we were only 17 weeks along. I also spoke with our OB, and told her we were considering termination because we were worried how this would affect our son. She told me she had a nine year old niece with Down syndrome,

and her two siblings hardly even know that there is anything different about her. I was amazed that everyone was encouraging us to continue our pregnancy when 90% of women decide to terminate.

We still weren't sure what to do, but I started reading blogs about younger children with Down syndrome, and I saw less doom and gloom, and many more happy stories. Yes, there were still struggles, but no one was spending 50% of their time in hospitals, and no one was suffering. This was a very different picture than the one I had originally painted in my head. When we got home, I continued to do some major soul searching. What was the purpose of life anyway? Some people say people with intellectual disabilities are a drain on society, but is the ability to work independently and earn enough money to care for yourself the only thing that matters? In my opinion, the ability to make people smile and change lives is far more important. Our daughter's health, from what we could tell at this point, didn't seem like she would be physically suffering. Even if she did have some health issues, it doesn't mean her life is any less valuable. We can't guarantee anything in life. In the end, I knew there would be one decision that I, personally, couldn't live with, and we decided to accept that our life wouldn't be what we expected. However, it would be what we wanted, and maybe even more. We would have our happy little family with one boy and one truly special girl.

The rest of my pregnancy went by without any issues. I had extra sonograms and no issues were ever noticed. I was expecting it to be a long haul because I went past my due date with my first. There were definitely times when I was scared for the future, but I was mostly just excited to finally meet her. One day, I found a box hidden under a desk and unpacked it. I found that special bib and the note I wrote her. It was very emotional reading how upset I was when seriously considering the possibility of giving up my

daughter and how much things had changed since then. She had changed me so much and she wasn't even born yet. I remember and smile every time she wears that bib now.

Three weeks before my due date, I started having contractions. They were off and on for two days, but they were still inconsistent. Finally, they were painful enough to make the 45 minute drive to the hospital, but I was still expecting to be sent home. When we got there, I was six centimeters dilated already. My first labor went from one centimeter to pushing in a few hours, so I was prepared for a quick labor. However, my nerves got the best of me, and my labor stalled. I had an unmedicated birth with my son, and I had hoped to have another unmedicated birth. I think the fear of the future, both near and far, was causing me to slow down labor. My contractions were still very inconsistent. After several hours, I ended up getting the epidural, which really sped my labor up. It was only about an hour later that my baby girl was born. All nerves were out the window, and I was in love. She was so precious, and I couldn't figure out why I was ever nervous. She got great APGAR scores and was very alert.

However, she couldn't figure nursing out. We tried and tried to get her to latch, but something wasn't working. Multiple lactaction nurses were trying to help, assuring me that I was doing a great job. I had a lot of practice with my son, after all. She was taken to the nursery to be under a warmer for a bit because she was having trouble maintaining her body temperature. She only spent an hour in the warmer before being sent back, but over half a day had gone by, and she still hadn't nursed. Finally, her pediatrician came to see her and with one glance in her mouth, he told us that she had a cleft palate. We were definitely surprised, but I don't think the shock was anything compared to her prenatal diagnosis. We handled it very well. She spent a couple weeks in the NICU because she was very small, had jaundice, and needed to get the strength

to learn to feed from her special bottle. At first, I continued to try nursing her with lots of encouragement from the lactaction consultants and NICU nurses. Not once did anyone tell me that it was probably impossible, like trying to drink from a straw with a hole in it. For the first few days, I spent most of my time trying to get her to nurse and then giving her expressed breast milk through a tube in her nose (NG tube). I finally researched and realized that if I wanted to get her home, I would have to give her a bottle. Two of my biggest concerns for her, hospitalization and not being able to nurse, came true. It's amazing how those things didn't even matter that much to me anymore. All that mattered was that I could take this precious little girl home to meet her big brother!

Ada is 7.5 months. She has only been hospitalized once for RSV, which was more because she was only 3 weeks old and about 6lb when she got it. She is eating great and just started prop sitting. Her big brother loves her and she is a huge momma's girl. She will have surgery around 18 months to repair her palate. No other surgeries are expected. She is amazing!

~ Jaime, Ada’s mom; 28; Arizona, United States

{Jacob}

It all began at the twelve week ultrasound and blood test. This was my fifth pregnancy, after having three miscarriages and our daughter, who was three. We had the twelve week nuchal translucency test, and it came back with a 1:52 chance of our baby having Down syndrome. We were offered invasive testing to confirm or deny Down syndrome, but after having three lost pregnancies, we decided against it because the risk was too high of miscarrying again. To say we were frightened is an understatement, but being strong Christians we decided to pray and put it all into God's hands.

Things went along merrily until the 19 week ultrasound. We had arrived to have the scheduled scan, and the ultrasound technician was taking a long time to do everything. She stopped after about 40 minutes and said that she needed to go check something with the doctor. I knew right in that moment that something was wrong. You get that sinking feeling in your gut, and you just know that "I'll just get the doctor" comment means that something is up.

The doctor came, and we were ushered into another room and shown the extensive array of ultrasound pictures. The most troubling thing was our baby's heart. They could neither confirm nor deny whether our baby had a life threatening heart condition, and that we needed to be referred to a specialist as soon as possible. Also, the baby's limbs

were measuring shorter than what was expected at that gestational age. They were pretty sure that with both of these indicators, our baby had Down syndrome. They again offered us the amniocentesis, and after some time on our own talking and praying, we decided to go ahead with it. It was pretty horrible, but still, our greatest fear was that we were going to lose this baby. We were also worried about the issue of Down syndrome, but at this point in time we were more afraid about the baby's heart, and if the baby would survive the invasive test. We left feeling very deflated and unsure of our baby's future.

The day we found out the truth about our baby's diagnosss was the hardest yet, and I will never forget it. The doctor called three days after the amniocentesis. It was a Friday, I had been waiting all day, and finally the call came at 2:00 pm. It had been the longest and hardest three days of crying, and praying that our baby would not have Down syndrome, and just be healthy. I will never forget his words on the phone. "I'm sorry love, it is Down syndrome," he said, "And, oh, it is a boy." I hung up the phone and rang my husband, and the grief and sadness we both felt was overwhelming. I have never cried so much for the baby I thought I was going to have, and never felt so helpless in all my life. To be honest, I cried for days, and struggled with all the 'what if' questions about his future. All I felt was a tremendous sense of grief, anger and fear. In saying this, though, there was never a time when we felt that termination was an option. We knew with a certainty that this baby was our son, and that we were having him no matter what. But it was still a confusing and emotionally challenging time.

After some days of feeling sorry for myself, I decided to get some help and support, and to educate myself about Down syndrome. I had spent the last several years as a high school teacher, and the last four of those working in the educational support unit. I had

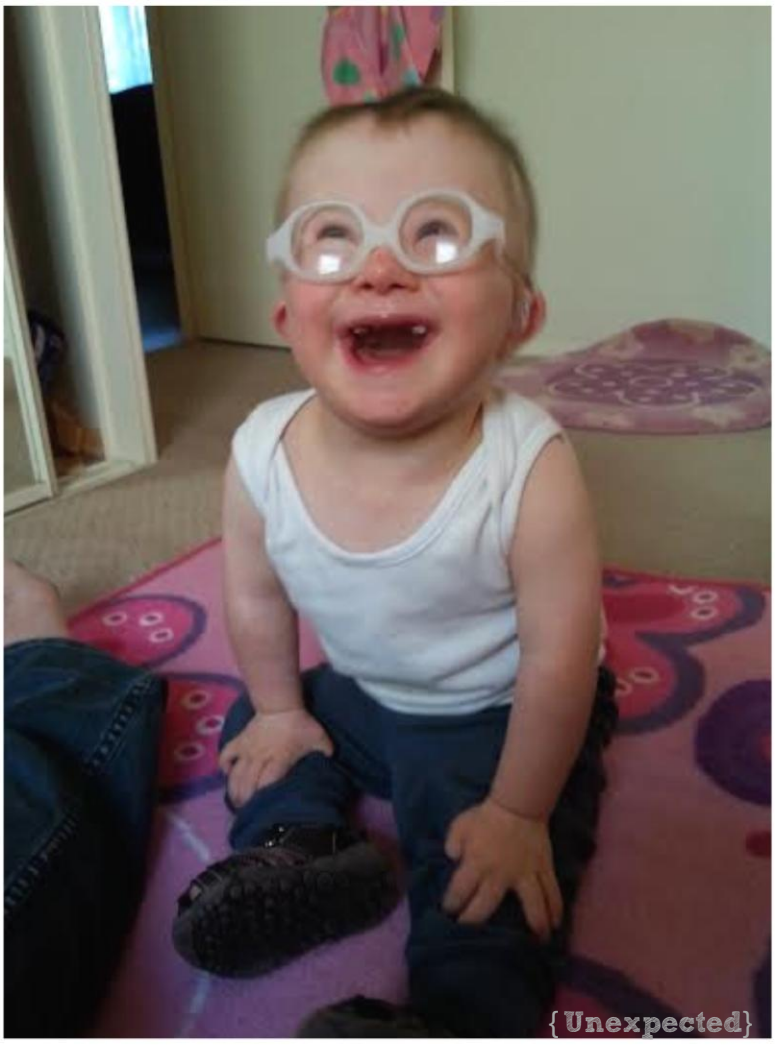
experienced teaching children with Down syndrome, but now this had become personal for me. I was now becoming the parent, the shoe was on the other foot, and I would be lying if I said I wasn't scared. So, I took my mum, and we went and visited the Down syndrome society. It was the best thing I could have done. I was able to talk to a mother who had been in my shoes, and ask her all about my fears for our son's future. I also spoke to a friend and colleague at work who had an 18 year old daughter with Down syndrome, and she was honest and supportive and full of encouragement. I think it really helped me to dispel a lot of the fears I felt, and for the first time, to actually feel hope for the future.

What then followed was a pretty difficult and worrying pregnancy. Our baby boy was not growing well, and at the 28 week ultrasound, he was only measuring a tiny 500 grams. One relief, though, was that we were able to see an amazing doctor for our baby's heart, and it was confirmed that he had holes in his heart -- but it was not life-threatening. This was an immense relief.

We made it to 32 weeks gestation, and after three days in the hospital, we were asked to make another tough decision: to have an emergency C-section as our son's umbilical cord was not working properly, and he was not growing. He was born weighing 1009 grams, and went straight to the NICU, were he spent the following nine weeks and one day. The moment he was born, and hearing his tiny little screech, changed everything for me. I just felt fierce love and protection for him, and all the sadness and grief just melted away. I really felt that it was time to get over myself, to stop feeling sorry for myself, because he needed me now more than ever, and that I had to be strong for him and to fight for him. I truly believe that was the defining moment for me of accepting his

diagnosis, and seeing him as just my son... nothing more and nothing less. I got to hold him the next day, and that was it. I was head over heels in love with my little man.

Since then, it hasn't been easy. There have been many health issues, and lots and lots of doctors visits, but he makes me and my heart smile everyday day, and I am always amazed at how he makes everyone in the waiting room at all these appointments smile too. I truly believe that God has a purpose for him, as he does for every child. He is truly blessed by God and he is incredibly brave, which is fitting because that is what his name, Jacob Coen, stands for.



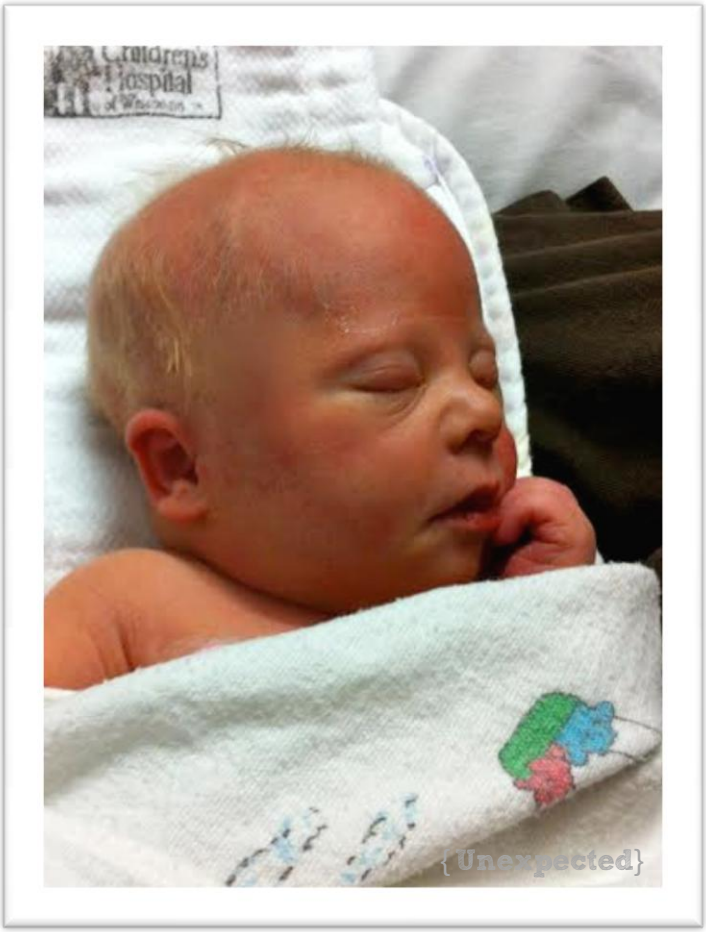
Jacob is 20 months, 18 months corrected. He still is our little man, only weighing 8.3 kg after being born premature at 32 weeks. He has sleep apnea, and is on thyroxin for an under-active thyroid. He recently got his glasses for short sightedness, and he is doing lots of verbalising with his hearing aids on. He is crawling, but we call it the caterpillar crawl, because he crawls on his tummy. He is a beautiful, happy, and content little boy. His development is taking a while, but the joy and happiness he brings to our lives far outweighs any delays or health issues. Those we

can continue to battle and fight while we enjoy having this beautiful person in our lives. His mum, dad, and big sister are so thankful for him and all the joy he brings to our lives.

~Sarah, Jacob's mum; 32; Sydney, Australia

{Edward}

In the fall of 2011, everything was starting to come together. I was 27, my husband was 31, and after two and half years of marriage, we were ready to start our family. After being diagnosed with a blighted ovum in the spring of that year we began to try again, and this time, it took a few cycles before those pink lines showed up again. When the "morning" sickness hit me, I was pretty sure that this time, things were going right. As much as I hated feeling constantly ill, I took it as a sign that there really was a life there this time around. This time, at our eight week ultrasound, we were both rewarded with the sight and sounds of our little one's heartbeat. Sure, the image looked more like a Squidbilly character than a baby, but that heartbeat was more than enough for us. Despite confirmation of a real pregnancy, I was nervous and we waited until the end of the first trimester before announcing our pregnancy to the world.



The appointment for my anatomy scan was at 19 weeks, and although there were no concerns from my OB/GYN leading up to the scan, you better believe that I was still nervous, and had been checking for a heartbeat several days a week with my own home doppler. Although I am not the youngest of my siblings, I was the last to venture

into the world of parenthood. My parents were already grandparents to six grandsons, with a seventh on the way, and no granddaughters... so you can imagine how much speculation there was regarding the gender of our child. I knew in my heart it would be a boy, and told people that the gender didn't matter as long as the baby was healthy -- but secretly kept wishing we would be blessed with a little girl.

The moment of our ultrasound arrived, and sure enough, we discovered we were having a boy. I remember feeling mildly disappointed, even though I already had a gut feeling about it. I internally repeated my mantra of "as long as he's healthy". The disappointment was fleeting, as I began to notice that the ultrasound tech was spending a lot of time focusing on the heart. While taking the other measurements she had been fairly chatty but now, as she increasingly pressed and pushed, trying to get new angles, she had fallen mostly silent. After 20 minutes or so of focusing on his heart, she told us she was going to go get the doctor so that he could try and get some different views. When she left the room my husband and I joked a little about some of the "cute" things we had seen while she was doing the measurements, like his relatively large head. I told him that it made me nervous that she spent so much time looking at the heart, and he admitted that it worried him too, but that it was probably nothing. It felt like forever before the doctor came in and introduced himself. He briefly checked the measurements the tech had done and then began to focus in on the heart. Time dragged and dragged, and then he finally announced, "There is a pathway in the heart that should not be there."

Now time didn't drag, it stopped. My husband and I squeezed each other's hands. We asked what that meant, and were told that our baby had a heart defect. He went on to say that the increased size of the nuchal fold and the shortened long bones of the arms

and legs were indicative of a chromosomal issue, most likely Down syndrome. He told us that we would need to get a fetal echocardiogram done to determine the exact heart defect, and that we could get an amniocentesis done to determine if there were any chromosomal abnormalities. We had declined prenatal screening at the 13-week mark, but being logical people and being faced with this unexpected turn of events, we both agreed that we needed to know. They did the amnio right then and there, and we were told that it would be a few days before the initial results were back, and even longer still before the full results would be available. On the car ride home, I cried, and we discussed what this would mean for our family.

It took three days for our FISH results to come back, which confirmed the presence of Trisomy 21 in every cell. Those three days were the roughest ones of our lives. I knew that I could not terminate this baby, and looked to the internet for information about Down Syndrome and what to expect. My husband wasn't sure that it was fair to our son to bring him into this world, where other people can sometimes work so amazingly hard to make sure that those who are different are denied the opportunity to thrive. In my darkest hour, I must admit that I sometimes felt the same way. After getting the FISH results, there was no point in waiting for the full results to make our decision. I told my husband that I understood if he needed to leave the

relationship, but that I would be having this baby. I will never forget his reaction: he told me that there were an awful lot of things in this life that he could live without, but I was not one of them. He told me that we were in this together, and that our baby would be wonderful and that he would always love our son no matter how many challenges we had to face together as a family. Once those words were spoken, the worry and anxiety over the future were still there, but the tension and strain on our relationship was gone and we began planning for the next step.

~Jennifer, Edward's mom; 28; Wisconsin, United States

{Jesse}

At 16 weeks, I was referred for an amniocentesis after receiving a 1:10 chance of Down syndrome after undergoing the standard blood and ultrasound tests. I had the amnio without much thought. To be honest, while my lovely GP had been sounding cautious, in the back of my mind I was thinking, "He doesn't realize, this is a miracle baby." I had been told a few years earlier that I would have to go down the IVF path if I wanted kids. Then bang, after a lovely relaxing holiday to New Zealand, I found out I was pregnant.

Our world was turned upside down, in a nice way. After being in a stepfamily situation with all its challenges, my husband and I were enjoying a wonderful equally shared experience. It was an exciting time after what we had been through.

On Friday, May 29th, 2011 -- a day I'll never forget -- the obstetrician called and said, "I have the test results and they are positive for Down syndrome. I'm sorry," he said quietly, like he was delivering a death message; and I felt every bit like I was receiving one. I felt shock and disbelief, like when someone dies unexpectedly. Time stood still, and I felt numb as I hung up the phone. Ever the optimist, I would have hung onto a 1% chance, but this was an irreversible, no-hope diagnosis. I felt stuck.

I sat on my bed and cried. When my husband got home, he just looked at me and didn't have to ask. He knew. We both cried together. I felt again that our lives were being turned upside down in a bad way. This pregnancy felt like a slap in the face. Why did I even fall pregnant if this was to be the scenario?

For anyone in my shoes right now, if I could be with you, I would say, go through what you have to and know it's normal, but trust me; it will change unbelievably. The single thing I regret the most is not having someone further down the road tell it was going to be alright... so much more than alright.

The first night was a sleepless night; and then I woke up Sunday morning, and a wonderful thing started to happen. Hope had started to slowly seep back into my heart. A Bible scripture was in my mind, and then I went to church, where this same scripture was preached. Somehow, I felt like I was in God's loving arms, and although I felt terrible, we would get through this the same way as other challenges we had faced.

When we caught up with the obstetrician a few days later, he was the first to utter the words that we would hear over and over: you have options. I looked at the photos of beautiful newborn babies lining his walls as we sat there. Not ONE of them had Down syndrome. Had every other parent taken the option, I wondered?

I will never judge anyone for aborting under the kind of pressure and negativity that surrounds Down syndrome in the medical field. You are so vulnerable during pregnancy, especially after receiving a bombshell. And if you haven't seen a living, breathing, cooing, smiling baby with Down syndrome and their adoring family, you forget about the child. None of the health professionals spoke positively about Down syndrome. Sure, Down syndrome is a condition, but what is overlooked is the person,

the beautiful baby. It was like we were dealing with a cancer, and expected to have it cut out. At times, it was a little intimidating, and I kept having to say to a room full of specialists, "Before you go on, we have decided to keep the baby." They kept making sure we knew we had options, even up to later stages of pregnancy.

One of the hardest things for us was who to tell about the diagnosis and when. My husband is a fiercely private person, and while I'd told a handful of people, he hadn't even told his family late into the pregnancy. Breaking the news was usually a tearjerker, and we would fight to compose ourselves during these conversations. What I found helpful was to ask someone else to tell people, just so I wouldn't choke on the words. Once the news was out, I could talk pretty freely about things and let people know it was bittersweet, but we were still excited.

One of the most lovely and unexpected things about this whole experience was the way relationships became closer and stronger, and wonderful new relationships opened up. The support was amazing, and one of the most helpful things was that they acted like it was not a big deal. We were spoilt with clothes and presents, and treated like something wonderful was happening, and not like the sky was falling.

It was also a powerful thing in our stepfamily situation, bringing love and bonding. Also, I look back on this time as one of the most intimate and special times in my marriage, building something amazing between us that still remains.

We knew we were having a boy, and soon after the Down syndrome diagnosis, we also found out he had a massive hole in his heart (AVSD). Our genetic counselor was very wise in organizing some visits for us to tour the Intensive Care Unit, seeing babies after heart surgery. That was tough. These days, which were so helpful later on, and also

when we had ultrasounds on the baby and his heart, were the bad days, but it would pass. Those were the days we held onto each other.

Finding out you are carrying a child who has complications of any kind is something you would never choose for your life. However, grief will be replaced with multiplied blessings. You will never be the same – in a good way. When you hold your baby in your arms, you will look at them and wonder what all the fuss was about. That's what happened to us.

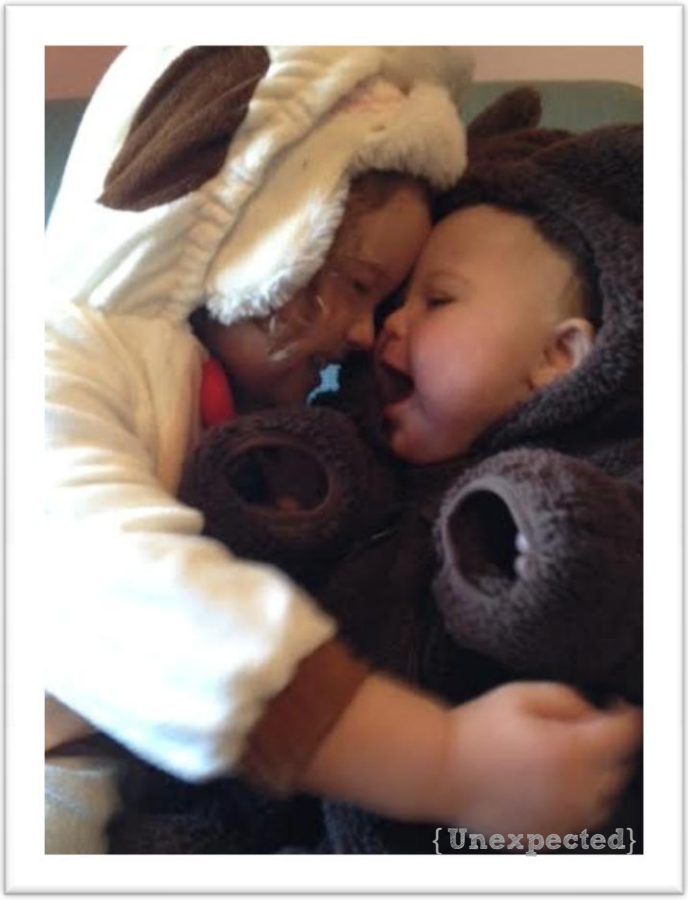
Jesse is now 22 months old. It's hard not to use cliches, but the feelings of my prenatal diagnosis seem a lifetime away. He is an absolute joy in our lives, and not a disappointment in any way -- quite the opposite. He is very cute and confident and sure of himself. He is king of the kids at childcare, and the bigger kids love him. He is clever and has a real sense of humour. Tonight he fell over in he town library and cut his eye. He cried for about a minute, then jumped out of my arms and carried on playing and giggling. I thank God I have a house full of love where there would have been a void if we had decided to have a termination. I have met a wonderful new community of Down syndrome families, and we also love our mainstream mums group and friends as well. I sneak in at night and give him big kisses as he tries to sleep through the disruption... I

can't help myself! Tonight, his eyes lit up and he smiled as I gave him a bottle on my knee before bed, and told him how he is terrific and the cutest kid in town... but to not tell the other kids and upset them.

~Jodie, Jesse's mum; 41; Australia

{Sibbie}

I had suspicions from very early into my pregnancy that my baby was extra special in a way that way that both exhilarated and scared me. I've had life experiences before that have led me to grow in ways that I may not have asked for, but have ultimately made my life very rich, and helped me to develop an appreciation for life beyond what I would have without the bumps. I had a premonition that it was time for another of these experiences. And I wasn't afraid of the challenge. Still, I did not find out for sure until well into my third trimester that I was correct: my baby did in fact have that extra chromosome that I had wondered and worried about.



I had my nuchal translucency scan done in the hospital, and was already being treated by a neonatologist in addition to a regular obstetrician due to a previous uterine surgery, a c-section and my proud title of "Advanced Maternal Age." Being a very detail oriented person, I went into my nuchal translucency scan knowing that magic number. Three. If the fluid on the back of the neck was higher than three, there may be a problem.

As I lay on the table, I had one eye on my daughter's adorable profile, and one eye on the lower right hand corner of the screen, where numbers flashed and flashed as the

tech did her work. The baby was very wiggly, and she had to measure many, many times. I saw 2.6, 2.9, 2.7, 2.9, 3.1, and then 2.7. When the neonatologist came in to review the pictures, he said all looked good. Since only one measurement out of the many, many taken was over 3, I'd passed that test. Bloodwork came next.

I got a call from my doctor a few days later. The combination of my nuchal translucency scan, my age and my bloodwork resulted in a 1:140 chance that my baby had Down syndrome. My doctor explained to me that this qualified as "high risk," but that my age had a lot to do with it, and although there were no promises, he wasn't overly concerned. In doing the math, I agreed, the chances were slim. But, in my gut, I knew.

I got my anatomy scan at 17 weeks. Everything checked out – two beautiful arms with 10 beautiful fingers. Again, the baby was extremely active, allowing for extra viewing time as the tech attempted to get all the pictures. When I visited my doctor to go over the results, he casually mentioned that there was a bit of "echogenic bowel", which basically means there are white spots present. According to him, it wasn't too concerning, and would most likely disappear on its own by the next ultrasound. It was also a soft marker for Down syndrome.

The bowel issue had not disappeared at the next ultrasound. I began to believe my gut more. This baby was special.

At the beginning of my third trimester, I decided to get a second opinion regarding an unrelated issue I was having with my doctor. I went to Dr. Hill with Ben and Raya one day after school to chat about birth options. We fell in love immediately, and promptly "broke up" with my original obstetrician. Although there was nothing wrong with him, it was one of the best decisions I've ever made. Dr. Hill took my concerns seriously. She

wanted to investigate more, and ordered another anatomy scan at her office. A week later, we learned that the echogenic bowel was still present. She called me at work the next day and offered the Harmony test. I knew all about it, but had assumed since it hadn't been offered to me, that it wasn't available in my area. Wrong. It just hadn't been offered to me.

I went to her office for a blood draw that day. I needed to confirm my suspicion. I needed to know before my daughter's birth so that I could look at her for the first time and rejoice rather that pick apart her features, and wonder if she'd cause a silence in the room. The two week wait for results was tough. I was emotional. I had a lot of "What if's?" running through my mind. My phone became an appendage. And then it finally rang. I was in school teaching a kindergarten reading group. I took that call.

"The results of your test came back. They are over 99% positive that your baby has Down syndrome." The rest of the conversation was a blur. I hung up, grabbed my essential belongings and ran to my car. I didn't make it out of the parking lot before bursting into tears. Although I wasn't surprised, I was still shocked. I drove and cried for about five minutes before I felt the most beautiful little nudge from the innermost of my body. Kicks. Rolls. My baby, unaware that anything had happened, reminding me that she was still who she was. And I loved her more at that moment than I ever had before.

That was a Monday. The days to follow were a blur. I stayed up all night, searching the web for all things Down syndrome. I called off work Tuesday, thinking I needed a day to absorb. I called an acquaintance, who quickly became a true friend in every sense of the word, who also has a baby with Down syndrome, and asked her tons of very factual questions. I talked to my family and my soul sister, who was also pregnant at the time. I

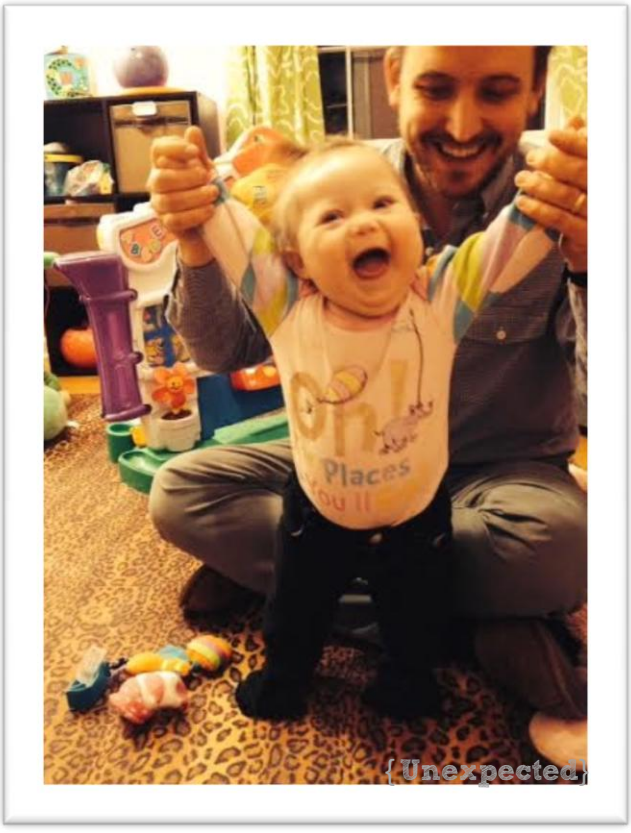
continued searching, reading, and asking questions on Baby Center's Down Syndrome Prenatal Diagnosis board. My husband jumped into action and started doing concrete tasks surrounding the diagnosis. I called off Wednesday, still in shock and unable to face the real world. I thought a lot about how others would react to this news. I hated that I knew this was news, and I needed to gain some type of control over how the information would be presented. Although I was scared and uncertain of so much, I did know that nothing at all had changed in the level of excitement I had to welcome this little girl into our family, and that in some strange way, we were extra blessed to have been granted her. I wanted to express my positivity before I sensed any whispers or pity glances as people began to hear through the grapevine. I also wanted to avoid the situation where people told me that they knew someone who had had a positive diagnosis and the baby ended up being "fine".

Thursday, I decided to send an email to those who I know love us, describing what we had learned and how we were feeling. I allowed them to share the news, and simply asked for people to welcome our daughter with the same love and light that we knew they would have done anyway. Eventually, after receiving the enourmous outpouring of love, I realized that I underestimated the people in my life. On Friday, I returned to work and to the comfort of the wild, but loving, students I worked with, the supportive staff, and the three flights of stairs I walked up and down over, and over, and over throughout the day as I serviced my small reading groups.

The rest of my pregnancy was a bit stressful. I was going into my doctor's office twice a week for non-stress tests and biophysical profiles of the baby. This was primarily due to the issue that caused me to change doctors, unrelated my baby's Down syndrome. My amniotic fluid level was high, and I was also diagnosed with gestational diabetes.

Between the four daily finger pricks and the stress of the extra fluid putting me at risk for preterm labor, I was pretty miserable. During a biophysical profile, it was also found that the placenta was showing signs of deteriorating early, which is a big concern with Down syndrome pregnancies. The stress got to me, and my doctor and I decided it was best for me to stop working and focus on relaxing to hopefully keep this baby in for a while more. It ended up being the smartest move I could have made.

During the next four weeks, before my darling baby arrived, I got things sorted, I went to lunches with my dad and with friends, I put my feet up, went to movies, and ate more nuts and cinnamon than I thought was humanly possible. My sugars leveled. Things with the placenta looked good. And best of all... my sweet girl stayed safely in my womb until 38 ½ weeks.



It was a snowy March day. I was very excited because my best friend had given birth that morning to a girl. That afternoon, during my bi-weekly non-stress test, I watched as the little line that usually lay flat on the monitor make mountains. Contractions! Real, consistent contractions! I was sent to labor and delivery, where I found out within the hour that my baby would be joining us that evening. At 7:07, with her proud mommy and daddy smiling from ear to ear, Sibbie joined us with a cry so strong, it sent me to the moon! We had a NICU team in the

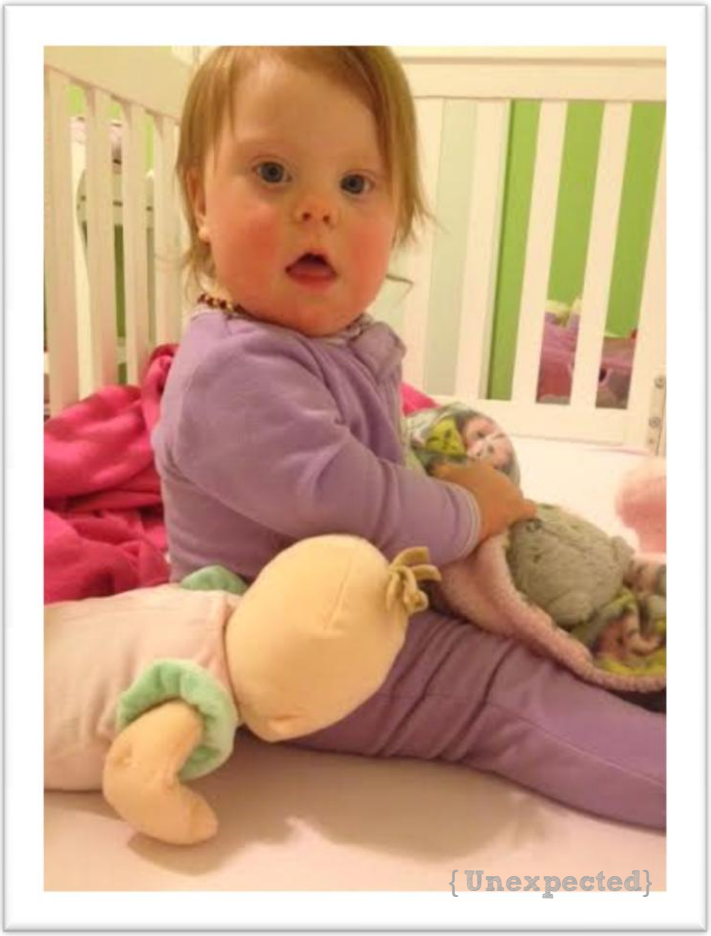
operating room with us, but after a quick check, they left saying that our daughter was doing beautifully.

She has truly been the love of her big sister's life, and is our newest pride and joy. Sibbie is four months old and already, I wouldn't change one single thing about her. She lights up a room with her her sparkly, deep blue eyes. She is the blessing I didn't know I needed, and I am beyond thankful for her presence in our lives!

~ Joy, Sibbie's mom; West Virginia, United States

{Emery}

We went in for what we thought would be quick 20-week anatomy scan at my obstetrician's office. We found out the sex of the baby four weeks earlier by paying for a 3D ultrasound. The day we saw little Emery sleeping on the screen, it was our third time seeing her, and I was thrilled when the ultrasound tech said she indeed was a girl. We made small talk with the ultrasound tech, and she said the doctor would read all the images and call us tomorrow, which is routine for their office. When she came in the room and asked how I was feeling, the next thing that came out of her mouth was, "Are you going to do the blood test for Down syndrome?" I was caught way off guard, and a little nervous, but I also wondered if it was something she maybe asked all her patients around this time in their pregnancy. We said no, just as we had declined all of the other prenatal screening tests so far. The next day, I was at work when I received a call from my doctor telling me there was some fluid on the baby's kidneys, which she wanted to monitor. After a scary Google search, we found that there could be a variety of reasons for dilated kidneys, most likely not life-threatening. When we went back in a week later for another ultrasound, again she mentioned the fluid on her kidneys had not changed, so we were referred to maternal-fetal medicine.



At maternal-fetal medicine, the ultrasound tech made no small talk. She took a lot of measurements, of her kidneys, heart, brain, and bones. There was silence in the room. When she left, my husband went over to read her screen, and most of the baby's measurements were small. He read that she had also marked down "no nasal bone". I saw the panic on his face. Then came the out of body experience that would continue for the next 16 weeks. The doctor came in and introduced himself. Then he told us, "Your baby has what we call soft markers for Down syndrome." We were in shock -- we wee only there for a little fluid on her kidneys, and I was only 29. He explained the absent nasal bone, echogenic intracardiac focus on her heart, overall measurements where she was measuring small, and the fluid on her kidneys were all the reasons he had his suspicions. He recommended that we undergo an amniocentesis, and we agreed. During the amnio, I felt completely numb. They said we would have the results hopefully within two days. We went home, cried, called some friends and family, Googled, and prayed that we were one of those people who has a scare like this and everything comes back ok. Overall, I wished we could push fast forward to hopefully put our minds at ease. I was clinging onto hope that this was all a false alarm that our baby indeed did not have any abnormalities.

Two days later, it was the Friday before Memorial Day. I went to work like I was scheduled. Around 3:30 pm, I received a call from the doctors office. When I answered, I told her I was still at work, and I would call her when I got to the car. I called Jeremy to tell him I finally heard from the doctor's office. I called her back, and she immediately said, "I'm sorry. Your baby does indeed have Down syndrome." She said we needed to set up an appointment in their office with the genetic specialist to go over our options. "What options?", I asked. "Options to continue on with the pregnancy or not," she

replied. I really had no clue abortions were even allowed this late in pregnancy. Well, apparently we were one week from the cut off, which was 24 weeks, and this is why they had pushed for an amnio.

I called my husband on my way home. Before I got home, he had called both his parents and my mom. Bless him for making that call -- I was not in the mood to console anyone, and I am not the type of person who likes to be consoled. Great combination, right? The second phone call I made was to our son's pediatrician's office. Looking back, I was in freak-out mode, knowing that these current doctors would disappear in the next couple of months, and we would be reliant on the medical advice of our kids' doctors. I think I just needed to know that we would have medical support after she was born.

The first person we had face-to-face interaction with in the medical community after her diagnosis was the genetic counselor. I can honestly say I hope to never see her face again. As we both sat in her office, she told us old-school textbook horrible stereotypes. One example she mentioned was that Emery would not be able to ever know that when it rains, she needs to take cover. Well, after that horrible experience, I can honestly say that the rest of my pregnancy was filled with positive interactions, and the most supportive friends and family.

Something we realized fairly quickly was that every family with a child with Down syndrome had a different story. Every baby was different, too. Down syndrome does not define these kids, they are all individuals just like every other person. They are people who just happen to have Down syndrome.

~Julia, Emery's mom; 29; Georgia, United States

{Davis}

It was a Monday morning in November, slightly warm but otherwise monotonous. I awoke as my husband left for work, gave him a kiss goodbye, and began to get ready for work myself. As I brushed my hair, applied my makeup, and listened to the morning radio, I looked at my round belly in the mirror; I was nearing the end of my second trimester with my first child. I imagined what my baby looked like; maybe he already had hair, maybe he was long and lean like my husband, maybe he had my eyes... and maybe his little heart was beating strongly inside me, regardless that it wasn't properly formed.

The ultrasound performed two weeks prior confirmed the diagnosis of Atrialventricular Canal Defect. This meant that where my baby's heart should have two tiny valves, there was only one; he would require surgery as an infant. The doctor recommended an amniocentesis to check for chromosomal abnormalities that may have caused the heart defect. I had refused blood tests earlier in the pregnancy which screen for these types of abnormalities, but after learning about the heart issue, and having only minutes to make a decision about the amniocentesis, we decided that we would prefer to know before his birth about any other potential concerns.

That day was extremely challenging. I was not mentally prepared to have a needle stuck in my belly, much less hear that my precious son would need heart surgery. I left the office in tears and spent the next few days searching for answers: How did this happen? Did I somehow cause this? What are the chances of a chromosomal abnormality such as Down syndrome? (With this particular heart defect, the chance was 1 in 10.) And then I waited... and waited... and waited... for the call that would change my life.

So on this ordinary Monday, I ate my breakfast standing in the kitchen like I always did, staring at the clock, chewing quickly so that I was not late. Halfway through the meal, the phone rang - who could that be at 8:05 on a Monday morning? "Hello?" I said eagerly. The woman introduced herself, and then said those words I will never forget: "I'm afraid it's not the news you were hoping for; your baby has Down syndrome." And right then and there, in a matter of seconds, my whole world had changed.

Initially, I was shocked. I had not prepared myself for the diagnosis; but I was relieved to have an answer as to why my baby's heart had not formed properly. Fortunately, my work and educational experiences had familiarized me with special needs, including Down syndrome. I was not afraid of the diagnosis; I was afraid of my husband's reaction. I stayed home from work with the company of my sister, and waited until my husband arrived home to tell him the news. He took it better than I expected. We got online and did some research, shed some tears, and then named our special child Davis Matthew.

Two days later, after sharing the news with family and close friends, I shared this statement as my Facebook status: "The last two nights as I laid in bed, it was as if I

could actually feel the love and prayers you are all sending our way. Maybe this is why I am able to take the news so positively. Learning that my baby will have special needs actually makes me MORE excited to be his Mommy; I feel like I know him better and feel more bonded with him... I know it won't be an easy road, but what road of parenthood is? I continue to celebrate my pregnancy and am SO excited to meet this little bundle of joy and watch him experience the wonders of life. So please, don't feel sorry for us - I don't. Share in the joy we feel as any new parent. And keep sending us peace and love!"

I realize that my reaction to my son having Down syndrome was quite positive in comparison to how other parents may have reacted. A more devastating reaction to this news is completely typical and acceptable. I was fortunate to have contemplated years earlier what it might be like to parent a special needs child, and I had decided that I would be completely okay with the scenario. After I had time to process the diagnosis, I just felt that this was my calling, this was how it was supposed to be, and this was how God wanted it to be; and I accepted it.

During the next few weeks, I visited doctors regularly for fetal echocardiograms, non-stress tests, and lots of ultrasounds. No medical expert or anyone else ever suggested that I should terminate the pregnancy, for which I will always be grateful. Despite no other issues besides a Down syndrome diagnosis and AV Canal defect, an induction was scheduled at 39 ½ weeks.

My labor was LONG. After about 40 hours, I finally pushed him out. I had a few seconds to hold his beautiful, wet, naked body to mine before he was whisked away by the NICU team. About two hours after his birth, my husband and I were able to visit him in the

NICU. We were in love, but also crushed seeing our newborn son hooked to so many machines. We went back to our room, where we held each other and cried.

Davis spent ten days in the NICU. His primary issues were actually the result of a pneumothorax, which is a little air pocket in the lung, that sometimes happens with vaginal deliveries and, according to the doctors, had nothing to do with his heart defect. The pneumothorax combined with the way that his heart worked led to low oxygen levels. I cannot even tell you how many times I heard that oxygen monitor beep during our NICU stay! But the NICU was not a scary place. My only complaint is that the NICU is not very conducive to establishing a healthy nursing pattern because of feeding schedules, time limits to feed, and the need to measure how much is consumed. Therefore, nursing was quite a challenge, and his low muscle tone and heart defect made it even more difficult; so I pumped.

I resided in the hospital during Davis' NICU stay and walked the halls every three hours to feed and snuggle him. After our visits, I went to my room to pump, walked the milk back to the NICU, and spent the rest of my time sleeping, eating, etc. It was a very lonely, frustrating time for me. But I got through it, and was finally able to bring my adorable, sweet baby boy home. However, this was nowhere near the end of our medical journey.

Davis' pediatrician and cardiologist kept a close eye on him over the next six months. We began medication when he was a few weeks old in order to combat the effects that the heart defect had on his body, so that he could wait for surgery until six months of age. Davis was actually quite a healthy eater, and gained weight appropriately. When

he was six and half months old, he had his heart surgery at Vanderbilt Children's Hospital.

The AV Canal repair, in very basic terms, involves making one valve into two. It is a very intricate surgery which has the possibility of resulting in all sorts of complications. The first forty-eight hours after surgery were extremely rough, and involved lots of scary moments. But believe it or not, we were only in the hospital for eight days. Somehow, I made it through those days. I blogged very openly about it, but even now, I have a hard time thinking about this time in my life, and looking at his pictures and what I wrote is heartbreaking. All I can say is, you just do what you have to do. You educate yourself, keep an open mind, think positively, and count your blessings.

Caring for Davis after surgery without the help of doctors and nurses was also very trying. I had zero medical experience, so the administration of medications, including an injection, was terrifying for me. Each day got easier, and each day Davis got a little closer to being himself again. After a few weeks, you could not even tell that he had been through such a trauma. His physical and emotional bruises had diminished, and his happy, carefree, sweet spirit was back!

Davis's heart repair was not a complete, perfect success; but it is good enough for now, and he is no longer on any medications. He will continue to see a cardiologist, and may have heart problems as an adult. But for now, he is absolutely thriving. He remains low on the typical growth chart, but above average on the DS growth chart. He receives early intervention services, physical therapy once a week, and occupational/feeding therapy twice a month. Davis is a social bug, and enjoys music class, play gym class, church nursery, play dates, DS support group outings, and a typical preschool program which he attends twice a week. He also enjoys books, Elmo DVDs, the outdoors, and anything involving a ball. He is learning sign language and already knows and initiates several signs.

Davis is an absolute jewel. I know I am his mommy and quite biased, but others feel the exact same way about him. He lights up a room and steals the show. There are countless people who have been positively impacted by his existence, and it makes me happy and proud to say that he has touched lots of lives already within his short life. Our journey has led us to meet some absolutely wonderful people along the way, and our lives are better because of that as well.

I hope that by sharing my experience, I can reach others who would otherwise not have known our story, and show that despite some of the scary stuff that Down Syndrome can bring, it is all worth it, and the joys far outweigh the pains. No matter who you are or what challenges life has brought your way, your ultimate path may be different than the one you had planned, and that is okay. Having a child with Down Syndrome is an incredible journey for which I will always be thankful. If I could revisit myself on that Monday morning knowing what I know now, and give myself some words of advice, they

would be to let go of expectations, have faith that everything will be okay, and trust in the beauty of every day.

~Kari, Davis' mom; 32; Tennessee, United States

Blogging @ happyheartofdavis.blogspot.com

{Jonathan}

On March 21st, 2012, I got the call I had been dreading. I knew it was him -- the doctor who would give me the news that would change my life forever. He had told us, quite unsympathetically, that we would only hear from him if he had bad news. So when the phone rang, and his number popped up, I knew.

Later that evening, as my husband and I sat prayerfully and tearfully considering our future with a child with Down syndrome, a sense of peace and calm settled over me. I started to count my blessings, and realized I had them in abundance. I had a beautiful family, strong faith, and caring, supportive friends. I could feel my baby boy moving and stretching and kicking in my ever growing belly. He was strong. I could feel it. I knew he was a fighter.

I began my research and information gathering in earnest. I learned everything I could about Down syndrome. I learned to cull out the often negative, outdated and archaic stereotypes. I learned to choose doctors who supported our decision to cherish our unborn child, and give him a chance at a good life, and to dismiss those who didn't. I learned to lean on the support of so many other mamas who had made this journey before me. I found comfort in the kindness of complete strangers, through websites and

blogs and on-line support groups. I networked with families in our area who had children of varying ages and abilities with Down syndrome. I looked at these beautiful kids through new eyes; through the eyes of a mother. I learned how frustrating it can be to have such little control over what's happening in your own womb, and yet how preparation for what is to come can be so therapeutic, and can make you feel as if you are reclaiming some control. I learned who my truest friends were, and how to deal with those whose response to our situation was unintentionally hurtful. I learned the meaning of true, unconditional love, and the fierce protectiveness one can feel towards her unborn child. I learned to hear the ugliness in words commonly misused – like the "R" word. It took on a totally different meaning for me, and I learned that it's not enough to say you don't like unkindness, bullying or exclusion of someone different, but that you have to take action to affect change in people's perception, because now it is personal.

When Jonathan arrived on July 22nd, 2012, I was unconscious. He had to be taken by emergency C-section with me under general anesthesia because we had lost his heartbeat. I remember my last thought as the anesthesia was taking hold: "Please save my baby." When I opened my eyes, through my fog, I asked where he was. Had he made it? "He's beautiful," my husband said, "he's perfect." And in fact he was. When I finally held him 24 hours later, my heart melted. His almond-shaped eyes, perfectly pink rosebud lips, button nose and wispy mohawk were so beautiful. His tiny 4 lb body fit perfectly into my arms. He was no longer a diagnosis. He was my baby, and his Down syndrome seemed such a small, insignificant part of him. He was welcomed into our family by his proud parents, a brother and a sister who adore him beyond measure, and a host of other family and friends who have never left our

side. He has grown strong, is smiley and giggly, loves Goodnight Moon, and to be tickled under his ribs. He's a big fan of sweet potatoes, and has a fondness for Elmo. He hates to be alone, and thrives on the abundance of snuggles he gets every day. He loves to sit up, and is working on perfecting his roll-over skills. We don't know exactly what the future holds for Jonathan, but whatever the case, he'll never have to walk alone. We will be his staunchest advocates, his fiercest protectors, his loudest cheerleaders, and his biggest fans.

I've heard it said that there are moments which mark your life, moments when you realize nothing will ever be the same, when time is divided into two parts – before, and after. March 21st, 2012, which ironically was World Down Syndrome Day, was our before and after moment. As we approached March 21st, 2013, I reflected on how our life has been after, and I have to say, it's been pretty darn wonderful.

~ Lara , Jonathan's mama; 43; Georgia, United States

{Audrey}

Our journey began at the 20 week anatomy scan ultrasound. Being my first pregnancy, I didn't know what would seem odd. The tech didn't mention anything to me, but when I went up to my see my obstetrician afterwards, she mentioned that she wanted a more detailed picture of the our little girl's heart. She made everything sound so casual that I didn't see it as a red flag, especially when everything else was normal on the ultrasound.

A week later, I was seen by a perinatologist for a fetal echocardiogram. After being there for a good while, the nurse left the room to get the doctor, and I knew something was wrong. The doctor told me about a white spot on the baby's heart and how it was a soft marker for Trisomy 21. She proceeded to tell me about a new non-invasive test called Harmony, and without even thinking for a second, I told her that I wanted to have it done. When I left the clinic, I called my husband, my sister, and my best friend. My husband assured me everything would be "normal", and quickly began searching the internet for information on other people's experiences. I only went on BabyCenter and asked on my birth club, which didn't really help. At the time, I didn't know that the Down syndrome Pregnancy board existed.

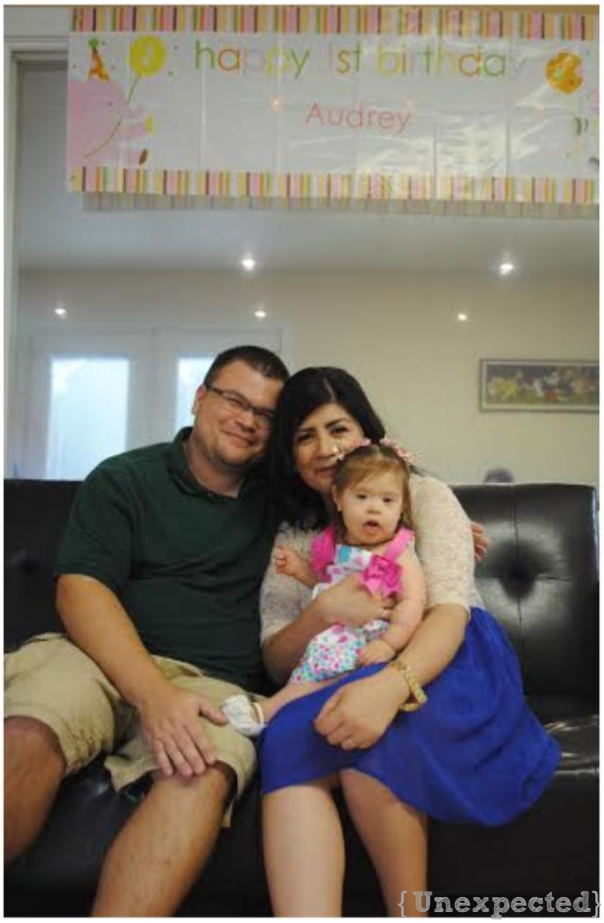
After a couple of weeks, I still hadn't received any results, and I began to think no news meant everything was fine. The clinic finally called to say I needed to go back so they could draw more blood and do the test over, because the results were inconclusive. I was angry and my blood was boiling. How could they put me through this again? I even considered not going back at all! Another two weeks went by, and then I finally heard from the doctor. She told me my pregnancy was high risk for Down syndrome, and that I needed to go in and be counseled. I had to go to work that day, right after receiving the news. The entire day I was lost, devastated, and even started doubting this new test. My best friend told me I should seek a second opinion, but somehow I knew it would be a waste of time. There was nothing to do.

In the first moments of telling my husband, he was very reassuring, supportive, and confident that our little girl would be fine no matter what. He and my sister were so accepting and ready to love this baby, and they really kept me together. When we saw the geneticist, I felt like it wasn't very helpful. I just kept telling her I didn't understand why. I told her I thought it was based on my age or family history -- at the time, I was 26, so I thought my age was not a factor. She began to take information about our families to make a family tree. It was so useless, I thought. I cried so much during the entire appointment, and so much on the way home that my husband had to drive. The young geneticist gave my husband a folder full of literature. He read everything when we got home. He said, "Our daughter will be fine, it's just going to take her a little extra time to do and learn things." I admire him to this day for being so calm and understanding.

I shared the news with my best friend and my boss. That was it. My husband and I decided not to worry our parents yet, and tell them after she was born. I cried every day.

Anytime I saw a kid, I would have negative thoughts of our baby not being able to do something because of the diagnosis. How silly of me!

On Tuesday, October 2, 2012, I began having contractions in the morning, and I stayed home because I knew it was time. I had a peaceful pre-labor at home, just walking around, taking baths, and preparing my hospital bag that I had left until the last minute. Around 8:30 pm, I had to go labor and delivery because I knew I was close. I was admitted at 5cm dilated, and I informed all the nurses and the attending doctors of my diagnosis. The night went so fast. I kept telling the nurses no medication, but they kept pushing for an epidural. The pain was brutal, but I made it through like I had planned. By 3:10 am, they said I was ready to push. Everything was very smooth and fast, and it all felt like a dream when I heard her cry. When I finally heald her in my arms, she looked up at me and greeted me by sticking her tongue out! I knew it when I looked into her eyes, the diagnosis was right, and it didn't matter. She was a dream, a little being so perfect, I would've never imagined her.



After the family and friends met her, my husband and I still stayed quiet, and decided to tell them later. We just didn't want to make a big deal about it yet. Plus, the attending pediatrician said she was runnig a chromosome karyotype just to make sure, saying,

"It's hard to tell in newborns." It didn't really sink in with me because I was so in love with this amazing little person that I carried and finally met. I was in love no matter what.

I think it finally hit me when the pediatrician called me with the results of the karyotype. Then it all became real, and my brain began to process what my heart already knew. As it all became real, I had to begin my quest for information. I wasted four and a half months, and I really regretted not preparing more, and just accepting it. Thankfully, my parents were very accepting and supportive. They gave me so much confidence that Audrey was really going to do great. We were blessed with a healthy baby that thrived from day one.

Today Audrey is 11 months old, and we are grateful for a year full of good health. Her personality is blooming, and she shows no sign of being stopped by an extra chromosome. She's crawling, wanting to get into everything, loves to dance, is very sociable, and has the best laugh. We have worked hard to get her where she is, but we still have loads of fun. She's my life, and I try not to worry or think too much about the future. I just focus on each day, and enjoy every second.

~Magaly, Audrey's mom; 26; Texas, United States

{Alex}

"There are multiple complications with your baby." With those words, the world stopped spinning. I floated outside of my body, and I entered a new reality that was no longer filled with joy and anticipation, but instead was dark and scary and unknown.

I was 3o weeks pregnant. I had wanted to have a baby for what seemed like forever. I knew I was destined to be a mom, and finally, after a few years of getting everything in our lives in order, two pink lines showed up confirming we were going to have a baby. I was elated, and began to visualize what this new little baby would be like. Would the baby have his daddy's curly hair? Would he have my big brown eyes? What would his profession be? I planned the perfect nursery theme, picked out names, and started reading all the books about pregnancy.

My pregnancy continued for weeks with no issue. I couldn't wait for that first ultrasound, and the chance to see our little peanut growing inside. My belly began to swell. I felt a few enchanting kicks. We gathered in the ultrasound room with anticipation. And there he was, floating around in his little cocoon, waving and kicking at us. He kept his hands up by his face as if he was already playing peek-a-boo with us. The technician invited

us back in 8 weeks for a 3D ultrasound because she said that we deserved a good 3D image of our little guy. I felt so lucky to be able to come back and catch another glimpse of our little guy.

Eight weeks later, we were back in that same room, watching our baby swim and play. As we waited to meet our doctor, we stared at our black and white pictures trying to ascertain who he was going to look like. Our doctor finally called us in to his office, where he informed us he wanted us to go see a specialist in town who could do a Level II ultrasound. He remained calm, and explained that there were some minor liver calcifications that he wanted to get a closer look at. The doctor could sense our anxiety, and downplayed the severity of any potential issues, even when my husband asked for the worst case scenario. After some quick research, we convinced ourselves it was just a little bump in the road. This must be usual for first time pregnancies, we thought. We left for our appointment with this new doctor in separate cars and ready for work, because we were convinced this was just a precaution, and that within a few hours we would be on our way back to our lives and routines.

Within the hour all the hopes and dreams we fed on the last few months were shattered, and instead the reality was bleak and depressing. The doctor began to go over each complication one by one. She started with the duodenum, and pointed out how it made a double bubble, indicating a blockage. She ended with the heart that was only half formed, and not pumping blood properly. She began to speculate on syndromes, and was unable to positively diagnose Down syndrome or Edwards Syndrome. She explained the differences between the two, and we knew Down syndrome was the better option. She proceeded to say that no matter the results, there was no guarantee this baby would survive the next 10 weeks in utero, let alone the trauma of delivery, and

it was highly likely we could be facing a still birth. She told me that while it was too late for an abortion in our state, she could provide me the name of the closest state that did allow late term abortions. She explained comfort care, and encouraged an amniocentesis so that we could be well informed as we weighed our options. The amnio, of course, came with a laundry list of risks -- the most threatening for me at my stage in pregnancy was preterm labor. After a quiet moment alone, my husband and I wiped our tears, embraced one another, and I entered the room where the procedure would be done.

Contractions started shortly after the procedure, and I was monitored, given a medicine to help stop them, and a few hours later, I entered the waiting room ready to go home. There sat my brother, stepdad and mom. In the mix of all the emotions, we had made a few phone calls, and those we loved were there waiting to pick up the pieces of our broken hearts. I embraced my mom, and whispered with all my strength, "Get me out of here." I looked around that room, at all the smiling expecting moms, and I knew I was no longer part of that world. I needed to be as far away from it as possible. Those moms wouldn't make eye contact with me either. They could tell we had just been given devastating news, and it was if I could read their thoughts and prayers to not let it be them. I couldn't stop asking myself "Why me? Why us?"

My mom drove me home. We didn't talk. We sat with the heaviness of the day. We arrived home, and I laid in our dimly lit living room, covered with a fuzzy blanket, and was comforted by the sounds of her cooking in the kitchen and my husband sitting by my side.

Two days later we received a call from our doctor that confirmed the news that our son would indeed have Down syndrome. In fact, he had translocation Down syndrome, and chances were either my husband or myself had passed on this gene on as a carrier. We clung to hope that translocation meant higher functioning. For a moment, we were relieved that we had avoided the more devastating diagnosis of Edward's syndrome. But of course, the questions of his health and complications remained. My husband and I both had seen that half heart, and heard the bleak prognosis of survival. We returned to work, we decorated for the holidays, we tried to entertain friends. We made phone calls to our family and closest friends. But mostly we clung to one another in our own ways, taking turns being the strong one when the other one needed us to be.

I dealt with guilt and blame. I had pushed for this baby, and painted a lovely quaint picture of a family for my husband, who was not as certain that a baby was what he wanted. I knew he would make a wonderful father, and dreamt about teaching him or her to play ball, Christmas mornings, trick-or-treating, sandcastle building, and little kid giggles. He loved me, and agreed that a baby should join our family. Still, I apologized to him for ruining our lives. Knowing that our son had translocation Down syndrome, I knew I was the carrier, and that I was to blame for this whole mess. I couldn't believe my doctor when she told me that neither I nor my husband were carriers, and that this was just a random act. But the question of why remained. I had done everything right -- went to college, had a growing career, fell in love, got married, and now was my time for a family. I deserved a "normal" baby just like everyone else. I cried myself to sleep on many nights, for the reality that the weight of parenthood now came with a whole new set of rules and responsibilities.

We started having numerous doctor appointments. We picked a hospital that was two hours from our house, but Johns Hopkins was known as one of the best hospitals in the country, and was the place for our son to be born. We met with surgeons who explained how they would repair the duodenal atresia on the first day of life. We toured the NICU, and had time to ask doctors and nurses there what to expect. I went to the doctor twice a week, and sat with a monitor hooked to my belly so doctors could monitor his heart rate, movement, amniotic fluid level, and monitor my progress. We had weekly ultrasounds where every nook and cranny of my baby was checked and rechecked. We had a fetal echocardiogram to check the progress of his heart. We sat in a dark room, where a silent technician took pictures of our baby's heart. I couldn't even watch the screen. I laid there quietly wiping my tears, trying to figure out how this had come to be my new reality. One of the best pediatric cardiologists in the country entered the room a bit later, hopped on a stool, and ignited a turning point for our journey when she said the sweetest words I had heard: "I'm looking at a fairly normal heart." She explained that it was possible that there might be some small holes, but nothing that gave her too much worry for the time being, and that she would see us again once our little one was born. A huge weight left our shoulders that day. Maybe, just maybe, this little one was going to live. Maybe, just maybe, everything was going to be ok. We didn't know how his heart had gone from being half formed to nearly perfect in just four short weeks, but we accepted the news with joy.

I started researching. I read blogs and memoirs written by moms of children with Down syndrome. I looked at pictures of babies with Down syndrome. I joined online support groups with other moms around the world facing my same reality.

Slowly a new vision formed in my mind. Gradually, our world seemed less dark and depressing. I would lie on the couch each night and feel my baby boy kicking and stretching. We started to laugh together again. My husband and I started talking about the things our son would be able to do. We talked about how much fun Christmas morning would be, and trick-or-treating, and sandcastle building. I started asking myself, "Why not me? Why not us?" I knew we would love this little boy. I knew we would teach him and support him no matter what. We wondered again would he have his daddy's curly hair or my brown eyes. We wondered what profession he would have. I planned the perfect nursery, and we researched the meaning of names until we settled on the perfect name. We couldn't wait to meet our son, Alex Daniel.

At exactly 38 weeks, I woke up with a new and intriguing pain in my abdomen. It didn't feel like anyone had ever described labor pains to me before, so I went about the day as normal. Throughout the day, I would stop as the pain would persist and then subside. We wrote the times down of the pains, but there was no pattern to them. Friends and family called to check on me throughout the day, each insisting we head to the hospital. We talked about it, but questioned the two hour drive. What if I wasn't really in labor and we drove two hours for nothing? Finally, after much deliberation, we decided it was better safe than sorry. We grabbed our already packed bags and headed for the hospital. We ran through a drive thru to get something to eat, and both of our phones started ringing off the hook. Within about one hour of the drive, it became clear that I was indeed in labor. The pains became more intense, and I was no longer able to talk through them. I glanced at my husband and he started to pick up the speed. We devised a plan for arrival at the hospital, and figured it was best to take me to labor and delivery, and then deal with the car.

We pulled into the curved driveway of the hospital, and when I stood up, my pants were soaked. I assured my husband I could walk myself the few steps to the elevator and that he should park the car and meet me upstairs. I waddled up to the desk, and with great excitement and a touch of fear informed the lady at the front desk of labor and delivery that I thought I might be in labor. They helped me to a room, and within a few minutes, my husband joined me. Nurses were in our room cleaning up the large puddle I had involuntarily made on the floor, and informing me that I was eight centimeters dilated.

We were quickly wheeled to a birthing room, and greeted by doctor after doctor and nurse after nurse. The NICU staff came and introduced themselves. I signed the waiver to receive an epidural. Contractions continued quickly and intensely. I didn't have the mindset to stop and count the people in our room, but at one point, there must have been 15 people total. Eventually, it was just me and my husband alone in the room with our fears and excitement. It was at this point, with no epidural, that I felt my son begging to enter this world. "He's coming, he's coming!" was all I could say. Soon, the doctors and nurses returned and told me it was time to push. I didn't think I could do it without the epidural, but the encouragement of my birthing team convinced me otherwise, and I realized that there was no going back. It was time to push. It was time to meet my son. There were pushes and screams and deep breaths and declarations of "I can't do this!!". They told me there was progress, and that he was crowning. Above all the commotion, the doctor forced me to focus, and explained that I had to get him out on the next push because his heart rate was dropping. She said if I didn't get him out, they would have to use a vacuum assist.

My mind flashed to the image of that half formed heart. My heart filled with fear. I remembered the words of our doctor telling us it was very likely our child wouldn't survive delivery, that he might be born blue and not breathing or not have a beating heart. I couldn't let this happen. I couldn't have come this far, fallen so madly in love with this unborn child, to lose him now. I instructed the doctor to use the vacuum now. I yelled at her to do whatever she had to do to get him out. And with that next contraction, he was out. I breathed with relief for my own body, but I couldn't hear Alex. The nurse next to me asked if I could hear him, and when I told her I couldn't, she yelled above all the noise for everyone in that room to be quiet so that mama could hear her baby. The sweetest cry I had ever heard came from across the room and filled my ears. I laid back against the pillow, filled with thanks for the first hurdle accomplished.

My husband crossed the room to sneak a peek. He told me he wasn't blue, that he was doing great, and I prepared to deliver the placenta. The placenta cord snapped, causing a look of confusion on the fellow, and the placenta remaining inside. That's when the resident explained that I would have to go to surgery. I begged to hold my son before I went.

They wrapped the most beautiful boy up in hospital blankets, and placed him in my arms. We posed for the first family picture. I looked into my little boy's eyes, and the love I felt is indescribable. I wish I had studied his face more. I wish I had whispered my promises to be the best mom ever to him. I wish I had cherished the weight of his little body in my arms. I didn't know it would be another nine agonizing days before I held him again.

I awoke from surgery to find my mom and brother sitting with my husband. They had all been to visit with Alex, and spoke of how beautiful he was. My mom told me how he grabbed her finger and stole her heart. I couldn't wait to go to his bedside.

The next morning launched me into a world I could never have dreamed of. I thought I was prepared. I had toured the NICU, I had met with doctors, I had asked questions. I knew what to expect. But nothing can fully prepare you for the despair you feel when your newborn baby lies in the NICU, hooked to wires and cords that beep and send chills down your spine.

We thought we would be preparing for surgery to fix the atresia. All the research we had done explained that once the atresia was repaired, it was a matter of learning to eat, and then we would be on our way home. We soon learned of a new challenge our little warrior would have to face. He didn't have enough platelets, and we didn't know why. Tests were ordered. I was about to be discharged from the hospital, and plans for where we would stay began. We found a hotel with a reasonable price, and my husband and I joined my mom in a double hotel room. The night I left my son behind in the hospital is a night I will never forget. I begged to go back. I had to see him one more time. We overpaid a taxi fee just so I could hold his hand one more time. No mom should have to leave her newborn baby, it's unnatural. Soon though, this became my new normal.

Soon I was waking at 5:00am to pump and catch the first hotel shuttle to the hospital. Bags would be packed for a full day of the hospital. I sat by his bedside as long as I could. I held his hand all day long, only letting go to go pump every 3 hours or eat lunch. If I couldn't be there, then someone else who loved him was ready for duty so that he wouldn't have to be alone. I cried each night as I had to catch the shuttle back to the

hotel. I would grab a bite to eat and a few hours of sleep. I would pump some more. This was the one thing I could do for my son. He may not have been eating my milk yet, but I could provide him with a stock of nourishment when he was ready. I had a sense of accomplishment as I filled those little 2.5 oz bottles by the hundreds. Our day revolved around rounds. We forged relationships with nurses, and attempted to give a halfhearted smile to the other moms and dads we saw coming and going. We saw babies come to the NICU, we saw moms and dads take their babies home from the NICU. We waited for test results about platelets. We waited for surgery. My arms ached to hold my son. Family and friends came to visit when they could. Surgery was postponed longer and longer.

One day, a new set of doctors showed up by our bedside. They smiled and seemed nice enough, until they told us their specialty: oncology. "ONCOLOGY?!", I thought. "Why are they here? Make them go away! I don't want to be talking to an oncologist!" Our son was merely a few days old, how could his little body have cancer already? They explained the reason for low platelets. On this day, a few new words entered my vocabulary: Transient Myloplerative Disorder, or TMD for short. On this day, I learned that there is always another wild card to be played. As scary as it seemed, TMD was not the death sentence I thought it was. It was rare, but it should go away on its own. Unfortunately, it would place my son at an even greater risk of developing leukemia within the first four years of his life. When the doctors left our bedside, I clung to my husband in full despair, unsure of how much more I could take. He was once again my rock, reassuring me we would get through this.

On day 11, they prepped our warrior for surgery, and on day 12 we walked behind his bed all the way to the surgery door. The hours ticked by, and we waited for news that

the surgery was over. Time seemed to stand still, but eventually, we got word that he did great and was recovering. We ran to his bedside. Within days, he started to heal. He started eating. He started getting stronger. We waited eagerly for that first poop. With help from nurses and lactation consultants, and to the surprise of some doctors and fellows, our boy learned to nurse. It was such a tender feeling to have him nestled against my skin as he drank the nourishment intended for him. I finally felt like a mother.

On day 22, they told us we were going home. We were filled with joy. We couldn't wait to take him home, to see his room that we had prepared for him, to introduce him to his dog. We were also filled with fear. How could we be ready to take this tiny fragile special baby home? What would I do without the nurses there to help me? We strapped his tiny body into the oversized car seat and drove the two hour drive to our new life as a family of three.

We settled into as much of routine as new parents can. We entertained family and friends who had been eagerly waiting to welcome us home. We napped when Alex napped. I got up several times a night to nurse a hungry boy. Then we had to make a first monthly required visit to the oncology team. TMD came with the requirement of monthly blood draws by the team, so we could stay ahead of any threats to his body. We placed our tiny boy in his oversized car seat, and made the two hour trek back to the hospital. They stuck his tiny arm with a needle, and he screamed while they drew blood. Doctors entered the room and start talking to us about bilirubins, and how Alex's were way too high. They questioned the effectiveness of his liver. The doctor explained a sepsis liver to us, and once again, questions of survival became the topic of choice. We were readmitted for more tests. Our warrior had more battles to face.

We worked with more specialists, and tried to remain calm as once again, our little boy was threatened and challenged. Doctors ordered more tests, and severe threats such as biliary atresias were ruled out. We were placed on a heavy dosage of oral medicine and monitored weekly.

One day, our liver specialists released us from the liver clinic with a healthy liver. We returned home and fell more and more in love with our son.

We found pleasure in watching Alex conquer the littlest challenge. The day he first smiled, giggled and rolled over gave us the greatest joy. Each day, I would look forward to spending some alone time with my son. I would sit and rock him for hours. I studied his features. I fell in love with his almond shaped eyes and his palmar crease. I would kiss the flat spot above his nose, confess my love, and give thanks for this beautiful child. The months continue to go by, and the baby that we thought would be so imperfect, that we feared would be such a burden, has proven time and time again to fill our lives with nothing but joy and happiness.

Today, Alex is a happy and thriving two year old boy. He is getting stronger each day. He uses over 50 signs, and some words to communicate his wants and needs. He loves to play ball, dance to music, and read books. Nothing makes him giggle more as

bubbles and balloons. Our lives are so much better for having him in it. I still rock him to sleep nightly, and often end up wiping away tears because I am so filled with love for this person. The number of his chromosomes truly are not important, but the love he brings to this world is unexplainable and irreplaceable.

~ Megan; Alex's mom; 34; West Virginia, USA

{Sophia}

The sonographer ran the transducer over my belly. I was 16 weeks pregnant with baby number three, something I had not planned for, but it was a lovely surprise and I was looking forward to being a mum again.

"I'm sorry Mresa, we can't seem to find the bottom valves of the baby's heart. Can you come back tomorrow so we can try again?" asked the sonographer. I just shrugged and said "Sure, I'll make an appointment now."

I went back the next day and again, the sonographer could not find the bottom valves of bub's heart. I thought this was weird, but no one said anything. I asked if everything was ok, and they assured me everything was fine. I was recommended to a specialist who deals with this kind of thing. Still totally oblivious to anything, I made the appointment to see Dr. Dickinson in a month's time.

A month later, I was lying on Dr Dickinson's table, and she was doing an ultrasound on my baby. By this stage, I knew I was having a little girl, and I was so excited. I already

had her named: Sophia Louise. I was in my own little world when I heard words that I had not prepared for: hole in heart... open heart surgery... Down Syndrome.

I looked at Dr Dickinson, and said to her "What are you talking about? My baby is fine, the lady at the hospital said so!" Poor Dr Dickinson was mortified. She said, "Melissa, don't you know that your baby has a hole in the heart?" I was shell-shocked. I was so sure she had the wrong person, and told her that it couldn't be right. She then pointed out the hole, and said, "Your little girl is going to need to have open heart surgery at some stage." I could not believe it, but then I remembered 2 other words, and said to Dr Dickinson, "I think you mentioned something about Down Syndrome." She looked at me. "Yes, I think it is very possible. With all the factors I have -- your age, the shortness of your baby's limbs, the heart issues -- I would say you have a high chance of having a bub with Down syndrome."

I felt like I had just been slapped in the face. How could she say that? Things like that don't happen to me! She suggested we do an amniocentesis, as when my baby was born the doctors would need to know everything about her. So I booked in to have an amnio done in a few weeks time. By the time I had it done, I was 25 weeks gestation.

Dr Dickinson rang me herself. It was a Tuesday afternoon. I answered, and could tell by the tone of her voice what she was going to say. And she did. She gave me some phone numbers, and I made an appointment to see her in a couple of weeks for another scan.

I hung up the phone. For as long as I could remember, every time I saw a child with special needs I would think to myself, "Thank God that's not me, I don't think I could do it." Was this punishment for not wanting a child with special needs? This was not fair.

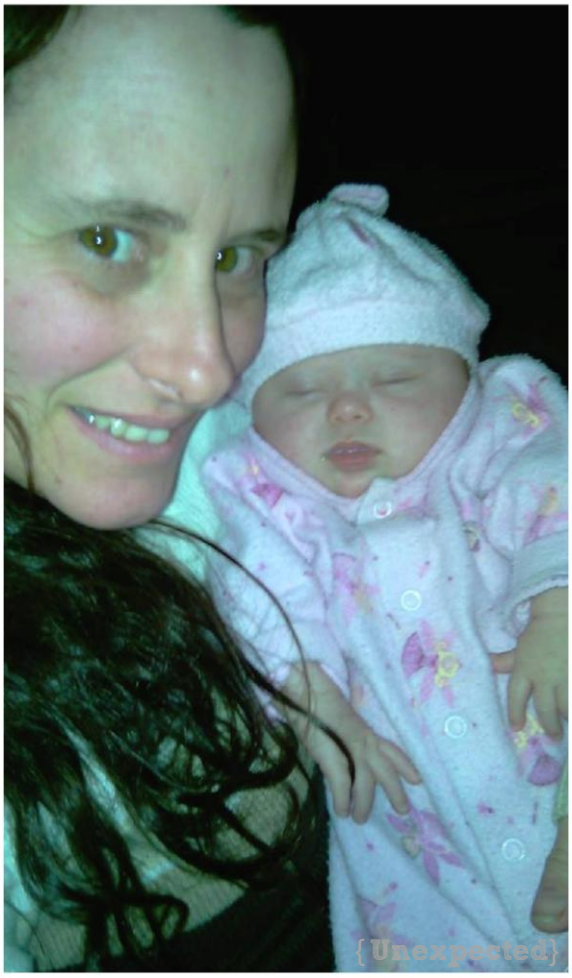
I decided to go shopping. I have no idea why, but I just felt like I needed to get out of the house. I went to Belmont Forum, and there were babies everywhere. I hated the women who had these perfect babies. Mine would be different. How was she going to fit into a society that doesn't like different people? Would I have the capabilities to raise her like I did with my other two children?

I researched all I could on her heart issues, AVSD, and Down Syndrome, but by the end of it, it was so much information overload, that I had to take a step back. I found that it was the best way to be. I kept it quiet to start with, and I only told immediate family and very close friends. Sophia's father had decided there and then that he wanted nothing to do with us, so he left me pregnant at 7 months, and at the time of writing this, we have not seen or heard from him. He was not happy about the pregnancy, and I think perhaps, her Down syndrome and heart issues were the final straw for him, although he has never said so.

I went to Kind Edward Memorial Hospital on June 23, 2011 for my 36 week check up. The doctor was about to say goodbye, but he asked if I had any questions or queries and I told him that hse wasn't moving as much as she used to. Alarm bells started to ring, and he ordered a scan there and then. Half an hour later, he came back out and said "Well, your little girl is doing fine, but you on the other hand... " My placenta was dying off, the blood flow wasn't the best, the cord wasn't in very good conditio,n and there was no way I was going to last another three weeks. The baby was going to have to come out now. I was horrified! I told them that I can't have my baby now, I have plans for the next three weeks! But the doctor looked at me and said "Well, best you change your plans, you're having a baby today!"

I had to get a taxi home, throw some clothes in the case, text the kids to let them know whats going, ring my mum and calmly tell her to get to Perth, update Facebook (as you do), and get back to the hospital!

My little Sophia Louise was born later that night, at 11:05 pm. She was perfect in every way. I looked at Sophia and realized there and then that I was worrying about nothing... she was going to be fine. I loved her more than I could ever put into words. Her Down syndrome? Pfft. Her heart issue took over from day one, so her Down syndrome has always come last. Most of the time, it's not even an issue.



Sophia is now two, and I look at her and can't believe how ignorant I was. I had no idea about anything of Down syndrome. I am ashamed to say that I didn't want a child with special needs, but having Sophia has opened my eyes to a whole new world that I probably never would have experienced, and I thank her every day for that. I love her so much, and would not change her for the world.

~Mel, Sophia's mum; 38; Western Australia

{Eli H.}

I was excited for this ultrasound. It was the only reason we opted to take part in a screening test. I wanted to see our baby on the "big" screen in the fancy office with the high tech equipment. I had no concerns that the baby I was carrying was anything but healthy. The maternal fetal medicine radiologist who was performing the ultrasound informed us of what he was doing each step of the way. He pointed out every ridiculously cute feature on our tiny baby. He took measurements while talking to us about everyday things like the weather. When he was finished he discussed the results with us. One measurement in particular stood out as a little high but not outside the normal range. It was the nuchal translucency thickness, the fluid beneath the skin behind our baby's neck. This is a marker for Down syndrome. He wasn't worried so we weren't either. We walked out of that appointment with 1 in 350 odds of our baby having a chromosomal abnormality, based on my age and the nuchal translucency measurement. I went to the lab for blood work without a second worry.

A week later we received a call from a genetic counselor. She left a message wanting to discuss the results of my screening test. I called my husband at work hysterically crying. Something was wrong. They said they would only call if there was a problem. I didn't

want to call her back alone so we called her together. Her words were the most terrifying I have ever heard - "The results from your sequential screen show that you have a 1 in 3 chance of your baby having Down syndrome". I have no idea what she said next. We set an appointment to meet with her the next day. I hung up the phone and cried uncontrollably until my husband got home (he left work as soon as we found out). He remained optimistic. I did not. I was devastated. The following day we listened to our options of what to do next. We decided to take the new, non-evasive blood test (MaterniT21). Then we waited.

"May 8, 2012 at 1:15pm our world changed forever. We got the call from the genetic counselor that we had been dreading. The baby I have been carrying for 15 weeks, is not healthy**. He/she has Down syndrome. What?! How can this be? I've done everything right. I don't drink, smoke, take medicine, eat foods I'm not supposed to. Why me? Why us? Cause I'm old? But I'm not old! I'm only 36. What will this do to our family? I've gotten mad, sad, anxious, confused. Will I be able to love this baby? What does their future hold? Bullying, dependence, frustration? What does our older child's future hold? Constant defending? Other people's intolerance? Jealousy? What does our future hold??? I can't even go there right now. Everyone assures us that they'll love the baby regardless and that they'll always be there to support us. Will they? Will we? Can we? I have felt thoughts that I never thought I could feel about my unborn baby. Those thoughts make me angry, sad, and feel very un-mommy like. I've prayed for forgiveness of those feelings. Can I handle this? Can my husband? Will our marriage survive? Is it worth risking? Right now, I don't know the answer to those questions. I pray for clarity, for love, and for acceptance. I pray for peace. I pray that everything will just be alright."

**Down syndrome does not make a child “unhealthy”. (This was written before I knew better.)

I wrote that journal entry a few days after we found out that our baby does have Down syndrome. It makes me sad to read it now. I felt so out of control. So desperately trying to understand what was happening. I'd go to sleep and wake up not remembering if it was a dream or real. I would pray it was a dream then remember it was not. We cried a lot. We stopped praying. We felt betrayed by God. We worried and worried and worried. We grieved for the child we thought we were having and didn't know if we could ever come to terms with the child we were given.

After three long, insufferably challenging weeks my eyes were finally opened when my OB doctor (of all people!) quoted the Bible during an appointment. Jeremiah 1:5, Before I formed you in the womb I knew you, before you were born I set you apart. All of a sudden, it all made sense to me. We were chosen by God to be this child's parents. He knows we are capable of loving this child unconditionally. He picked us for him and him for us. I walked out of that appointment knowing everything would be ok. There was a feeling of calmness and acceptance that was such a new, welcomed feeling for me. My husband still wasn't there. He was still depressed. I feared he may never get to a point of acceptance like me. But, a few days later, we named our son. He was no longer just a scary diagnosis. He was our baby. He was created out of love. He was who we had prayed for. He completed our family.

We spent the following weekend on the coast. If there's a perfect place to reflect and

gain insight, it's the beach. There, we were surrounded by peace. We were filled with love. That weekend, amongst the crashing waves and the sunlit sand, we both accepted the child we were given. Not only accepted, but embraced.

Six months into the pregnancy, we learned our baby boy had a heart defect. At first we were told it was most likely a rare and complicated defect. We felt defeated. Once again, we found ourselves angry and depressed. Again we asked - Why our baby? Why us? We were sent to the cardiologist for an echocardiogram. She found it not to be the major defect that was originally suspected but instead a hole in his heart called a VSD. This is the most common heart defect amongst children. Oddly, we felt very relieved.

Our son was born via a scheduled repeat c-section at 39 weeks. The night before his birth, I wrote him the following letter: "My precious baby. Carrying you in my womb has been a journey that has strengthened my faith, enhanced my compassion, and changed my outlook on life. Let me start by apologizing to you. I am sorry that I ever questioned my capacity for love. I am sorry that I was afraid. Please know though, I never questioned my love for you. I was not afraid of you. You are our son. You were wanted. You were created out of pure love. You are a miracle, as is every baby. I have never taken that for granted. I promise to always protect you. I promise to be your biggest cheerleader and a foundation of support. I promise to always be proud of you. I promise to help you reach your fullest potential. I promise to always love you unconditionally. I am already proud to be your mama. I am already proud of you. Thank you for changing my perspective on living. Thank you for teaching me that through the rain and the clouds there will always be a rainbow. Life is beautiful. I know you'll be beautiful too. You are the true meaning of living. I can't wait to meet you tomorrow and hold you in my

arms and tell you what I've learned from this long journey we've been on together - everything is going to be ok! With all my love, Your mommy"

I fully expected everything to go smoothly. I never envisioned that he wouldn't be placed in my arms. The surgery itself was uneventful. But, after he was delivered, he had trouble keeping his oxygen levels up. They held him up to me briefly then rushed him to the warming table. He wasn't crying. They gave him oxygen and then told me they needed to get him into the NICU. I asked my husband not to leave his side. They brought him over to me for a quick second. I told him I loved him and he was rushed out of the room. Just like that. All the anticipation turned into worry and fear. What was wrong with him? Would he be ok? So many feelings came rushing over me. I was terrified. What was happening? Was I being punished for my previous doubts and fears? I begged God not to take my baby. It turned out, he had a pneumothorax, or a hole in his lungs. The hardest part for me was being away from him while I recovered from the c-section. I had to wait 4 very long hours before laying eyes on him again. My husband stood by our baby's side the entire time, giving him comfort when he could. Eventually, I was able to be wheeled into his small room in the NICU where I was able to hold him and talk to him and pray for him. I was finally able to tell him, “Everything will be ok”. At that point I wasn’t sure if I believed those words. But, he showed us how strong he was. We already knew he was a fighter but I was hoping he wouldn't have to go to battle so soon. After seven very long, trying, tiring days in the NICU, our son was discharged. We were finally able to bring our baby home. We were ready and excited to start our lives as a new family of four.

I won't lie; the first couple of months were a struggle. Eli's heart was working too hard

too often. He couldn't keep up the stamina needed to eat. He had trouble gaining weight. It was decided that he would need to undergo open heart surgery sooner, rather than later. Three days before he turned 3 months old, we handed our baby boy to the surgical team. The minutes leading up to that were the most excruciating moments I've experienced in all my life. While he was in surgery, I actually felt an unfamiliar calmness come over me. I trusted God to watch over him and I trusted our son's amazing cardiac surgery team to care for him as if he were their own. Thankfully, his surgery went smoothly and, incredibly, we were back home in five days with what seemed like a brand new baby. He now ate with a purpose. He gained weight and thrived. He smiled often. Each time he did, our hearts filled with pride.

We have encountered other health issues since heart surgery. Our son was hospitalized for seven days with bronchiolitis at 5 months old and then diagnosed with Infantile Spasms, a catastrophic seizure disorder with a higher incidence in children with Down syndrome, one week later. There may be nothing worse in the world than seeing your child slip away. Our once happy baby stopped smiling. He stopped playing. He stopped babbling. He stopped doing what babies do. After six weeks of intensive treatment (which involved me injecting his leg with a high dose steroid daily), he had a clear EEG and was officially declared seizure free. One month later, we found ourselves at yet another specialist’s office. This time, we were reviewing a CT scan of our son's skull in the craniofacial department. Turns out, he has a very rare skull deformation called Lambdoid Craniosynostosis. One of the sutures on his skull fused in the womb. The only way to correct this is skull surgery, which he will undergo when he is 11 months old. This is NOT more common amongst kids with Down syndrome. In fact, I have yet to be connected with any other parent whose child has both. The chance of a child having

this type of Craniosynostosis (Lambdoid) is 1 in 400,000. We haven't done the exact math, but combining the odds of a child having Down syndrome, a heart defect, Infantile Spasms, and Craniosynostosis makes our son truly one in a million. But we already knew that.

Rocky Balboa once said, "Let me tell you something you already know. The world ain't all sunshine and rainbows. It's a very mean and nasty place, and I don't care how tough you are, it will beat you to your knees and keep you there permanently if you let it. You, me, or nobody is gonna hit as hard as life. But it ain't about how hard you hit. It's about how hard you can get hit and keep moving forward; how much you can take and keep moving forward." Those words feel very true to us at times. This past year, our life has felt a lot like the tango - two steps forward, one step back. But, we always keep on moving. And you know what? I wouldn't change this journey for anything. I regret absolutely nothing. Where I once felt so scared, I now feel empowered. Where I was once angry, I am now enlightened. Where I was once filled with questions, I now patiently let the answers unfold themselves to me. Each day our son amazes us - with his strength, determination, and courage.

Very recently we reached the one year anniversary of the day we got "the call". One year ago we thought it was the worst day of our lives - the ending of our life as we knew it. Truth be told, it was just the beginning. The beginning of actually living life. A second chance to appreciate the world and all that is in it. My eyes were opened the day we found out our baby had Down syndrome. My heart was opened when our little boy was born.

We went back to the beach. The same beach that we went to last year that helped to cleanse our souls and pointed us in the direction towards acceptance. This trip, I spent a lot of time reflecting. I thought about the scared woman who cried so many tears after receiving that phone call. The husband who physically and emotionally checked out for a week. The friends and family members who offered their condolences. The baby that was growing inside me, completely unaware that we were all so devastated. It seems like a lifetime ago. Yet I remember it like it was yesterday. If I only knew then what I know now, I wouldn't have wasted so much time grieving. I should have been celebrating. Rejoicing in the blessing that was being bestowed upon us. If I only knew...We are good enough parents to "handle" this. We can do more than we ever expected (and do it well!). If I only knew...I would be fortunate enough to meet a whole group of new friends, some who have become like a sister to me (and reconnect with many old friends throughout this whole process!). If I only knew...I will find strength in myself that I never knew existed. But, that strength will never compare to the strength I see from my child. If I only knew...Our oldest son will be ok - even through four hospital stays, a host of health issues, doctor visits, and therapy all for his brother. He still goes to bed each night telling us he loves us and that his daddy and I are his best friends. In fact, the other night, he told me his brother is his best friend. If I only knew...Dreaming about his future is ok. He will have a future. If I only knew...Super heroes are real. My son proves it. If I only knew...I will eventually forgive myself for the feelings I once had.

I can tell you now that life certainly is ok. In fact, it is more than ok! Through our challenges and subsequent triumphs we, as a family, have made it through stronger, tougher, and more appreciative. Life is different. It is actually better than I could have ever imagined.

Today, Eli is 10 months old. He recently started sitting, and two weeks later started commando crawling. Now, he really enjoys standing. His strength and determination impress us on a daily basis. After so many health challenges, he has proven to be a total rock star. His smile lights up a room, and his laughter is infectious. Watching our two boys play together completes me. I don't know what I was ever afraid of. Life is perfectly what it was supposed to be, and our hearts are overwhelmed with pure joy.

~ Melanie, Eli's mom; 36; Washington, United States

Blogging @ Our Journey Through Life at www.mellbugg.wordpress.com

{Bryleigh}

My pregnancy started out like so many others I took a pregnancy test (and then two more), and once the double pink lines were confirmed, I started anticipating the exciting months that would soon be ahead of me. My husband and I weren't actively trying for a baby at the time, so it took us both by surprise, especially this being our first. He was in the middle of a big career change -- balancing school and a part-time job -- so timing wasn't exactly ideal for us.

My routine doctor's appointments began shortly after finding out we were expecting. I remember seeing my little raspberry-sized baby for the first time on the ultrasound, and hearing the steadily beating heart; each beat caused my own heart to skip. I felt so connected to this tiny baby inside of me, and it brought so much joy to me. It was little moments like that when I really understood the sentimental connection between mommy and baby.

When I went to the much-anticipated appointment at 20 weeks to find out the gender, we were elated to be told that we were having a girl. I remember that day more clearly than most. The ultrasound lasted close to an hour. It didn't take my husband and I long to start the celebrating and name-deciding upon finding out. Our fingers couldn't type

out the text messages to our families fast enough, and just when we thought we were in the clear and could begin the necessary preparations, we were told the earth-shattering news that only three of the four chambers of her heart were visible on the ultrasound. All color drained from my face as I intently listened to everything the doctor was trying to explain. My first concern was, of course, whether this baby would make it. After I learned that she was fine while she was in the womb, I sighed out of relief, but I immediately knew this was certainly not the typical pregnancy. . This unknown heart problem resulted in us being referred to a specialist for a detailed ultrasound. I left the doctor that day with tears in my eyes and a script in my hand that read "Atrio Ventricular Canal Defect."

I wasn't able to grasp the severity of the heart problem for quite some time. A lot of questions went unanswered as more and more filled my mind. As weeks went by, I went through any and every message forum and blog that I could find relating to the topic. My husband and I were overcome with emotion, but we just kept on trusting in God, that this is His plan, and deep down we knew that everything would work out. After going through the motions of the ultrasound with the specialist, it confirmed what we came to accept by that time: our child's heart was flawed and would need surgery. What I soon found out was that it didn't just end there. Another curveball was being thrown our way, and not only was there a heart problem, but now our child could potentially have Down syndrome.

This was one thing I had not prepared myself for. All the other soft markers that they look for on ultrasounds seemed to be normal, so I had already ruled that possibility out of my head. I never pictured being a parent of a child with Down syndrome. I never knew or met anyone that had Down syndrome. Surely, there was a mistake. I couldn't

even tell myself that this was an option, because it was too large of a burden to bear -- or so I thought. We decided to have testing done to determine whether or not this would be the case, and I opted for the less-invasive MaterniT21 over the amniocentesis. I wasn't worried; after all, I was a healthy 25-year old, and my chances of this actually happening were 1:1400. The doctor called about a week and a half later with the results, explaining that the blood work came back positive for Trisomy 21, which meant that our baby girl would in fact have Down syndrome. Looking back, I remember that day being the most difficult of them all; I was at work when I found out, and I wasn't able to reach my husband for quite some time because he was in school. I cried until my head throbbed and my vision blurred; it lasted for hours.

I felt that the emotional connection I previously had with my baby had been lost. My co-workers tried to console me, but I couldn't wrap my mind around it. It felt like I was living in a bad dream that I couldn't wake myself up from. I was ashamed, depressed, upset, angry, and feeling completely helpless and alone. I prayed so many times for God to change my situation. I was ready and willing for Him to intervene in any way -- as long as I wouldn't have to go through this.

Weeks passed, and I very gradually came to a place of acceptance. I still cried and felt sad at times, but I knew that the outcome wasn't going to change. On the outside, I held it together, but inside I was losing hope; doubts continually crept in. My family really came through for me during the rough times. They listened. They cried with me. They also reminded me what kept me grounded, and that was my faith in God and his sovereignty. Why did I think God would only be present if I had a "normal" pregnancy? In my weakness I had to rely fully on Him, and He gently reminded me of that. He chose this baby for us. This wasn't a mistake. My husband was really there for me too, and he

also struggled with envisioning our future, not sure what our life would look like. In the midst of the tears, he was my rock and it really comforted me knowing that he was by my side through it all.

When it came time for our first pediatric cardiologist appointment, I remember the nerves rushing back up to the surface again. The stark white walls of the building and fluorescent lighting had been everything but consoling upon our arrival. I had my first echocardiogram that day, which is basically an ultrasound of the baby's heart. I was always so excited to see my little girl moving about on the ultrasound screen, and I became happy knowing that I still felt so much love toward my baby throughout all the tears I had endured. When we met with the doctor and came face to face for the first time, we were so relieved to have someone with a very gentle and wise demeanor. She thoroughly explained to us about our child's heart condition, and what this would mean post-pregnancy. I felt confident in knowing that she would be the one overseeing my baby and that to me was a godsend.

Many appointments and countless echocardiograms later, I had a scheduled induction date at 39 weeks. By this time, I felt more confidence in having a child with Down

syndrome; I was ready. At 38 weeks, our baby decided to make her grand debut, and on October 24, 2012, my sweet Bryleigh Kai came into the world and changed our hearts forever. Immediately following her birth, my nerves were still a mess, because I wasn't sure what her condition would be, but I had an unexplainable sense that it would be okay. In those first moments after she arrived, my husband kept kissing me and telling me how beautiful she was. I was able to hold my baby for a mere few seconds before the nurses rushed her off to NICU. But in those seconds, my world was pieced back together. My nerves vanished. My Bryleigh opened her precious almond-shaped, twinkling blue eyes and for a split second stared deep into mine. I couldn't help but feel remorse for every bad thought I had of her. She was a beautiful, angelic baby all along, and I was so worried about my own insecurities and couldn't see past them until that defining moment. I was so proud to be her mom, and couldn't wait to be with her.

Bryleigh's NICU stay was exactly five weeks long. During that time, we struggled with feeds, irregular oxygen levels, and various heart issues. It was certainly a trying time that seemed to last forever, but alas, there was an end to it. We took our sweet girl home and loved on her with all we had.

Just before she turned four months old, she had her scheduled open heart surgery to repair the two holes in the upper and lower chambers of her heart. Since then, she's had an amazing recovery; she is still on heart medication and is being followed by her cardiologist. There are still so many obstacles to be faced, but we wouldn't trade any of it for the world if it would mean not having our miraculous, beautiful daughter, extra chromosome and all.

~ Melissa, Bryleigh's mom; 25; Florida, United States

{Olivia}

Our story starts on the most highly anticipated day in my pregnancy, the 20 week ultrasound. This was going to be the day we found out if our baby was a girl or a boy! I was so excited that I had planned ahead to take the entire day off from work just so I could shop for all of the gender appropriate clothes and baby items I could get my hands on after we found out the sex. I would be lying if I said I remember completely what happened next, and in what order, so I will start with the good news -- we were having a girl! My excitement didn't last long, because as the ultrasound continued, we could tell that something was not quite right. The ultrasound tech just stared at the screen. He tried over and over again to get a different angle. My stomach began to sink, and I began to feel nervous. My husband asked what he was looking at, and all he would say was he was looking at the heart. For the details, he said we would have to speak to the doctor. So we waited. Our doctor came in, and told us what we both feared. There was possibly something wrong with our baby's heart. He told us that the left side of her heart looked much smaller than the right. He wrote a referral to see a perinatologist for a level two

ultrasound, for possible hypoplastic left heart syndrome (HLHS). I went home from the doctor that day with tears in my eyes. How did something that was supposed to be one of the happiest moments in my pregnancy turn into one of the worst moments in my pregnancy?

I was so upset, even the idea of shopping didn't sound fun. I didn't want to buy anything for the fear that she wouldn't be okay. The week long wait until the next appointment was one of the longest weeks of my life. At first I cried... and then, I did what I do best. I researched! I scoured the internet for anything and everything I could find about HLHS. I learned that HLHS was one of the rarest and worst heart defects. It required a series of at least three surgeries, and if this was not successful, a heart transplant. As scary as this all sounded, by the time my appointment rolled around, I had researched out the best hospital in the nation to handle HLHS, and was confident that no matter what, we would do everything in our power for the baby.

The day arrived for us to get answers. As we started the ultrasound, the doctor confirmed our worst fear: yes, our baby had a heart defect. He told us that our baby had an unbalanced AV Canal Defect. What?! That is not HLHS -- our baby had a totally different heart defect, one that I hadn't researched, and knew nothing about. But that was not all. The doctor then informed us that she also had a "double bubble", which he told us is usually caused by duodenal atresia, an intestinal blockage. Not only would both defects require surgery shortly after birth, but because our baby had both defects, he thought there was a high probability our baby had Down syndrome -- 1:3 odds, to be exact. We were shocked... devastated, really. We had gone into the appointment prepared for one problem, and we left with two confirmed defects and the type of odds I would play the lottery on for having a baby with Down Syndrome. How did this happen?

Our doctors gave us information, facts really, into the health risks and probabilities. Our family was great, saying that no matter what, we can handle it and we will love her. But not knowing for sure was just not an option. We needed to know. So we agreed to have an amnio. For two days I cried so hard that even my dogs weren't sure what to do. I cried because I was scared of the unknown, because of the fear of our baby having Down syndrome, because of the fear that our baby would need multiple surgeries. It just didn't seem fair! Why us?! I was so careful. I didn't even touch a drop of caffeine my entire pregnancy.

Finally, the amnio results came back. Our baby girl did in fact have Trisomy 21.

After we found out that there was a chance our baby would have Down Syndrome, I would be lying if I didn't say there was a moment that I thought, could we even do this... could we actually raise a child with Down syndrome? That thought, and the thought of any option of termination, didn't last long though, because all I could think of was that little life inside of me, and how much I loved her and would love her no matter what. The turning point in my grief really occurred when my brother put things in perspective for me by saying that raising all children presents challenges, and that this was just a different set of challenges. From that point on, I stopped worrying so much about my baby being born with Down Syndrome, and more about her heart. Olivia's heart defect was still very serious. The left side of her heart was much smaller than the right side, and we wouldn't know until she was born if the left side would be large enough for a biventrical repair. My fear completely shifted from the fear of raising a child with Down Syndrome to whether or not my baby would survive, and if her heart would be fixable. And so we had no choice but to wait until her birth.

You never think your pregnancy is going to be super stressful and eventful. Miserable and exhausting, yes, but the former, not so much. My pregnancy was easy as far as sickness goes. I pretty much didn't have any. That is where the easy part of my pregnancy flew out the window. After finding out about our baby's heart defect and intestinal defect, along with her Down syndrome, my entire pregnancy plan changed. No longer could I give birth at the small hospital near my home. We needed a level three NICU now. This also meant that my planned delivering doctor now could not be my delivering doctor. Additionally, not only did I have to continue to see my OB/GYN, but I also had to start seeing a perinatologist, in conjunction with a cardiologist. Suddenly I had twice the amount of doctor's appointments, and tons of ultrasounds and scans.

My main concern, and my doctor's main concern for the remainder of my pregnancy, was to keep Olivia healthy and in the womb for as long as possible. You see, Olivia was diagnosed with a more complicated than normal AV Canal Defect because she had an unbalanced AV Canal Defect. The most concerning part of Olivia's heart defect was the unbalanced nature -- that the left side of her heart was much smaller than her right. The cardiologist explained the implications of the size of our sweet baby's heart -- that if there is enough tissue and size, she will be able to undergo a biventrical repair. If not, the only option is a single ventricle repair, which according to our cardiologist, was not often successful in Down syndrome babies. This was my greatest fear, and the worst possible scenario that I prayed daily would not occur. The most stressful part of my pregnancy was the fact that we wouldn't know until she was here exactly how big the left side of her heart would be, and what type of repair she would be a viable candidate for. It was for this issue that I scoured the internet for hours researching, trying to find answers to my questions, trying to find hope. Due to this fact alone, as soon as I found

out about the heart defect, I decided that we would do everything in our power to ensure that our baby received the best health care possible to overcome this hurdle. I researched heart programs, and was ready to travel all the way across the nation if need be in order to save my daughter.

I happen to be a person who believes that everything happens for a reason. So when we found out that the cardiac surgeon who works closely with our local children's hospital cardiologist was also the very highly thought of and nationally recognized surgeon to whom I was recommended by a pediatric doctor in our family, I knew that this doctor had to be our daughter's surgeon. This meant that now not only was I going to have to deliver in a different hospital, by different delivering doctor, but in a whole different city, over three hours from home.

If the stress of extra doctor's appointments and changing birth plans was not enough, my body decided to throw another curve into my pregnancy. Around week 31, I began to have high blood pressure. I had to be monitored even more closely from that point on, if you can even imagine. This meant more doctors appointments, more labs, more urine tests. It was critical at that point to ensure that my high blood pressure didn't turn into pre-eclampsia. If this were to occur, then the doctors would take the baby early, which may or may not give the baby -- and particularly her heart -- enough time to grow strong enough and big enough for her impending surgeries. No pressure, right? In addition to high blood pressure, I had more amniotic fluid than normal due to Olivia's duodenal atresia, which was not only uncomfortable for me, but also required close monitoring as it could cause premature labor. By this point in the pregnancy, I was being followed by three doctors: my obstetrician, my perinatologist, and my new delivering doctor in Dallas. All three doctors were monitoring me very closely and

threatening to put me on bed rest, something I was dreading, as I work as an attorney with a high volume practice. Who has time for bed rest? I managed to make it a few more weeks, but when my blood pressure continued to persist, the doctors made the call that I had to be put on strict bed rest.

From this point on in my pregnancy, I moved up to Dallas, where I stayed with my parents for the remainder of my pregnancy. Strict bed rest did wonders for my swollen feet and ankles, and managed to keep my blood pressure somewhat under control. In fact, I was able to make it all the way to 37 ½ weeks!

It was November 24, two days after Thanksgiving, when in the early morning hours, my water broke. We called the doctor, and were told to head up to the hospital. I was almost in shock... this was really happening. On the way to the hospital, the contractions began. Of course, this early on in labor, the contractions I was feeling were child's play.

Once we arrived at the hospital, I began fourteen hours of labor, which culminated in pushing for two hours, and a baby who refused to move down the birthing canal. Can you say stubborn? Finally, my doctor, who was showing some concerns about the baby's heart rate, told me that we could either move to trying out forceps or prepare for

a c-section. Ultimately, although either choice had risks, I felt that the best option was a c-section at that point.

Literally five minutes after entering the OR, we heard the wonderful, loud screams of our sweet baby girl, Olivia Grace. She was born with an Apgar score of 9 -- I always joke that Olivia is the healthiest baby who ever had multiple defects -- a super high number for a baby with both an intestinal blockage and what turned out to be two heart defects. That's right -- I said two. It turned out that not only did Olivia have an unbalanced AV Canal Defect, but she also had a coarctation of her aortic arch. The latter heart defect was one that required more immediate surgery than the AV Canal would have by itself. In fact, if Olivia had not had the intestinal defect and surgical repair, she would have had the heart surgery even sooner than she did.

Olivia was a fighter from the day she was born. She underwent intestinal surgery on day two, and her heart surgery at two weeks old. Luckily, her heart surgeon felt that she would likely be a candidate for a biventrical repair, and he was going to go in and repair both conditions at once. This surgeon, Dr. Joseph Forbess, is a doctor that I can honestly say performed a surgery on our daughter that, from my worried research, not many doctors would or could perform on such a small baby. In my eyes, he performed a miracle, and he allowed my little miracle to recover and flourish. We stayed in the NICU and the hospital for just over six weeks before we were released on New Year's Eve. I couldn't have asked for a better way to start the New Year than to be able to go home with my family!

I am not going to say that undergoing several surgeries and spending day after day in the hospital was easy or fun. Day after day we endured ongoing labs, blood draws, x-

rays, tubes, wires, echocardiograms, and that incessant beeping. We had to hand over our child to essentially perfect strangers numerous times to have her rolled back to surgery, where she was put under and came out looking like a completely different child. If I hadn't seen numerous pictures beforehand, and mentally prepared myself for what Olivia was going to look like immediately after surgery, it probably would have been even more difficult.

In my mind, I had pictured my baby being born around the holidays and having a wonderful Christmas with family and our new baby. I had never imagined that we would be spending our baby's first Christmas living in a hospital -- never in my wildest dreams. I learned from this experience that life happens, and while you can make all the plans in the world, you really have no control. I am so thankful and grateful that we had my family nearby to support us and to be there every step of the way, and that we were able to receive such wonderful healthcare.

On our return home to central Texas, we embarked on our new journey of struggling with feeding, weight gain, and yet more appointments. There were in-home nursing appointments, cardiology appointments, pediatrician appointments, occupational therapy appointments, ECI evaluations, and more. There were so many appointments, and all while struggling to get our sweet baby to take her bottle and transition from the feeding tube. If we couldn't get her to successfully transition, the next step would be a g-tube, not something I wanted to occur, as it meant yet another surgery. Luckily, our little fighter was strong, and as it turns out, loves to eat. After a couple of months, she finally made the transition successfully to bottle feeding, such that we were able to pull the feeding tube.

Olivia is 8 months old today, and she is doing wonderfully. Her scars have healed, she is holding her own bottle, eats anything and everything we give her, and is the sweetest, best natured baby I could ever have asked for. She has always slept through the night -- one benefit of NG tube feedings was that she didn't technically have to wake up to be fed. Everything about her development thus far has been on par with her typical, non-Down syndrome peers. If I could go back now to the day I found out about Olivia's diagnosis, I wish I could have better comforted myself and saved myself some tears. I wish I could have told myself what a smart baby I would have, how alert she would be, and how downright adorable she would be. I wish I could have told myself how just seeing her smile and hearing her laugh would erase any of the fears I may have had about her future. My daughter is perfect just the way she is -- extra chromosome and all.

~Julie, Olivia's mom; 31; Texas, United States

{Noah}

Perfect. That was what we had expected to hear on that rainy summer afternoon. We had decided beforehand that we did not want to know the gender this time. The 20 week ultrasound felt more like a formality. We joked about whether we would be able to tell the gender or not. When things became quieter in the room, that's when I knew we were about to be hit with some news. "There is a shortened femur. In comparison with the head size, there is a small chance that your baby could have Down syndrome." That was all it took to push me to tears. My husband stayed strong, and we made plans for a level two ultrasound in a larger city. The last thing I remember being told was, "I'm 99% sure you will be back here in a few months telling me that I had you worried for nothing."

I spent the rest of the night researching anything I could find about shortened femurs and other markers for Trisomy 21. A week later, we had another ultrasound that showed basically the same thing. There was a disparity between the head size, which was measuring a little bit ahead, and the limb length, which was measuring a little bit behind. There was also a choroid plexus cyst in the brain. We were told the cysts were typically inconsequential, but are more common in a child with a trisomy. Afterward, we met with

the genetics counselor, and were given lots of numbers and probabilities. I was just 25 years old at conception, so the chance that our child would be born with Trisomy 21 was minute. The risk of complication from an amniocentesis was higher. We had declined all testing in both of my pregnancies, because we were solid in our beliefs that life is a gift from God. We declined the amniocentesis and moved forward. We opted for closer monitoring to ensure that if the baby had a trisomy, we could catch any organ anomalies and be prepared. Following an ultrasound at 34 weeks that showed a more round head shape, we opted for an amniocentesis to give a definite answer. The risks were less severe to the baby at that point.

We told ourselves that the outcome didn't matter, but it was a long weekend waiting for the results. On Monday, I called the genetics counselor. Our child did indeed have 47 chromosomes. I couldn't have expected how it would feel in that moment. I tried to pull myself together to make the call to my husband. I can't remember exactly what I said, but I do remember breaking down, wishing so bad that we were together instead of hours apart. We talked for a short time about how resilient we are, and that our love for this child far exceeds any other challenges we would face. As I drove home that day, I did a lot of thinking. I thought about the changes that this meant for my family and my life. How would this impact my daughter, how would it impact my marriage? I also thought a lot about how fiercely I loved this child, and that I would do whatever it took to make sure that we would be okay. After my husband got home, there were more tears, a lot of hugs, and even a few laughs. We did our best to go along as normally as possible for the sake of our daughter. After we talked to our parents, it really sank in for me. This was real. This was not happening to someone else, it was not a dream, this was our new reality. We talked to our close friends, and there were more tears shed.

For me, the sadness was not that my child would have Down syndrome. It was about the fact that as a parent, your job is to make life easier for your children, and be able to protect them from the cold, cruel world. We didn't know anything about raising a child with special needs. I think that we were terrified that people would treat our child differently, or even that we would treat our child differently.

We met with the genetics counselor to discuss a few things and ask some questions that we had. On the way, we discussed whether we should find out the sex of the baby. In our meeting, we decided that we wanted to find out the gender. It was a BOY! We were absolutely overjoyed, and we both started crying. We were so excited, and the rest of the information went right over my head. All I was thinking was about this boy growing inside of me, and I felt more love for him than I ever had. I felt so connected to him and on the way home, we began thinking of a name for him with a new mindset. We focused on being together as a family and dreaming about our newest addition. I can't say that my mind didn't fool me in to thinking that we couldn't handle this more than once. It was hard, there were a lot of tears, but beyond it all was hope and joy. Knowing the diagnosis before he was born

meant that we could just be happy and focus on our son after his birth. We couldn't wait to hold him. Perfect is no longer a word I use to describe people. Not one of us is perfect. The love I have for my son, however, is absolutely perfect.

~Jenny, Noah's mom; 26; Wisconsin, United States

{Ethan}

My husband and I have been married for seven years. We have a four year old little boy Eli. We had been trying for two years to become pregnant, and had a miscarriage very early during my second pregnancy. In December of 2011, we found out we were pregnant again and would have an August baby! The first 14 weeks were very exhausting with extreme nausea/vomiting, near syncopal, or fainting, spells, a subchorionic hemorrhage (bleeding hematoma inside the uterus), low lying placenta, and then a heart abnormality noted on my 16 week ultrasound. I received the phone call at work that my unborn child had a heart abnormality. Unfortunately, my regular physician was out and another physician triaged the call, and a nurse called me with this information. I was frantic. What did this mean? I met with my regular OB/GYN, who referred to a specialist at Riverside Maternal Fetal Medicine (FTM) to see Dr. Minginone in Columbus, Ohio. Unfortunately, we had to wait a very long three weeks. I clammed up immediately after receiving the news. I just knew something was not right. I remember sharing the news with my husband, and he assured me that everything was going to work out just fine. Our baby was going to

be just fine. I just could not see past this. I lived in a box for the next three weeks. We only shared this news with our immediate family.

On Tuesday, April 3, 2012, we had a very long one hour drive to the city where we met Dawn, who would perform the level II ultrasound. She was very kind, reassuring, and soothing. She asked us if we knew the reason for the referral. My husband spoke up and said, "Yes, a problem with our baby's heart." I was about 20 weeks gestation. We had decided we did not want to know the gender of the baby. As Dawn started the anatomy scan, the first pictures popped up between his legs, and there it was! We were having a boy. I asked, "Is that what I think it is?" Sure enough we were having another BOY! I had a huge sense of relief, watching him wave and kick around. He sucked on his fingers a lot and blew bubbles. Once she was finished, she let us know the doctor would be in soon. Then I got a huge knot in my stomach. I started shaking. My hands were sweating. My heart was beating out of my chest. My husband was so calm.

He held my hand tight as Dr. Minginone came in through the door to greet us. He did a quick scan, and then he proceeded to tell us that he was certain our baby had Down Syndrome. He had three markers for Down syndrome: the heart defect, which accounts for 40% of Down syndrome, the flat nasal bridge, and hypoplasic mid phalanx of the fifth digits of the hands. Everything else checked out fine -- ventricles in the brain, bones, abdomen, etc. We opted for an amniocentesis. This would give us 100% confirmation of the diagnosis. They needed to do the procedure anyways due to increased fluid, and could not see all of the organs clearly. The procedure wasn't bad at all. I've had worse menstrual cramps and those last a lot longer!

My heart stopped. I felt like I was living a nightmare. This could not be true. I asked him over and over if he was certain, and he told me that he was 99.9% certain. He told me he did not need to do any further testing unless I wanted it. He also said under the Ohio state law, I had to make a decision if I wanted to abort the baby before 22 weeks. Even though I had my fears and unanswered questions, abortion was not an option for us. I proceeded to have an amniocentesis for my peace of mind. I needed the confirmation for my sanity. He sent me out the door with lots of resources. We received the FISH results in five days, which confirmed Trisomy 21. Exactly 14 days later, we received the final confirmation that our little boy would have an extra special chromosome.

I cried the entire way home, and I cried for weeks. I found myself in a deep depression. I felt selfish. I knew they could repair his heart. But we could not fix Down syndrome. I feared how society would accept him. How would other people accept us? I feared what he would look like, what his facial features would look like. Would he look like us, and like his brother? I found myself not wanting to get out of bed for days, but I had to continue with my life. I had a family and needed to care for my unborn son. I knew it was not going to be the end of the world, but it certainly felt like a piece of me died that day.

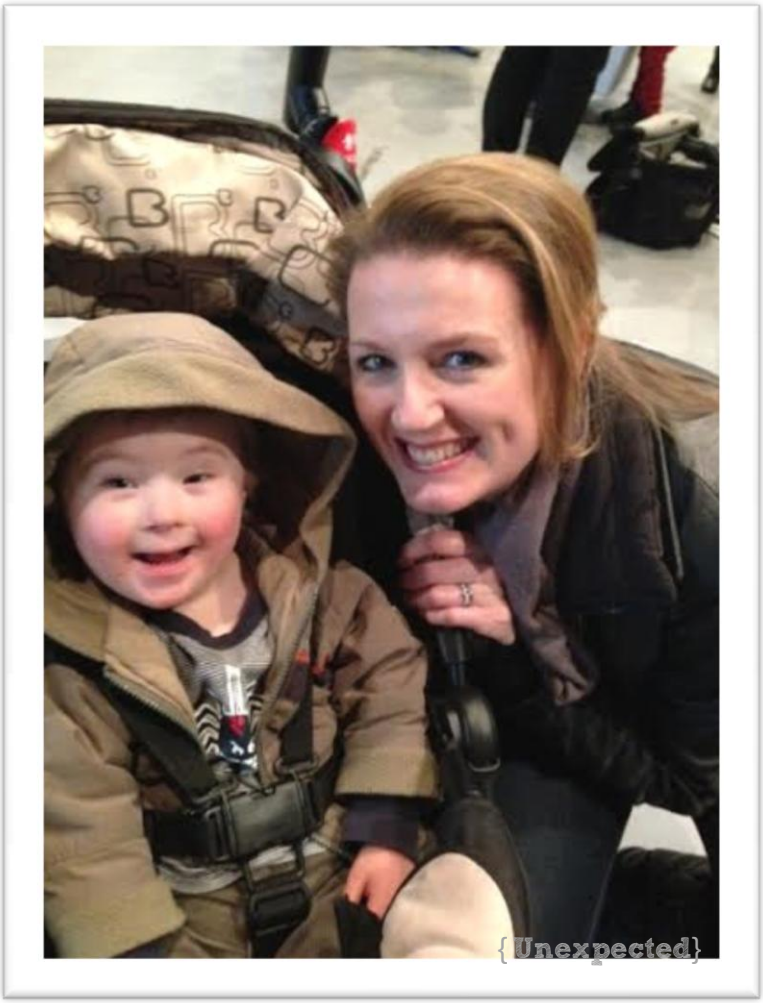
On August 17, 2012 at 38 weeks, my water broke at my weekly appointment. My labor went very smoothly and quickly. Once my contractions started with the Pitocin, I delivered a beautiful baby boy at 6:56pm named Ethan Matthew Wolfe. I was numb. The cord had been wrapped around his neck twice, but they got it off quickly. The NICU nurse was ready, and checked him over. He was doing great. It was hard to believe he was doing this well. Everything seemed like a nightmare, and now we were floating in a

dream. I got to spend the first hour with him. I breastfed him, and he latched right on to my breast. The tears were flowing down my face. I still felt no emotion. I could not shake this feeling. They took him away to the NICU where they could monitor him more closely. He required oxygen and a feeding tube by the second day. He was very red from the high red blood count, which is common with babies born with Down syndrome. Even though he seemed like a mess, I wanted his big brother to see him. I kept thinking that I could not live with myself if something had happened to him. So that evening, Eli came to visit. I was holding Ethan, and Eli was very quiet and nervous. But he gave me a kiss and a hug, and then leaned over and gave his little brother a kiss. Then it hit me. Eli did not see Down syndrome. He did not see the oxygen tubing, feeding tube, heart monitor, IV lines, or wires. He saw his little brother, Ethan Matthew. I then started to see Ethan through Eli's eyes. My heart melted. No words will ever describe this feeling. He is a true blessing!

~Renee, Ethan’s mom; Ohio, United States

{Reuben}

My husband Carl and I had been blessed with three amazing boys, but we felt there was one more child to come, so we were happy to find ourselves expecting baby number four in the August of 2010.



At 10 weeks and six days gestation, however, I was shocked to find I was bleeding. The general practitioner I saw told me I'd "had a mis", as she put it, and sent me to have a scan to confirm this. Thankfully, we heard a beautiful heartbeat, and the scan showed our little one was fine. We went home relieved.

At 19 weeks and five days, we expectantly went to our major anatomical scan, hoping to find out the sex of our baby. The sonographer told us we were having a boy (surprise!), and then went to get the senior doctor who examined our little fellow. "Is everything all right?" I asked anxiously. "Baby has some markers of a chromosomal abnormality called Trisomy 18 or Edward's Syndrome," she said. "The outcome for these little ones is not good." At that point, my heart dropped to my stomach. We were completely shocked. Our little boy's hands appeared to be clenched, he had chorio plexus cysts in the fluid of his brain, a heart defect, and fluid around his heart. We left feeling devastated and lost.

After getting home, I started searching for a name for our son. I said to Carl, "If he's not going to be with us long, he needs a name, and he needs one now!" We found Reuben John. Reuben meaning "Behold, a son" and John meaning "God is gracious".

At the High Risk Clinic of our hospital, a compassionate obstetrician spoke to us about Trisomy 18 and our options of termination or birth. We were also offered an amniocentesis, which we accepted, as we wanted to know what we had to prepare ourselves for. We decided we would continue the pregnancy -- that we would love him and hold him close for as long as he was with us.

We had to wait for the results of the amnio for nine agonising days. Finally, a nurse rang and gave us the results. "Well, it's not what you were expecting. There are two dots beside chromosome 13 and 18, and three dots beside chromosome 21, so that means Down syndrome," she said. "Oh, ok... thank you," I managed to reply. Everything went very still, like I was in some kind of limbo-bubble. We were thankful that Reuben was not going to die soon after birth, but in a 180 degree change, we were suddenly facing a life of long-term care for our son. "It's Down syndrome... he has Down syndrome," I heard myself say to Carl, but it didn't feel like it was me speaking about our son.

The next day we asked the neonatologist and obstetrician about the medical conditions associated with Down syndrome. As the doctor quietly listed them, Carl slid lower and lower in his chair. A termination was offered, and then we were left alone for a moment. "How will we cope?" he asked slowly. The prospect of dealing with extra medical issues and trying to juggle the needs of our other boys was overwhelming.

Carl went back to work, and I went home and Googled every image of children with Down syndrome that I could find. I sat at the laptop with tears streaming down my face,

looking at pictures of so many beautiful children, and searching for families that looked something like ours. I wanted to see them doing normal everyday things... I needed hope that the future would be ok.

That night, when Carl came home to a teary wife, he said he had been thinking and praying about what to do and felt strongly that it was not our call to make. We didn't know what Reuben's destiny or purpose would be. So we decided that Reuben was not going anywhere. Our parents, while shocked, were supportive and encouraging.

We invited our senior ministers from our church to come the next night to tell them about Reuben, via text message. That night, a friend named Annie told me when she had read our text, she heard the words "Angel Unaware". She knew this was a book written in the 1950s about a father and his child who had Down syndrome. Hearing this brought me great comfort, and confirmed to us that Reuben was meant to be here. I figured that if God had told Annie that Reuben had Down syndrome to prepare her to help us, then He knew what was going on, and I could trust Him with Reuben's future and the future of our family. Annie encouraged me to be very gentle with myself with the emotions and grief I was experiencing, and to allow myself to accept all of it, without self-judgement. We later told our extended family and a few close friends, many of whom sent words of love, acceptance, and encouragement.

As the days passed, the feeling of numbness lifted, but the emotions of shock, anger, guilt, and fear came. I just could not believe this had happened to us. I grieved and released one dream and tried to embrace a new one. And fears, I had so many fears... fears of the future, fears of the medical issues we'd face once he was born, fear of leukaemia, fear of him dying, fear of rejecting him just because of how he looked. I shed

many tears and asked many unanswerable questions, yet I still wanted to believe that everything would be alright. I kept reminding myself to trust God, and to love Reuben. When I focussed on these two very simple things, peace came, and I knew we would be ok.

Reuben arrived early at 36 weeks (yet another surprise!) on March 24th, 2011. He was born naturally, weighing six pounds and one once (2.765kg), and was 45cm long. After some suctioning and a little oxygen, I was able to hold him. He was pink and soft and velvety, and had a beautiful little round face. His hands were fine, and a later scan showed no signs of any cysts in his brain. We were relieved and grateful he didn't have to go to the NICU or special care, and was doing well. I knew I was concerned about a great many things, but I also knew that without a doubt, I loved our Reuben-boy.

The next few days were a blur of family and friends visiting and check-ups including heart, brain, and hearing checks, blood tests, a visit from the hospital physiotherapist to show us how to position and wrap Reuben, lactation consultant visits, and phototherapy for jaundice. We were able to go home after four nights in the hospital, only to be called back in twice due to Reuben's high bilirubin levels for more phototherapy. It was an unsettling time for us all. All I wanted to do was settle into being at home and love my boys! It turned out Reuben was only just getting enough breast milk from me to sustain his weight. His body could not flush the bilirubin out of his system or put weight on, so I started expressing breast milk for him.

A day after being discharged from the hospital for the third time, we were sent to Melbourne to see the paediatric cardiologist at the Royal Children's Hospital. Travelling by myself with a 15-day-old baby, born a month premature, was certainly an

experience! I got some interesting looks from older ladies who saw me bottle-feeding my baby boy. It was my first taste of fixing my eyes on Reuben and declaring in my heart that it didn't matter what others thought about what I was doing... I had to do what was right for him!

The visit to the cardiologist went well His oxygen saturation levels were good, and to my great excitement, the Patent Ductus Arteriosus (PDA) that hadn't closed at birth had now closed. That meant no operation to close it! All in all, Reuben was doing well, and we were sent home to return in a month.

After trying to breastfeed and express for three weeks, I decided to stop breastfeeding and continue full-time expressing. Trying to do everything and still be Mum to my three other boys was becoming overwhelming, and the anxiety from trying to breastfeed added to the mix. While I was upset about not being able to feed Reuben, I realised it was nothing either Reuben or myself was doing wrong... he simply did not have the oral muscle tone to take what he needed from me. Being premature with a heart defect also caused him to tire more easily. He was happy drinking expressed milk from a bottle, and I was more relaxed knowing how much he was getting each feed. The expressing also served two purposes for me. It continued to build the bond between him and myself, and it gave him all the nutritional benefits of breast milk. Holding him and looking into his eyes as he fed were beautiful, often teary times for me.

We were told Reuben's prolonged jaundice was possibly an indication of hypothyroidism, so he had a nuclear imaging scan at three weeks of age. This showed no sign of any thyroid gland at all. So we found ourselves yet again grappling with a new diagnosis. This involved giving him daily doses of thyroxine, for life.

At seven weeks of age, Reuben and I went for his second visit to Melbourne, which showed the small Atrial Septal Defect (ASD) had closed, leaving the small AVSD. The cardiologist was happy with Reuben's growth, and to our relief, the remaining defect was not hindering Reuben's heart function.

We returned six weeks later to find out more good news – the ventricular part of the AVSD had spontaneously closed, leaving a four to five millimeter ASD. The cardiologist said we didn't need to see him again for another year, and that we could see him in our hometown, so that meant no more 6:00 am flights! We were so grateful.

Slowly life began to settle, and in between doctors appointments, we began our fortnightly visits to early intervention at eight weeks. We both benefited from attending these sessions –- Reuben got all the necessary monitoring and help with his development from his teacher, a physiotherapist, a speech therapist, and an occupational therapist, and I felt "normal" going there. I got to meet other parents with children with special needs, and a few with Down syndrome. I also got to talk about how I was processing the new journey I found myself on.

While going to early intervention was great, I found I struggled with comparing Reuben's development to the other children there who had Down syndrome. In fact, in the early months, without realising it, I also compared his weight and height to typically developing babies his age. I did this until I realised it was utterly pointless doing this. He was running his own race, and would be the weight and height he was, and would do things when he was ready, and that was ok.

To help Reuben communicate, we were all encouraged to begin using AUSLAN signs (Australian Sign Language) with him. I have always loved watching people signing, so

learning some basic signs to teach Reuben was fun. Reuben watched and watched, until one day, about a year later, he signed "dog." We cheered, and he looked so proud!

Reuben loves to sit on my lap and read books. I remember an incredible moment when he was 14 months when I said, "Turn the page Reuben," and he did it! I realised he understood me! Tears flowed, and I felt incredibly relieved. From then on, I started asking him questions, and giving him choices, and waiting for a response. Something as simple as asking and seeing him turn the pages of a board-book became cause for celebration. These seemingly little things became encouraging moments of hope.

As time went on, I began to find going out with Reuben less challenging. Initially, I used to tell most people I talked to, be they strangers or friends, that Reuben had Down syndrome, but then I realised that was like me introducing myself by saying, "Hello, I'm Elisa. I have a cold." I realised it was unnecessary. He was simply my son and I found the more at ease and smiley I was with strangers, the more at ease they were with us.

The remaining ten months of his first year were full of paediatrician appointments, monthly blood tests checking his thyroid function, hearing and eye tests, and more early intervention sessions. We also negotiated the chicken pox at six months, started solids shortly after, had problems with constipation, and saw a dietician to monitor Reuben's nutrition levels at 11 months. We also celebrated the milestones of smiling, giggling, rolling over, and sitting unassisted. Reuben's smile was, and still is, amazing! His auntie says he has rainbow eyes and sunshine smiles!

We also went to our first Buddy Walk with Reuben at seven months, and our first Down Syndrome Tasmania Family Camp with Reuben 11 months old, both of which were confronting and wonderful all at once. Meeting so many beautiful families was incredibly

encouraging, and so good to know we were far from alone on our journey. On returning from camp, I realised that Reuben would not suddenly turn into a 20-year-old man who had Down syndrome, but that he would gradually grow into becoming one, and that as he grew, so I would grow also into being his Mum. I had to remind myself to not look too far ahead and become overwhelmed, but to focus on today and the coming week, and to just keep loving my little boy.

To my great excitement, we discovered World Down Syndrome Day (WDSD) occurred three days before Reuben's birthday, March 24th, on March 21st, so we decorated the house and celebrated many things that March. I watched WDSD videos like 'Will you Let Us In?' and 'Ordinary Miracle' from the International Down Syndrome Coalition with tears streaming down my face, incredibly thankful to find ourselves part of a global family, with all of us somehow connected by the extra copy of chromosome 21.

On the 24th of each month, and at the time he was born, we always remembered Reuben's arrival day and sang him Happy Birthday, and so to finally celebrate his first year birthday was wonderful. We rejoiced that he was here and was so well, and that we had gotten through an incredibly tough year. We had Reuben dedicated at our church on his birthday. To be able to say thank you to God for the gift we never knew we needed, and to acknowledge again that He truly does know best, was emotional and so very beautiful.

Every night, after getting Reuben ready for bad, I put on his sleep-time CD, and would hold him close, often cheek to cheek. Most nights I found tears would begin falling as I told him how much I loved him. I would say through my tears how I trusted God's plan for the future, that I knew we would be ok. Those times were, and still are, times of

healing and acceptance. They are times of bonding and of love. It was during one of these times, when Reuben put his head on my shoulder for the fist time, that I realised Reuben knew I was his Mummy. Knowing that was incredible!

When Reuben was about 18 months, I remember a friend asking me if I was doing ok after me telling her I'd been feeling a bit low. She said she wondered if I was still in shock about Reuben's diagnosis, and I burst into tears. Even with a prenatal diagnosis at 20 weeks, I realised I was still in shock about it at 18 months! To acknowledge this was a turning point in my journey, and helped me to move forward. The ever-present fear of the unknown, the "what-ifs," and the feeling of treading water, slowly began to ease. I could finally say my son had Down syndrome without my heart aching. I saw Reuben as perfect because he is. He is not flawed in some way just because of the way he looks sometimes, or because of what he cannot do or say.

Not so long ago, I realised a wonderful thing. I realised that Reuben has helped me to become the woman and mother I always wanted to be. He has helped me to be more accepting and less critical and judgmental of differences in others, more compassionate, more playful, patient, and loving. He has enlarged my heart, and has changed forever my idea of perfect. Perfect is not a beautifully-dressed model or an immaculately-styled room in a magazine. It is life, with all its joy and grief, it is happiness and it is pain; perfect is God's plan for our lives, and perfect is our son Reuben, our gift.

~ Elisa, Reuben's mum; 37; Tasmania, Australia

{Zarilya}

From the moment of conception, the princess was mine. There was no doubt in my mind, no second thoughts, no hesitations -- she was planned and very much wanted. From the moment that second line appeared on the pregnancy test, faint as it may have been, the unconditional love was there.

We were given a 1:3 chance that our baby had an abnormality. For the lottery these odds seemed great, but not for the baby lottery. Every parent hopes for that 'perfect' baby, with twenty three pairs of chromosomes, ten fingers, ten toes, and society's expectations of what a child should be. Down syndrome: the words rang in my ears for the longest of moments, deafening me, paralysing my every thought, my hopes and dreams. It felt like someone had punched me in the heart. Would you terminate all because of an extra chromosome, and what exactly does that really mean? To some it may mean the end of the world, but to those of us who know better, it is the beginning of a whole new one. Faced with the prospect at the time though, is not a decision to be taken lightly and definitely not an easy one. A life commitment to the well-being and development of a child who has Down syndrome requires courage, and at

that particular moment in time, I remember feeling very weak and insignificant as my world caved in around me, my courage and strength failing me.

Our story began on a sunny Wednesday morning, arriving at the hospital for a twelve week scan. My husband parked the car and took our toddler while I went up to wait. To my astonishment, they called me in very quickly, and my husband still wasn't there. We waited for what seemed like a lifetime and the sonographer said we had to start. I was so excited, I couldn't wait. She started, and immediately, I could see something wasn't right. Having worked as a midwife had given me some insight into what a "normal" scan should look like, and mine was not one of them. I felt the tears welling in my eyes, and the knot in my heart. Hubby arrived somewhere after that moment. He took one look at me, and one look at the ultrasound as I could see his heart breaking. Our princess had a thickened nuchal fold and no visible nose bone. The sonographer made some phone calls, sent off the results to the genetic lab, and organised for us to meet with the genetic counsellor. My tears would not stop flowing, and my heart was breaking. We were in too much shock to even communicate with each other. We waited and saw the counsellor, and the results of our combined scan and my blood tests were rushed through. They came back at 1:3, so she offered us a CVS, or the option to wait four weeks and have an amniocentesis. I am unsure as to why we chose to have a CVS, but thinking back, I believe it was for 100% clarification. However, we knew the picture and the odds were there in black and white. The counsellor organised a CVS for later that day. I now had something else to fear -- that needle looked mighty big, and I was not happy about where it was going to be placed. But the procedure went without a hitch, and we went home to await the results.

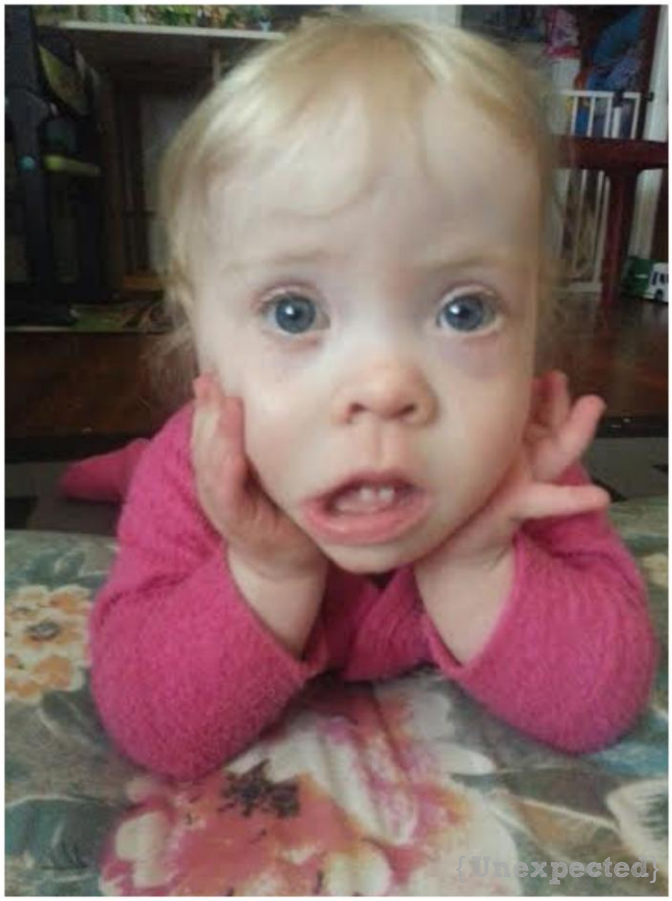
Thursday came and went with no phone call, while our hearts ached and my eyes were bloodshot and cloudy from all the tears I had shed. Somehow, through all these tears, I had decided that there was no way I would terminate, but feared that my husband did not feel the same way. We were still finding it hard to share our feelings. Friday came, and late in the afternoon, the phone call finally came. Our princess had Down syndrome. I cried again, but this time I think it was relief. Confirmation had come, and now we could get on with life.

So life was about to take a major turn onto what would probably be a bumpy road. Little did we know at this point in time exactly how bumpy it would really be. At our twenty week ultrasound scan, there was more bad news. Our princess had a major heart defect, known as Tetralogy of Fallots. This meant my precious baby girl was going to need open heart surgery. We took this information, prepared ourselves, and kept soldiering on, eager to meet our precious bundle. Then, somewhere around thirty weeks into the pregnancy, my placenta started to deteriorate. Monitoring increased, ultrasound scans were more frequent, and by thirty four weeks, I was in hospital. At thirty five weeks, it became critical, and our princess had to be delivered early. This scared me even more, as I knew being premature as well as having a heart condition was not a good combination. As they lifted my baby up for me to see over the drapes, my heart melted and I fell in love. She was so tiny, so beautiful, and so precious. She was quickly whisked away to be stabilized for transfer to the Royal Children's Hospital. It seemed like forever that they worked on her in a little room next to the operating theatre. I couldn't hear her crying, and I just wanted to hold her.

Eventually, they wheeled her into the room. She was wrapped to keep warm inside a transport cot, and had a breathing tube in. Tears streamed down my cheeks as I got to

hold her hand for about a minute before they whisked her away. I sent my husband to stay with her so she would not be alone, but it was several days before I could even go to see her. It was extremely hard being on a ward and hearing other babies cry while my baby was somewhere else, sick and without her mummy. Three days after she was born, I finally got to hold her. She smelt so sweet and felt so soft. Her breathing tube had been taken out, and she was doing really well. Surgery was to be when she was around six months old. Only a few days more in hospital, and we were allowed to take her home.

Since the moment we knew our baby was a little girl, we were calling her our princess. Trying to name all our children had been hard, as we do not like conventional names. Our oldest daughter we named Kiarra, our second daughter we named Jamayka, and our little man we called Jaspa. So her name had to be special, and while searching for names, I came across the name Zahlia, which it meant princess. We didn't like the spelling, so we changed it to Zarliya, and we had a beautiful name for our princess.



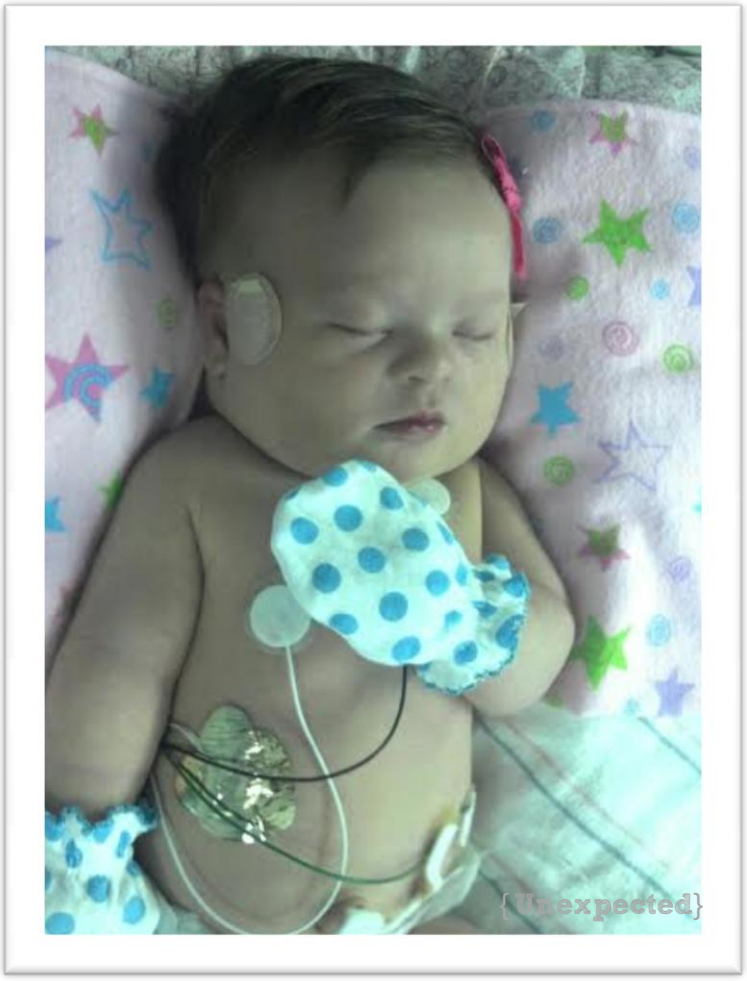
If I were to write about all the in between stuff, it would literally make a whole book. So I will skip through the six hospital admissions for respiratory problems, including a six week hospital stay for bronchiolitis, RSV and pneumonia. With each admission, her symptoms and stays were less and shorter. At four months of age, Zarliya started having blue spells from her heart condition. She was admitted, but due to complications, the surgeons could not perform her full repair. Instead, they inserted a shunt. After that, there was fairly smooth sailing through her first Christmas, her first birthday, and growing, learning, and surprising us every day. Every single second spent with her was a miracle, special and cherished. A month after her first birthday she was admitted for her open heart surgery. The wait was excruciating, with eight hours of trying to keep busy and not think about what was happening. In intensive care she looked so tiny, even though she was one year old. Our little hero recovered miraculously, and was discharged six days after this major surgery, and was soon blossoming and thriving.

Since her surgery, our princess has thrived. By sixteen months, she is sitting independently, commando crawling, rolling everywhere, talking and babbling, playing, smiling, laughing, kissing, hugging, and loving just like any other baby. We don't see her as delayed, and she is accepted for who she is. In some ways, she still looks like a baby about half her actual age, but after what she has been through, it's no wonder. Each day I give thanks for the blessing that she is, and could not imagine my life without her. Children with Down syndrome are not burdens, but blessings.

~ Samantha, Zarilya's mum; 38; Victoria, Australia

{Josephine}

At 5:15 pm, my cell phone rang. I remember because my cell phone never works in my office. It was the genetic counselor from our perinatal office. I already knew what she was going to say; nevertheless, I held my breath and answered.



"Stephanie, we've received your MaterniT21 results back. It was positive for Trisomy 21. I'm sorry because I know this isn't the result we were hoping for." I calmly responded, "Well, it's what we were told to expect." She replied, "Please let me know if I can be of any assistance to you during the remainder of your pregnancy."

I worked in a zombie like state for another 30 minutes before I said goodnight to my coworkers. I barely made it to my car before the tears started.

This was our first pregnancy, and like most first time mothers, I relied on my doctor to guide me to the ways of being pregnant. When my obstetrician strongly suggested I decline any prenatal screening – because "they only create more stress in an already stressful situation" – I agreed. I distinctly remember sitting in her office at eight weeks pregnant, when she asked if we would terminate if our baby had Down syndrome. My

husband and I immediately responded no. At that time, they were just words. We never knew we'd be putting our money where our mouth was.

Our 20 and 24 week ultrasounds were textbook, except for a baby that refused to sit still long enough to have her heart examined. "It's no big deal," the tech said. "This happens. Just to be safe, let's send you to the high risk perinatal center to get better pictures". As I waited for them to make the appointment, I overheard the tech say to my obstetrician, "I believe that the baby has a heart abnormality." At 25 weeks, the perinatal center confirmed what the original tech had suspected – our baby had an AV Canal Defect. After our ultrasound at the perinatal center, we were placed in the waiting room to speak to the genetic counselor. I used that wait time to Google "AV Canal Defect". I was scared, more so because no one wants to hear that their unborn child has a heart condition. Was this survivable? When the words "Down syndrome" appeared in every article, I remember leaning over to my husband and saying, "We might have a bigger problem here." We were offered an amnio during our genetic counseling session, but declined for various reasons -- fear of needles, the late stage of pregnancy, and our very active baby.

At 26 weeks, I found myself having another ultrasound done, this time at the pediatric cardiologist's office. I had already researched to death how an AV Canal Defect would be handled, and felt somewhat more at ease with the situation. Unbenounced to me, the cardiology ultrasound tech was actively looking for Down syndrome soft markers while he took pictures of our daughter's heart. I remember him pointing out that kidney function was great, and that the stomach and bowels were functioning perfectly. I thought this was odd for a cardiologist tech to mention, but was happy to have the information.

"Your Daughter has a complete, balanced AV Canal Defect," our pediatric cardiologist would go on to say. "It's completely repairable, but she'll need open heart surgery when she's around four to six months old. The survival rate of these surgeries is higher than those of a boob job." My husband and I laughed at that comment. He paused. "I do need to tell you, there's a 90% chance that your daughter has Down syndrome."

That was the news I wasn't expecting. My research had all pointed toward a 33% chance, not a 90% chance. 90% odds weren't great odds. I remember sobbing in the elevator on our way home.

I had to know – for sure – what our situation really was. I knew I couldn't get past this part of my pregnancy, couldn't be happy again about our baby, until I knew. But I was still very uncomfortable with the idea of an amnio. After doing more research, I discovered the MaterniT21 test. I called the perinatal office to ask if they offered it. I would be the first person in their practice to have the test performed.

The three week wait for my results was excruciating. I read every blog written by parents of kids with Down syndrome. I googled things like "Down syndrome child ruined my life", looking for the flip side to special needs parenting. But the more I researched, the more I found out it wasn't a parenting death sentence to have a child with Down syndrome. Sure, their lives weren't always rainbows and butterflies, but their lives also looked pretty darn normal to me. Unfortunately, every time I came to the conclusion that we could raise a child with Down syndrome, this little voice that said "she may not have it" would slip in and ruin it all.

The day the test results came in, I was angry with myself about my reaction. I had spent three weeks going through the acceptance cycle –- denial, anger, bouts of uncontrolled

crying -- and I was finally coming to terms with it all. So why was having a confirmed diagnosis so upsetting? Why the tears? Why did I feel like I was back at step one?

I called my husband to give him the news from my parked car. I remember apologizing repeatedly, feeling that I was to blame for this. It would take us several more weeks to find peace in our new situation. We went through a range of emotions, and had those hard conversations that you never expect to have to have with your spouse. But we always came to the same conclusions: no one was to blame for this. This wasn't the path we would have willingly chosen, but it was the path we'd been given to travel for a reason. It wasn't always going to be easy, but we'd be in it together. And, come hell or high water – we were going to be awesome.

The last 10 weeks of my pregnancy went by with absolutely no commotion. We painted the nursery, attend baby showers, and did all those last minute things you think you have to do right before you bring a new person into this world. We had been receiving weekly ultrasounds beginning at week 33. Each ultrasound showed that our baby girl was growing, but very slowly. I questioned if the "growth algorithm" they used during these ultrasounds took into account that our daughter would be born with Down Syndrome - a condition that lends itself to short "long" bones. At our 38 week appointment, we were told that we would be lucky if she broke the 6 lbs. mark. I would be induced at 39 weeks and 5 days - a week longer than my obstetrician wanted -but a week I knew my baby needed, so I fought for it.

Named after her great-great aunt, Josephine was born on the evening of a very beautiful September day. I remember laughing in surprise when the nurse announced

that her official weight was a whopping 7 lbs. 12 oz.!! She would spend exactly one week in the NICU of our local children's hospital, mainly for oxygen saturation issues (a common side effect of babies with heart conditions). Once her oxygen levels had stabilized on their own, we were happily sent home. Approximately four months later, we would be back at the hospital, only this time Josie would undergo open heart surgery to correct her AV Canal Defect. She was a superstar during the entire process – recovering so amazingly well that we were released from the hospital exactly one week post-surgery!

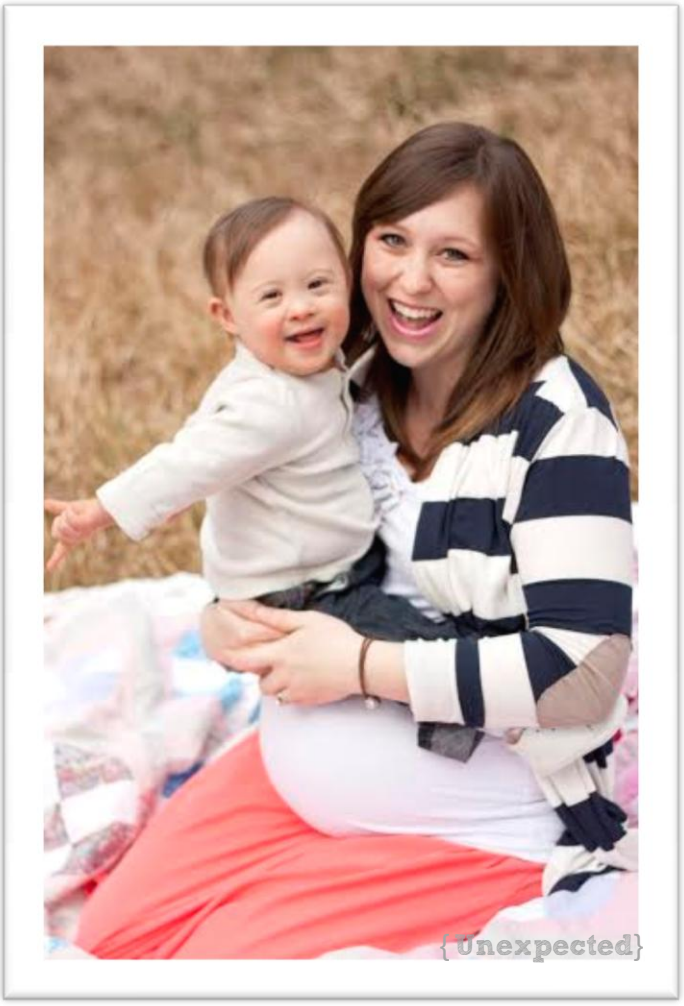
Since then, our lives have been remarkably normal. Josie attends a typical day care full time – where she's in a room with 7 "typical" kids. She's developed a beautiful and hilarious personality. She looks like her Daddy – but has her Momma's stubborn streak. We have play dates, take swim lessons, attend church regularly, and make all attempts to get out of the house every chance we get. We also attend weekly therapies to help Josie reach important milestones, and we proactively see various medical specialists throughout the year to ensure that we're monitoring Josie's overall health and catching any pesky medical concerns before they become issues. Most importantly – we celebrate. We celebrate milestones, we celebrate life, we celebrate

knowing that this wild ride isn't as scary or as untraveled as we originally thought. And when we're done celebrating – we eat animal crackers, because life really is – normal.

~Stephanie, Josephine's mom; 32; Tennessee, United States

{Eli N.}

The story of our family journey began in 2010, when my husband and I became pregnant for the first time. We had been married for five years, bought a house, had stable jobs, and we were ready. Our pregnancy came easily, and we were blissfully happy with our little secret.



A cold reality closed in on our excitement when only a week later, our pregnancy ended in miscarriage at ten weeks. We felt lost, crushed, and abandoned. No one seemed to understand our grief, and nothing filled the void we felt. It was one of the darkest moments in our marriage.

Although our hearts had not completely healed, we began to try again. This time, our efforts were fruitless. We tried for six months before seeking help from my obstetrician. She asked us to be patient, and continue to try for six more months. At the end of a year, we had been through three doctors, and still had no answer as to why we couldn't get pregnant again. I had begun to believe that we were not meant to have a family at all.

My husband's cousin recommended one last doctor. He was far from us, but we felt like we had to give this one more try. After a battery of tests, we were told that I had a rare

blood clotting disorder called MTHFR and a thyroid issue. My husband was informed that he had male-factor infertility.

That feeling of defeat returned. We had so many questions, no answers, and no baby. But our new doctor had a plan: IVF. It was hard to take it all in: miscarriage, fertility struggle, infertility and now IVF.

To put it into perspective, my husband felt responsible for our fertility struggles, while I felt inadequate as a woman, and we were both worn down by the year-long ordeal. But we trusted our doctor and his plan, so we decided to go through with it. IVF is a costly procedure -- financially, physically, and emotionally. We had to raise $20,000, drive back and forth to the doctor's office almost daily, and we were filled with anxiety and fear. This was it; this was our only shot at a family.

I self-injected hormones daily, underwent surgery, and my husband was, for lack of a better word, debased. During the egg retrieval, they were able to get ten eggs, of which eight were mature and seven fertilized. We had seven little embryos, and our life was about to change. At the implantation procedure, our doctor selected two embryos, which were transferred back to me. The result was two pink lines on a pregnancy test just 14 days later. Finally, we were pregnant!

The pregnancy was wrought with fear, complications and cautious optimism. At around nine weeks, I was admitted to the hospital for bleeding. I was put on bed rest for four weeks until it resolved. I was very highly monitored -- I literally have an unltrasound picture for every week of the pregnancy -- because we had already miscarried, and we had been through a unique process to get pregnant. At 12 weeks, the bleeding vanished and we had our nucal translucency scan. This scan is combined with

bloodwork to help determine a baby's risk for chromosomal abnormalities. The nuchal translucency measurement was 1.2, and we were told we had a 1:1200 chance of having a child with Trisomy 21. We were no longer considered high risk, and began to see our doctor as any other pregnant couple would.

At our 20 week anatomy scan, my doctor requested a thyroid panel for me. A week later, he called to tell me that there was a lab error -- the lab had actually run AFP bloodwork, the results of which gave us a 1:243 chance that our child will have Down syndrome. This is considered a "screen positive" for Down syndrome.

At this point, our doctor was not convinced that our son would have Down syndrome, nor did he have any markers on the ultrasounds. But he did offer us a new test called MaterniT21. Houston was one of the first cities to gain access to the test, and because it was a simple blood test and posed no risk to our pregnancy, we had it performed. The results take two weeks to return, and while we had not confirmed a diagnosis, I knew in my heart that our child would have Down syndrome. Call it a mother's intuition, but I just knew.

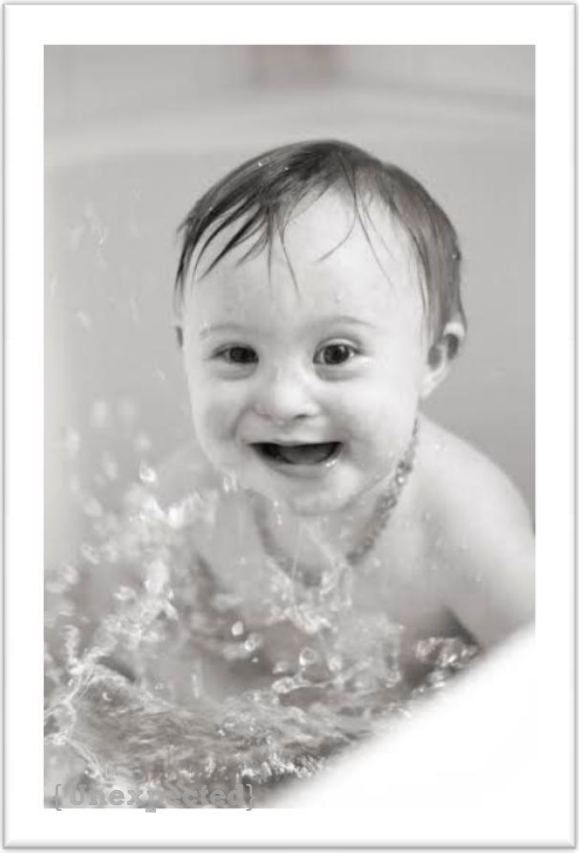
Two weeks later I got a call that I will never in my life forget - the test had come back positive for Trisomy 21. Even though I "knew", confirmation was a hard reality to accept. In that moment, I realized how many expectations we had placed on our unborn child, of things we wanted, and plans we had for their life. At the same time, I bitterly realized that I had deemed our family "untouchable"; we had been through so much that a diagnosis of Down syndrome wasn't something that could happen to us.

Because the MaterniT21 test was so new, my doctor insisted that I follow up with an amniocentesis. We were in such a severe state of shock and disbelief that we agreed to

the procedure. Thinking back on it now, I only went through with it hoping that the MaterniT21 test was inaccurate... and in my darkest moments, that perhaps the amnio itself would end my pregnancy so I wouldn't have to worry about anything else.

Two days later, my doctor called with the news: our son would come to us with Down syndrome. I was 22 weeks pregnant, and we had just found out that we were having a boy.

To say that I fell on the floor and sobbed for days wouldn't be far from the truth. Graceful was not in my vocabulary, clearly. Once I got off the floor, I began to throw myself into researching and gathering all the knowledge that I could find about Down syndrome. Slowly, my heart began to feel joy again, as we waited for our son to arrive. In retrospect, I feel like it was a blessing to have a prenatal diagnosis. We were able to prepare our hearts, learn, share with our family and friends, and prepare with our doctors and hospital for our son's birth. His birth was a celebration, and his life has been the biggest blessing on our family. I know -- corny. You will read that everywhere, but it's true, because he is ours, and he's perfect. Having Eli has been exactly what we imagined being parents would be. Our son is more than just statistics, more than what medical journals describe, more than a diagnosis with negative stereotypes, and we feel blessed because we've done nothing to deserve him.



Eli, this is for you. Mommy and Daddy love you, and we love our special journey into parenthood. Thank you for making me a mommy.

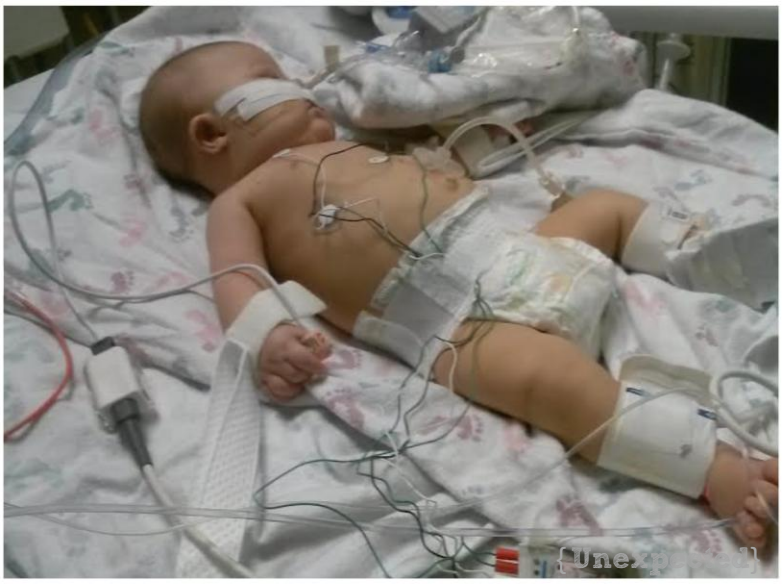
When we decided on the name Eli, we joked that it stood for "Extra Light Inside", not knowing how true that would be. God had a special plan for him and our family. It was scary at first, but he really is that extra light in our lives. His name really means "Ascend my God", and that is our prayer of blessing over him: that he would come to know God, and that he would bring glory to Him, that he would be able to use the unique gifts God has given him to bless others, and that his light would shine brightly, reflecting God's love and grace.

~ Ashley, Eli's mom; 27; Texas, United States

Blogging @ www.barryandashley.wordpress.com

{Dominic}

My journey began during my pregnancy. The day I went to my first ultrasound appointment, I was 13 weeks. The doctor saw several soft markers for Down syndrome, and she told me to go for a level two ultrasound. I went to my obstetrician again for one of the new non-invasive blood tests. That came up positive for Down syndrome. At the time, I was not accepting it. I just did not understand what was really happening. I asked to do the amniocentesis just to be sure. I prayed the whole time, "Lord Jesus, please give me a normal baby."



Three days later, I got a call. I was all alone at home. The doctor said, "We got the results, and it's positive for Trisomy 21." I felt like someone dropped the world right on my chest. I could feel my heart shatter. I cried, screaming and cursing God.

I called my grandma. I couldn't even get the news out without crying harder. I wanted to crawl under a rock and never leave. My pregnancy was ruined! And so is my life. Why God? Why me? What did I do? I'm only 19 years old; this doesn't happen to people like me.

The doctors told me every bad thing will happen. They said your child will never function normally. He will be retarded for the rest of his life. Through the pregnancy, I still felt alone, but somehow I found a way to move on.

On September 11th, 2012, I went to a routine check-up for the baby's heart. After looking at his heart, the doctor advised me to go downstairs; I would be delivering the baby today. He had fetal hydrops. The doctors warned that my baby would be born very sick. He may not be breathing when he was born. He may die within 24 hours. He was five weeks early. At 9:12 pm, Dominic came into the world SCREAMING. They took him away to the NICU before I could see him. Later, I was able to see my tiny four pound baby boy. He had tubes all over him.

The very next day, the neonatologist came into my room, sat down beside me, and said that his blood work came back, and it didn't look good at all. They found leukemia cells. Dominic had Transient Myeloproliferative Disorder (TMD), or transient leukemia. I couldn't help but scream. Why? She told me this is just one of those things that happens; it's rare. She had me sign a paper giving consent to treat my two day old with chemotherapy. I never heard of such a thing. He was born so very sick, and on top of that, he had to do five days of chemo.

My heart ached for him. I just wanted to shut down. All of it just hit me like a ton of bricks. I would argue with God, and then cry and pray for my son. He was on chemotherapy for five whole days. He was so tiny and soft. He was just so sick. He had to get multiple blood transfusions. His platelets were very low, and so were his white blood cells. This all made him at a greater risk to catch any little bug going around. He was kept isolated for weeks.

As the weeks went by, God answered my prayers and Dominic's health seemed to be improving. He got off the oxygen. We were working on feeding. After weeks of trying, I agreed to have a feeding tube put in. After God's healing, Dominic finally came home after three months in the NICU. For a while, I believed he would never come home to me. But he did, just before Christmas.

He was only home for just a few weeks, and then his feeding tube site started getting red and he had fevers, so I took him to the emergency room. When they checked his oxygen, it was low. They admitted him into the PICU, and when they handed me my parent badge, I just started crying.

I had faith he would come home in a week or so. But his breathing continued to worsen. About a week after being there, he went into respiratory distress. They hooked up the ventilator to Dominic, and now the breathing machine was breathing for him. My faith in God was, and is, strong. I knew my boy could get through this. I checked into the Ronald McDonald house so I could take a shower and get at least one night's sleep.

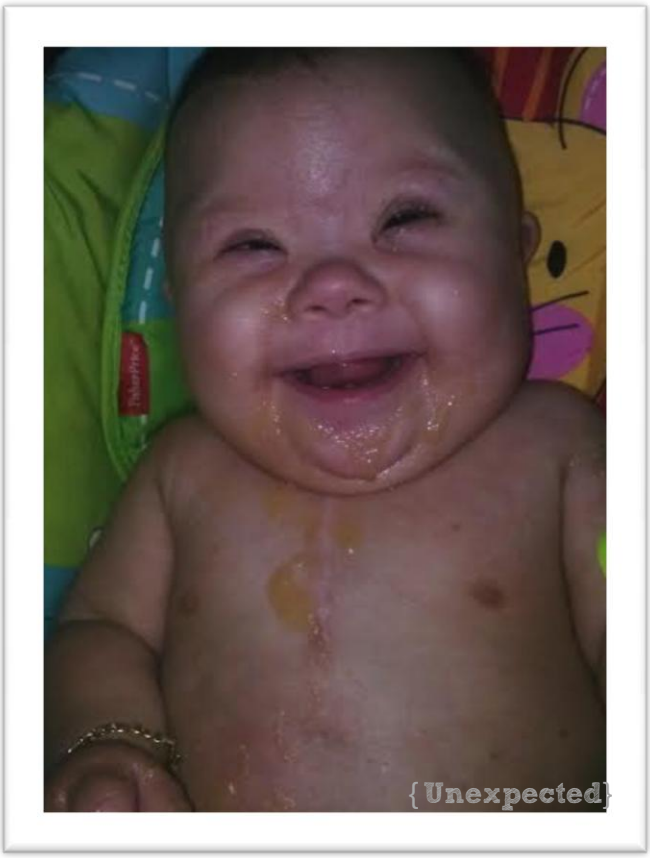
Dominic did great, and they took him off the vent, but he was still on the oxygen. Every morning, the doctors would do their rounds. I hated to keep asking them the same question: "Do you think he will be able to come home soon? When?" But I never got an answer.

Days went by, and we had a plan just to keep him there for a few more weeks to fatten him up for his heart surgery. Two weeks later, we scheduled a heart catheter. We were transferred to the fifth floor, to the CVICU. Dominic wasn't doing well. He developed fevers as high as 106 that caused seizures. His breathing was getting worse. The

doctor came in and told me that she was amazed that he was still actually breathing, and that this does not look good.

He had to be intubated again. They also paralyzed him, so his body did not have to work so hard. I was so scared. I was alone. I had no family there -- it was just me.

I called my family that lived about an hour away, and told them what was happening and to just pray. I couldn't even look at Dominic without crying. He looked lifeless; he was white as a ghost and colder than a ice cube. They had to give him a blood transfusion to see if it would help his oxygen and body temperature. I never left my son's side.



I prayed to God. I blamed myself. What did I do, God? Why is this happening to us? Please God. I don't think I can take anymore.

Dominic was intubated for six weeks. I was not able to hold him for so long, I would crawl up with him in his crib. I felt like I had been robbed of my baby boy. We waited until he was healthy and strong again to extubate. He still had a fever that always seemed to be there. Many specialists came to find out why, but nothing ever came back. We finally decided to do the surgery and see if that would help.

He went into surgery on April 9th. He did wonderfully! He had no more fevers. He was breathing just right. After five long, long months, Dominic was able to come home.

Dominic had become like a celebrity on the fifth floor. Everyone knew us. He changed my life, and still is. I knew there was always hope.

I love him so much, and he truly is an amazing, strong little human. I still don't understand why I was chosen to mother a special needs child, but I believe God has something in store for me and Dominic, even as a young single mom.

~ Dayna, Dominic's Mom; 19; Florida, United States

{Aiden}

After two miscarriages, we made an appointment to do a procedure to soften the lining of my uterus. The Friday before my appointment, I took a pregnancy test -- and the results were positive!

Our first prenatal appointment was super scary; my age was a huge factor, along with the two miscarriages prior. We were so excited, but the doctor was so negative. He talked about all test I would have to take and he kept talking about how high risk I was... ugh!

At our first sonogram, we were told about how thick my baby's neck was, and it was right at the measurement to cause concern. Again, they took away the joy of our first child together, the child we so desperately wanted.

We did the blood test, because that's what the doctor said to do. My doctor kept referring to me as a "high risk pregnancy". No, I thought; my name is Bonnie or Mrs. Scott. His office ended up losing my blood work results, so he did an ultrasound in his office to see if he could see anything, and to show my daughter that was visiting from college her baby brother or sister. At that ultrasound, he started talking about how big

my baby's head was, and it was a sign that he had some kind of birth defect. "He has Down's," the doctor told me. I walked out of his office that day and never planned on going back. I was so offended! He made my baby sound like an alien in front of my other baby.

I started seeing a perinatologist, and she was a dream; her voice comforting and soothing. We talked about my age, the sonograms, and all the other visits to "that doctor". She did an ultrasound, and it was a boy! It also showed some markers for Down syndrome, and she recommended an amniocentesis. My husband wanted to know; I didn't. We were never going to abort my one and only son, I dreamt of him. I prayed for him. I was so in love with him. I named him!

We got the phone call with our results; my son had Down syndrome. My world went black. I hung up the phone, and cried and cried and cried. I called my husband, and he was not answering... and I started to panic.

What will I tell my family and friends? How will he look? What will happen to him? How would he grow? This can't be happening to me. I don't know how to raise a child with Down syndrome! I don't know anyone with Down syndrome. What is Down syndrome? My husband came home, and I finally told him the results. We sat there together and cried. I was hysterical and he was calm, as always, but I could see the look in his eyes.

We looked up Down syndrome on our computer, and that made it worse. There were no African-American faces. What was in store for us being so far away from our support system and family? My mom would never understand -- she lives in Jamaica. What would our friends and family think? My oldest called to find out the results. I told her the news about her brother, while sobbing. All she could say was, "That's just my brother and this makes me love him even more."

The next two weeks were full of quiet and tears and just telling my core people, a select fifteen, listening to their feedback and words of love, encouragement and support. I mourned the ideas and my dreams of a "typical" son. His dad was calm like always, but deathly quiet. We took it one day at a time. There is no preparation for Down syndrome, I felt so alone. Our world was going to change. I was not looking forward to it. I couldn't handle it. I was not strong enough for this. I'm not one of those kind of moms!

~Bonnie, Aiden's mom; 38 Iowa; United States

{Charlotte}

This is the story of our third child. And I'm going to start at the end. Charlotte is now six months old. She is beautiful, and perfect, and oh-so-loved. Her arrival has changed our family dynamics yet again, and she is a perfect fit for this family.

We had always talked about three being the magic number for our family. For a while, we toyed with the idea of staying at two, probably somewhere in the never-ending sleepless nights that we had with Bailey. But we made the decision, and yet again, we were blessed in falling pregnant first shot.

The first trimester passed slowly, with constant nausea and exhaustion, but we hit 12 weeks, and things sped up. All of a sudden, we were having our 19 week morphology scan. We took Alyssa, who was very excited to see the baby. Everything looked good to our eyes. But then the sonographer said she wanted to get the doctor, who came in for a second look. The nuchal fold measurement was larger than it should be. An obstetrician was called in, and she told us that the nuchal fold was around the nine millimeter mark, when it should be less than six millimeters. And within the nuchal fold was something called a cystic hygroema – a pouch of fluid from the lymphatic system. There were a few things it could be caused by, and we were referred to a maternal-fetal medicine

obstetrician. But we couldn't see her until Monday morning. It was Wednesday afternoon at this point.

We spent the weekend stunned, and trying to stay away from Dr. Google. Monday morning, we met the lovely MFM doctor. It could have been a number of things, but the front runner was a chromosomal abnormality, with the main culprit being Trisomy 21. I went from having a risk of 1:900, to being high risk at 1:57.

We discussed, but declined, the offer of an amniocentesis. We would not act on the results, and so felt it was not worth the risk to the baby, something our doctor fully supported us in. She arranged frequent monitoring and extra scans. We had weekly appointments with her for the first few weeks, and by week 24, we had been given the all clear from an echocardiogram scan of the baby's heart. Another scan showed that the cystic hygroema seemed to be reducing in size. Everything was looking great, and with Christmas upon us, it was decided that we would not have our next scan and appointment until 28 weeks.

A couple of days before our appointment, I started to get a little bit worried. The baby's movements didn't feel right, and were quite reduced. As we had the appointment scheduled, I let the thought sit at the back of my mind, and hoped that the scan would show that I was worrying about nothing.

I went along to our 28 week scan, and again had a feeling something wasn't right, despite the reassuring presence of a heartbeat. I sat down in the doctor's office, and she told me that she wanted to deliver my baby... the very next day. I was only 28 weeks and four days along. I knew that it wouldn't be good. I burst into tears, and after a hug from my lovely doctor, she briefly explained why. The baby's lungs were full of

fluid. She sent me home to get Daniel and pack my bags, and we arranged to meet her later that afternoon, when she would go through everything.

But our baby must have a guardian angel watching over her, because whilst we were gone, the doctor decided to ring a colleague at the main birthing hospital in the city, who referred us to the head doctor in the maternal-fetal medicine department there. I got a phone call from our doctor telling us of a change of plans. This doctor was expecting us that afternoon to see if he could drain the fluid off whilst the baby was still inside me, and hopefully buy us time to keep the baby in for longer.

We met the new obstetrician, and he took us straight to an ultrasound room. He didn't waste any time in taking a closer look at what was going on with the baby. He explained that the main reason our doctor at the first hospital wanted to deliver was due to a lack of blood flow back through the cord to the placenta caused by the pleural effusion (the fluid on her lung). The baby's left lung was so full of fluid that her heart had been pushed way out of position, so the aorta and arteries at the top of the heart were being pushed out of line, which was pinching them, and the heart was having to work harder than it should be. At that stage, the blood flow around the body was ok, but she was showing signs of heart stress. He didn't want to deliver –- if we delivered, her lungs would not be able to inflate because of the fluid in the cavity and she would not be able to breath, and they would have trouble ventilating her until the fluid was drained. He felt that if we delivered at that moment in time, it wouldn't have been a good outcome for our baby.

As scared and upset as we were, there really was no choice but to drain the fluid to try and save our baby. The procedure took less than 10 minutes, and the relief on the

baby's heart was immediate. He removed 80ml of fluid from her left lung. He also suggested that he do an amnio whilst he was doing the procedure and we agreed: it was already invasive, so we might as well try and find some answers to what had caused the buildup of fluid.

I was admitted to the antenatal ward that night for the foreseeable future. I was given two doses of steroids overnight to help mature the baby's lungs, just in case we still needed to deliver.

Our new obstetrician arrived early the next morning to do another scan and see how things were looking. The bad news was the fluid had accumulated a lot quicker than the doctor would have liked. The good news was that the blood flow through the cord had improved. The doctor commented that she must be tough and pretty resilient.

It was decided that, rather than drain the fluid with a needle like the previous day, he would place a stent into the baby's lung cavity to drain the fluid continuously into the amniotic sac to prevent it building up again. The procedure had an even higher chance of causing me to go into pre-term labour, or for the baby to go into distress, so it was carried out in operating theatre under sterile conditions. I was prepped and ready for a caesarean, just in case they needed to put me under and get the baby out quickly. I was freaking out on the table, praying that the procedure would work.

They tested the fluid, and it was lymphatic fluid, and the pleural effusion was classed as a chylothorax. Her lymphatic system was immature, and so not draining the fluid itself, which was causing it to build up in the lungs. The most likely cause of this was a chromosomal abnormality, so we waited for the results of the amnio.

I spent another six days in hospital, as things with the baby stabilized and her blood flow through the cord returned to normal levels. I was scanned each day, and each day, I was grateful that we had gotten that little bit further with the pregnancy. For the remainder of my pregnancy, we had weekly scans. I drove around with a bag packed in the back of the car, and each time we met with the doctor, I expected that to be the day he told us he wanted to deliver the baby. And each week, she was stable. There was no more sign of fluid, and she was growing nicely.

At week 30, the amnio results came back. The baby was most definitely a girl. And she had an extra copy of chromosome 21.

Even though we were high risk (1:57) and I felt like we were prepared for this result, it was still a shock. I felt like I had been hit by a bus. I kept telling myself that my world hadn't ended, it had just changed the angle it was rotating at. I phoned Dan, and after a minute's silence, he said "Well, now we know." We were both stunned and unsure.

I later texted a very good friend, who told me that it would be ok, and that our baby would be perfect. Another good friend overseas told me that this baby would still bring joy and love to our lives, and would still be perfect.

Dan processed and came to terms with the karyotyping quicker than I did. I felt like I was grieving. I was upset that I wasn't getting the baby I thought I was, and for the future that I thought I had lost. I didn't know what the future was going to look like for us now. I was scared of the challenges she would face, and I was scared that I wouldn't be good enough. I didn't want this diagnosis, but I worried that the baby would think that I didn't want her, which was never the case.

As the weeks went on, my fears began to fade, and whilst every now and again, I would catch my older two children doing something, and wondered if this baby would do the same, I began to believe what my friends had been telling me. It would be ok, it really would.

By week 33, both the doctor and the sonographers were having difficulties finding the stent. But she was lying deep down on that side, and so it was assumed to still be there, as there were no signs of fluid building back up.

During week 34, we met with a neonatologist, who went through some likely scenarios. They were pretty certain we were in for a NICU stay, but it could be anything from weeks to months. The best case scenario was that the chylothorax would resolve in utero; worst case, they would have to put a more permanent drain in once she was born whilst they waited for it to clear. She would most likely need breathing support, which could be just through nasal prongs, but there was a possibility that she would need to be on a ventilator. We had already toured the NICU at 29 weeks, and had some idea of what to expect. Both the neonatologist and our obstetrician were very keen for her to stay put as long as possible, as it would mean less complications associated with prematurity.

At our scan in week 35, the sonographer finally found the stent – our little monkey had managed to pull it out, and it was floating in the amniotic fluid, up near her face. But the good news was that no fluid was building up so our doctor was happy for us to continue with the pregnancy. Just over 36 weeks along, I woke up in the night with what I thought was pre-labour. I was in denial that it was real labour right until I hit transition... which just happened to occur when I was sitting on my mum's toilet, an hour away from

the main birthing hospital. Even then, I was still thinking I could drive in to get checked over, but it was quickly apparent that an ambulance was needed.

Because of the potential problems with the baby, we had a second ambulance meet us on route and follow behind us. To begin with, the plan was to still take us to the city hospital, but after about ten minutes, a decision was made to divert to the nearest main hospital. We would have been no more than a couple of minutes away from the hospital, when all of a sudden I couldn't fight my body any longer, and in one push, my waters broke, the head was out and then there was a baby lying on the bed. The paramedic had no time to put down her notes and catch the baby -- all she could do was yell, "Pull over!!"

Charlotte Rose came out crying at 9:45 am. She was quickly placed on my chest, and Dad got to cut the cord. As we were so close to the hospital, I got to hold my baby for the two minute drive. We were met by a NICU team, who triaged her. Whilst she was breathing, she still needed some oxygen support, so once they had done a quick check over, she was off to NICU, and I went to labour and delivery.

After I was checked over and had a shower, I was wheeled round in a wheelchair to meet our baby properly. By then, she had been hooked up with all manner of wires and tubes. Charlotte spent just over a week in intensive care, on hi-flow oxygen to help her lungs inflate. A chest x-ray showed remnants of fluid, but her chylothorax had cleared up in utero. An echocardiogram showed that she had a PDA, but they weren't too concerned.

We quickly realized that in the NICU, it was often a case of a couple of steps forward, and then a step back. But slowly, things began to improve. By the middle of her

second week, she was moved to special care, and by week three, she was taken off the oxygen support. Her only issue then was with her feeding. She wasn't tolerating her feeds very well, and she went backwards and forwards from hourly tube feeds to three hourly, back to hourly, and back to profuser feeds. But by the end of week three, the doctors decided to challenge her with three hourly feeds, and she began to tolerate them more. Her growth was still an issue, as was establishing suck feeds.

By week four, she was well enough to come home, but her feeding continued to be an issue. A doctor mentioned the possibility of her coming home on a naso-gastric tube, and I clutched that idea, asking the doctors every day if we could do that.

In the end, she spent 30 days in the NICU. Given what we had been told during our pregnancy, she far exceeded all of our expectations, and we really feel like we had the best possible outcome. All the same, an extended NICU stay really hurts the whole family. The day I was discharged and drove home without my baby, I sobbed for what seemed like hours. And each day, I would walk out of the hospital with the nagging feeling I had forgotten something. I was exhausted from the drive, pumping three times hourly and trying to continue a normal life for our other two children. I was torn, because I couldn't not go to the hospital daily, but I felt guilty for not being at home with the other two. My eldest daughter couldn't understand why our baby couldn't come home, and for the first week, didn't want to touch the baby.

At home, Charlotte seemed to be thriving on a mix of breastfeeds and NG tube feeds. But at eight weeks old, she was losing weight, and starting to work harder at breathing. She was readmitted to the NICU, and then transferred to the PICU, where she was diagnosed with laryngeal-tracheal malacia, and this was causing her breathing issues.

It's something that she will grow out of eventually, and in the meantime, she is on home oxygen support to ensure she's getting enough oxygen through her airways.

Being the youngest of three and having compromised airways means she's since had three hospital admissions for bronchiolitis. A cold for the other kids has seen her end up in the PICU. She's also still got the NG tube, as it's been a struggle to get the weight on her, and to keep it on. The constant worry about keeping her out of the hospital, and getting her to grow has been the hardest thing for me to deal with. The older children don't give the tubes a second thought these days, and have adjusted to Charlotte and I being in hospital on a monthly basis. It's just the way of life for us right now. But I will be so happy to lose the NG tube and the oxygen. And I'm hoping that spring will mean no more illnesses.

These days, Charlotte having Down syndrome doesn't really factor into things. We're just starting therapy, and attend an early intervention play group. For us, her health issues have overridden our initial reaction to the diagnosis. When we were faced with a sick baby, we stopped caring about that extra chromosome. We just wanted her to be born as healthy as she could. At times, I do wonder if we've dealt with her diagnosis properly, or whether we've filed it away in the too hard basket whilst we focus on her health. But I don't think that is the case. We're ok with the diagnosis. It's part of who she is. But so is her determination and resilience, and her gorgeous smiles and attention-seeking personality. She is perfect just as she is.

Charlotte is almost 6 months and things are getting easier. She lost the NG tube last week and is going beautifully on the bottle. She's had her first taste of carrots and is loving them! Her weight gain has been slow but she's finally got some gorgeous fat rolls, and is finally out of newborn nappies. She loves attention, and gets quite vocal if she feels she is ignored. Her smile is beautiful and she gets quite chatty. She's beginning to roll, and trying to sit up unaided. She is totally adored by the whole family, and by most people who know her. At times, the future still scares me, but then I remind myself to forget about what may happen, and focus on what is happening now. Life with Charlotte is beautiful and awesome.

~ Samantha, Charlotte's Mom; 31; South Australia

{Kate}

I remember being pregnant the first time with my son. Every time I went in for an ultrasound, I was terrified -- terrified in the beginning that there wouldn't be a heartbeat, terrified later on that there would be something wrong with the baby. Every ultrasound went off without a hitch. I was delighted when he was born absolutely perfect.

My husband and I were ecstatic when, seven months after our son was born, we found out we were expecting our second little miracle. I was given the choice to follow with the same perinatalologist that I had with my son. I decided I would have all the prenatal testing offered, the same that I did the first time. I remember going for our nuchal translucency screen in the first trimester. It was so different this time, because I had such a sense of calmness and excitement to see our baby. That appointment went great, and the doctor said our baby was doing wonderful. A few weeks later, my husband and I went back at 15 weeks for our second trimester genetic screening. We were so excited for the possibility to potentially tell the gender. We kept prodding at the tech to tell us if our son would have a brother or sister. I remember watching her face really focusing and concentrating. She told us she was done with the scan and was going to grab the doctor to come in and speak with us, like usual, to go over the results. When the doctor came in, her face was solemn. She

proceeded to tell us that there were a couple of abnormalities viewed on the scan. The baby had an echogenic intracardiac focus, the bowel was also echogenic, and lastly and most concerning to the doctor, was that the amnion had not fused to the uterus. This apparently is done during the first trimester, and I was well beyond that. I asked the doctor what this indicated for our baby. She had replied that the baby likely had a chromosomal abnormality, and was in danger of not surviving the pregnancy. The unfused amnion posed a grave threat, and it was likely that the pregnancy would not go full term. I was at risk for miscarriage at anytime. We had my blood drawn that day to check my hormone levels for the second part of our sequential screening. I remember going home and crying in the car with my husband. He was trying to be positive and kept saying we knew nothing for sure and we couldn't stress.

We talked a lot over the next couple days while waiting for the blood work. I was terrified of a Trisomy 18 diagnosis. I kept saying that Trisomy 21 was fine with me. "I can do Down Syndrome," I told my mom. "My baby will laugh, learn and love. I can handle that. I can’t handle my baby dying inside me or right after birth." I remember spending those days feeling like my world was knocked upside down. I felt like God was punishing me for being too greedy and wanting a baby so soon after we had our son, as he was only ten months old. My biggest concern was losing the pregnancy and miscarrying more than receiving a diagnosis.

The blood results came back and the doctor called me at home. She said she had the results of the sequential screening, and it came back positive for having a baby at high risk for having Trisomy 21. I remember I let out a sigh of relief. The doctor was unsure of my response. I explained to her that I never had a fear of Down syndrome. I'm pretty sure I'm the only patient who ever responded to the news that way to her. We were

given 1:16 odds of having a baby with Down syndrome. That day, I knew in my heart our baby would be born with Down syndrome.

We went back and had an amnio at 16 weeks. The results came back that our baby girl would be born with Down Syndrome. I can say that I was not surprised by the results, and felt ready to hear them out loud, as I had already known this in my heart for some time. I spent hours and days prepping for that moment by reading and learning as much as I could about Down Syndrome.

I spent plenty of time on BabyCenter and downsyndromepregnancy.org. I also read books, blogs and websites. I joined our local Down syndrome support group. There, I met so many women who have now become dear friends. I accepted her diagnosis and saw it as an opportunity to learn. I can honestly say that I was at peace with her diagnosis shortly after receiving it. I was able to enjoy my pregnancy.

Kate Gianna was born at 37 weeks and six days, just two days before her scheduled induction. She came out fast and furious at eight pounds, ten ounces, and 21 inches long. I remember the neonatologist coming in to see her and whispering to me that her heart and lungs were great, but that she had Down syndrome. I remember thanking him

and smiling, telling him I knew that she did. I cried tears of happiness as they put her on me for skin to skin. I cried as I proclaimed to my husband how beautiful she was. I was, and still am, such a proud mommy of how my daughter was so truly perfect.

~ Janessa, Kate's mom, 30; Florida, United States

{Conner}

As I sit here and think back on our diagnosis, it seems just like yesterday... but at the same time, it seems like it was a lifetime ago. It all started out as a very normal ultrasound at twenty weeks -- or at least, I thought it was normal. Nothing was said, and there was no indication from the tech that they noticed anything wrong. So after the ultrasound, we went home and put our picture on the refrigerator. The excitement was growing in the home. Here comes our precious baby number two! I guess when I look back I should have followed my motherly intuition, because from the moment I thought I was pregnant, I had this feeling something was not quite right. I kept telling myself that it was just because I was so sick the first sixteen weeks, but I just couldn't shake this feeling that there was more.

Two weeks later, we were scheduled for our monthly visit to the obstetrician. I had written down the wrong day on the calendar, and so in the end, we had to reschedule for the next day with a doctor we had never seen before. I was upset that I would not get to see my doctor, but I figured it was just a regular appointment, where we would hear the heartbeat, do a measurement and be sent on our way. When we arrived, the

doctor walked in, and very quickly our appointment turned scary. First, he said that he tried to call us two weeks ago but they mustn't have the right number, so I was frustrated. He very quickly said that they saw a few things on the ultrasound that appeared to indicate that our child may have Down syndrome. My heart sank. What did this mean for us? I was so confused and worried. He scheduled us for a level two ultrasound the following week to check the baby again. He said we had to hurry, because I was twenty-two weeks pregnant and we are running out of time to make any decisions. What did he mean? What would I do? I knew from day one that this baby was meant to be. That didn't mean I didn't have any worries. Would we be able to handle everything we would have to deal with? What about our baby's future? How would I care for this baby? How would we care for him as an adult? Both my husband and I are older parents, and we do not have much family support. I was so terrified he would be alone when we were gone. How would this affect our older son? I wanted him to have a sibling that he could grow with, and now he would have extra burdens of taking care of his sibling. I kept thinking, what did I do?

For the next week I lived in denial. I went about my business, and I was convinced that the ultrasound tech was wrong... until the day I drove the hour and half to get my second ultrasound. That was such a sad and lonely drive all by myself, because my husband had to stay home with our son. I remember laying there, watching the ultrasound and seeing this little baby just kicking and moving so much in my belly. I kept wondering how something so perfect could be so wrong. Afterwards, the doctor quickly came in, and said again they couldn't see a nasal bone, and there were possible kidney issues. My husband and I had talked about it ahead of time, and decided if they again saw soft markers, we would go ahead and do the amniocentesis. If our baby would

have health issues, I wanted to know and prepare as much as I could for his delivery. My stomach was in knots, but I never cried. Not yet.

It was exactly one week later that we got the phone call. That phone call changed my life forever. It was so early, and I thought I heard my phone ring, but by the time I found my phone I had missed the call. I waited a few minutes, got my son settled with breakfast, and then called the doctor back. I remember thinking, why did I have to miss that appointment those several weeks ago? Now that OB that I didn't like was my doctor of record for the test, and he was the one calling me with results that could change the future I imagined. He quickly came to the phone, and was very abrupt. Who knew it would only take 30 seconds to change someone's life? He very quickly stated that he had the results and they were positive. WHAT? Next, I was asked if I had any questions. What?? I was in shock, and so overwhelmed. I quickly said no. I hung up the phone and just cried. It was the first time I cried since this all began, and all those questions started racing through my head again. Then the guilt came. "What did I do?" raced through my head. I quickly tried to call my husband, but he was in a meeting. I decided to proceed with my day as best as I could.

We had to take the dog to the vet 45 minutes away. I cried the whole way there. I again tried my husband, and received no answer. I needed someone, so I went to visit a woman that I had worked with for years. We were talking and catching up, when I quickly blurted out that we were expecting another child, and the baby would have Down syndrome. It was the first time I said those words. She quickly grabbed me and hugged me tight. All she said was that it would be okay, and that if anyone could take of this baby, I could. I needed someone to tell me I could do it. Later that afternoon, I finally got in touch with my husband, and had to tell him the news. There was silence on

the phone, and it was deafening. Finally, after what seemed like forever, he just said, "I love you and we will get through this together."

As the day went on, I cried off and on all day. I would see another woman with a baby, and I would cry. I lay in bed all night and cried. I knew I loved this baby no matter what, but I worried for his well being. Would he be healthy? Would he be ok? What if I delivered and he was ill? The next day, I woke up, and I started to learn all I could. I needed to be prepared for the worst case scenario, but hope for best. In the early days of the diagnosis, I had a great amount of guilt, because I felt it was my fault due to my age. I thought I needed to do everything I could to be ready and prepared to take care of this little baby that was going to need me so much. At some point, I had to step away from the computer for a week, because it was all just too much information.

Some days, I was so sad that I just didn't want to deal with anything. Then I would be mad and have those "Why me?" days. I even worried that, with all this crying and stress, the baby would think I did not love him. Quickly, those days began to become less frequent. It started to become clear that I wasn't sad about the diagnosis, but over the fear of the unknown. I wasn't mad about the title of Down syndrome, but I was scared for this baby's well-being. What I realized in those early days is that through my anxiety and stress, I can't control everything in life -- but I can control how I handle the life that I was dealt. This little baby growing inside of me was the same little baby that I dreamt about. He was the same baby that I felt kicking in my belly each night. He was same baby that I would read to each day. He was the same baby that I would talk to about all the fun things we would do together as a family. With all that was going on I realized that this little baby was just like any other baby. He needed love, care, and

someone to always be his protector, just like his brother before him. He is our blessing. Life may not always turn out the way we envision, but it turns out the way it should.

The rest of my pregnancy was filled with appointments and complications. I developed polyhydramios as I did with my first, which meant bi-weekly non-stress tests and weekly ultrasounds. Sometimes, though, God works in mysterious ways. There was a nurse at the hospital that would sit with me during my tests and talk to me. She told me about her sister who had Down syndrome, and what a blessing she was. It was so comforting to me at that time. As I reached my 32nd week, my amniotic fluid actually stabilized, so that was not a huge concern anymore. I also developed gestational diabetes with this pregnancy, so I had to poke my finger four times a day, and watch very carefully what I ate. They also had me go for a fetal echocardiogram to check the baby's heart, because I would be delivering in a small hospital. Overall, there were issues and obstacles during my pregnancy, but it was a little smoother than my first since I didn't have to be on bed rest for ten weeks this time.

It was December 16th, and we had two more days until we were scheduled to deliver our baby via c-section. I was looking forward to just relaxing, finishing my Christmas preparations, and just spending time with my other son, because I knew when the baby arrived, we would not have that one-on-one time anymore. As the morning was nearing an end, I began to feel uncomfortable, so I decided to go lie down and rest. Within two hours, I was having contractions every four to five minutes. Then I thought I would go rest in the tub for a few minutes -- within fifteen minutes, my contractions were coming every one to two minutes. That is when the nerves and fear started to come again. We called our friends to watch our son. It took them 45 minutes to get here. Once we got to the hospital, we had to wait for the on call doctor because our regular doctor was out of

town. I was so scared, because I depended on my doctor so much, and he was always able to calm me down. Again, God works in mysterious ways. The doctor that came to deliver my son had a thirteen-month-old little girl with Down syndrome at home. She was such a blessing to me those first few weeks. I remember her and I crying in her office about the overwhelming feeling and fear that comes with little babies in the beginning. It was a long and painful day, but my beautiful son was born 7:21pm via c-section, and he was just precious.

I remember lying in the operating room, just waiting to hear that cry. Once he cried, and the pediatrician came over to me to let me know me was ok, I could finally breathe again. When I got to hold him for the first time, it was amazing. He was just beautiful. When he looked at me for the first time, I felt like he could touch my soul. There is just something about those blue eyes that made me feel such peace. We spent four days in the hospital. We were very fortunate that we did not have to spend any time in the NICU. Conner had a hard time keeping his temperature up, so we spent a lot of time under the lights. They discovered that I had an infection, so they started me on antibiotics, along with Conner just as a precaution.

Our big concern was his feeding. I could not get him to latch. We tried and tried, but we would eventually go to the bottle. When I think back on that time, I felt alone, scared, and anxious. I was scared for the unknown, anxious about the future, and lonely because I spent most of that time in hospital alone. My husband had to stay with our older son at home. I am so thankful for the nurses at the hospital. They were a true godsend, and were helpful, especially those first few days.

The first few weeks were consumed with trying to get him to gain weight. Conner had lost almost a pound before we left the hospital. I was still trying to breastfeed, and he was just not getting enough milk. We spend the first three weeks of his life going to the doctor every few days to check him. We tried several combinations of breastfeeding, pumping and bottle feeding. We realized that even after 45 minutes of breastfeeding, he only got 15ml of milk. He was just too tired, and his suck was so weak, that he was not able to get milk. I finally decided to exclusively pump and bottle feed. That has been my biggest struggle and stressor, because it is so time-consuming and overwhelming, especially with a three-year-old at home also. I am proud to say that I am still pumping, and it has gotten easier, but it is still quite annoying at times.

I feel like we have been fortunate that Conner has had some minor health issues, but overall, we have been very lucky. After we got his weight stabilized, we were able to take a moment to relax. Conner was born with low muscle tone, which has affected things such as gross motor development, and even contributed to constipation issues. At our eight week appointment, our doctor noticed a heart murmur, so we were referred for another echocardiogram. Those results showed that his murmur that should resolve itself, so we wouldn't need to check it again until he turns three. Around twelve weeks, we began to think Conner was not hearing well. We scheduled an appointment with an ENT. After two attempts, we were able to get a good ABR. We discovered Conner has perfect hearing in his right ear, and severe hearing loss in his left. The whole process took several months, but we have been fitted for and received our new hearing aid. Although hearing problems are common in kids with Down syndrome, the doctors believe that his hearing loss may be the result of an infection I had before his birth, and the preventive antibiotic they put him on at the hospital. This was another time in which

my guilt flooded my thoughts for a few days. Conner continues to have feeding issues that we are working through. Starting solids has been a struggle, but he is slowly beginning to grasp the concept, and we are very proud. He started early intervention at eight weeks, and has slowly begun to increase his therapies over the months. We have physical therapy, occupational therapy, speech therapy, and a feeding specialist. I think my biggest struggle has been to juggle the appointments and therapies. On the bright side, this whole process has helped me become more structured and organized, which I have wanted to do for years. At Conner's six month appointment, we had his thyroid and eyes checked, and all is well. Overall, I am happy with how things are going, and feel very proud of my little man and how hard he works each day.

As I sit here writing this, I have realized it has been almost one year since our diagnosis. What a difference a year makes. I do know now looking back how truly lucky I am to be blessed with my little boy. There are still days when those fears and worries overwhelm me, but they are becoming less and less over time. Now our days are filled with pride and love for a little boy who exceeds my expectations every day. When I see that smile, or hear that laughter, my heart melts. When I see him conquer a milestone that I took for granted with my first child, I am overwhelmed with pride. I know in the future there will be struggles and fear, but I know we will get through it. I still have fear for the future, for his health, and for his life when we are gone, but it is my job to prepare him and us for all the possibilities that could arise.

What I know is Conner has taught me to look at life in a new way. Small accomplishments are sometimes the best things. He has shown me a new love, and he is teaching me patience. All good things come to those who wait. When we hurry, we miss those small things that many take for granted. He is showing me that I am stronger

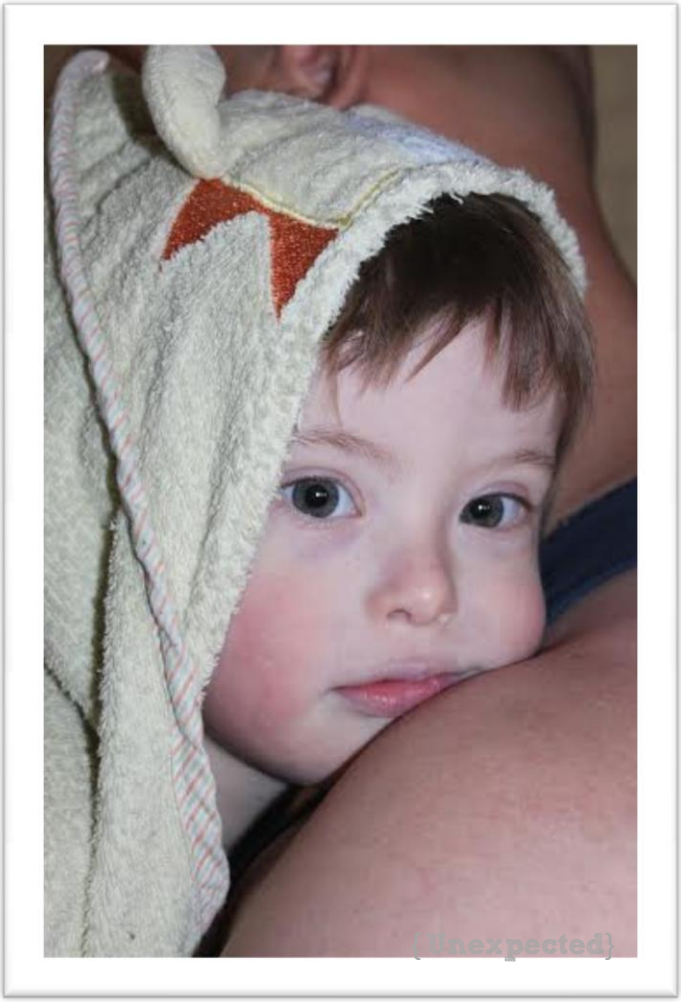
than I thought, and I can handle more than I imagined. I need that strength to be his advocate, so he has the most rewarding life possible. I have many dreams for him and his future, and I believe with my help and the help of other parents, our children can accomplish whatever they want. We can teach society all the things that our children can offer. Finally, no matter what the future holds Conner has been a true blessing, and he is truly loved by his mom, dad and his big brother. We could not imagine our lives without him.

Today, Conner is a happy and healthy eight month old little boy. He is working on sitting unassisted, and learning to crawl. Learning how to eat solids is a work in progress. Each day, he seems to make more and more strides in these areas. We are so very proud of him and how hard he works. His older brother just loves him to pieces, and it has been such joys watching the love between the two of them flourish. It has been a year since our diagnosis, and it has been hard at times, but I would not trade it for the world. He has brought us so much love and happiness. His smile just melts my heart. I can't wait to see what a wonderful man my little boy will become, all that he will accomplish, and the love he will bring to others.

~ Kari, Conner's mom, 39 Washington, United States

{Felix}

After much discussion, and changing our minds at least a dozen times, we decided in November 2009 to try for our eighth baby, and our first together. We figured that if it happened, it happened. I was a month away from turning 39, and my husband was 30 years old.



On February 16, 2010, those two pink lines appeared to confirm that we were having a baby. I was five weeks pregnant. We were extremely happy to know that, in late October, we would welcome the newest member of our family into the world.

The early part of my pregnancy was stressful. I bled off and on quite a bit, and on my husband's birthday, when I was about eight weeks pregnant, I thought for sure we had lost the baby. We went up to the hospital to have it checked out, and cried tears of joy when we saw that tiny little heart beating strongly. My husband still says it was the best birthday gift ever. The bleeding continued for several weeks, but another scan at 12 weeks pregnant again showed that strong little heart chugging along beautifully. This baby wasn't going anywhere!

At exactly 19 weeks and 2 days, we excitedly headed to the hospital to have our routine morphology ultrasound. We had 95% decided to find out the sex of our baby, but in the end, the decision was made for us when the first thing we saw on the scan was a little something extra between the legs. We were having a boy!

The scan was going so well. There was that little heart again, thumping away, ten fingers, ten toes, a little round tummy, and wriggling limbs. And there was that face... that beautiful little face! He was sucking his thumb and opening and shutting his mouth. He was just perfect.

Up until that point, the sonographer had been very chatty. She suddenly went quiet as she looked at his little face over and over again. My stomach sunk. There was something wrong. My baby was going to die. It was all I could do to keep from bursting into tears. It was then I asked, "Is everything OK?" She made a fairly evasive comment about needing to just check something with the radiologist, and then left the room.

It was then I cried. I told my husband there was something wrong. They never say they need to check something if everything is fine. I told him that if the radiologist came back in with her, then we'd know there was something wrong. And of course, the radiologist came back in with her. My husband asked what was wrong. The radiologist was not forthcoming, but said she just wanted to check a few things again. And there was his face... that gorgeous little face again.

We waited for what seemed like ages while things were checked, and then the radiologist turned to us. She said she was concerned about a couple of things. Our baby did not have a nasal bone, hence all the checking of his face. That meant nothing to us. All I could think was that our baby was going to die. "I think your baby has Down

Syndrome", she said. I cannot explain the feeling of relief that washed over me. Here I was thinking our baby would not live, and all he had was Down syndrome! We could handle that! My husband shocked the radiologist by saying, "Is that all?" She told us she didn't think we understood what she was saying, but we assured her we did. We were in love with our baby from the first time we saw those two pink lines. Him having Down syndrome did not change that one little bit.

We were stuck sitting in a room being 'counselled' by a doctor from the hospital for a couple of hours. His recommendation was to have an amniocentisis with a view to termination if the results came back positive. He reinforced every negative stereotype about people with Down syndrome that I had ever heard of. It was all negative information, and the pressure to terminate was intense.

We repeated to him several times that if our baby had Down syndrome, we were OK with that. We did not want an amnio, which carries a small risk of miscarriage. We were happy to continue with the pregnancy, and love our baby regardless of the outcome. He did not want to listen, so we asked if we could leave. After making a booking for a follow-up ultrasound at 25 weeks pregnant, we left.

We had discussed Down syndrome before I even got pregnant. I was 39 years old, and at an increased risk due to my age. Neither of us had an issue with that possibility. Looking back, I remember reading a lot about Down syndrome during those first few months of pregnancy. Maybe it was a mother' instinct.

Once we got home, we read all we could find about Down syndrome, and ordered some books for us and the kids. We also contacted the Down Syndrome Society, who were a

wonderful help with information. Our family was incredibly supportive, and we all looked forward to meeting our little guy... even more so than before!

What happened next crushed us.

We returned for our 25 week scan excited to see our little man once again. We enjoyed watching him wriggling about on the screen. He was an incredibly active baby and barely ever stopped moving. After the scan, we went to see our obstetrician for a check up. He looked through the report from the scan, looked at us and said, "I suppose you were told this is not going to end happily?" I was a little confused. I told him we were aware that he probably had Down syndrome, but we were happy with that, and not sad at all. He replied, "No, your baby has hydrocephalus -- fluid on the brain. He may not survive the pregnancy, and if he does, possibly not for long after that." I felt a rush of emotion, and was totally devastated. Our baby may not live after all. This active, wriggling baby moving inside of me was very ill. I found it hard to believe.

We told him that no matter what happened, all we wanted was to hold our baby in our arms. He assured us that he would do everything he could for our baby to be born alive. We were to have scans every two weeks to measure the ventricles in his brain and the size of his head, which was already bigger than normal due to the fluid. We left the hospital with heavy hearts, and shut ourselves away from the world for a couple of weeks to grieve for our beautiful baby.

Over the coming weeks, the fluid levels in his brain stayed the same: still dangerously high, but no worse. We allowed ourselves a little glimmer of hope with each passing day, and in the last couple of months, started to get a bit excited. Maybe everything would be OK.

On September 29, at 36 weeks pregnant, I rolled over in bed, and my waters broke. I woke up my husband, who nervously drove me to the local hospital. We were then air-lifted by the Royal Flying Doctor Service to the city to have our baby. My pregnancy was considered high risk, and the paediatric neurosurgeon, obstetrician and others who were reviewing my pregnancy were all on call there in case of any problems.

My labor only lasted four hours, and all things considered, was quite easy. The time came to push, at which time my husband got the giggles... nerves, I think. He and I both reached down, grabbed our baby under each arm, and lifted him onto my belly. Our precious little guy! I took one look at his little face and said, "Yep...he's got Down's, and he's perfect!" Our little man was alive. He was alive, and he was healthy, and to look into his eyes was one of the most overwhelming moments of my life.

We named him Felix Sawyer. He was 3110 grams (7lb 1oz), which was not bad for four weeks early. He was 47cm long, and his head measured 33.5cm.

Apart from having poor muscle tone, which is common in people with Down syndrome, he was completely healthy. He needed to be tube fed for a couple of days until he was

strong enough to feed, partly because he was early, but fed like a champion after that. A brain scan the next day came back NAD (Nil Abnormality Detected). Even the paediatrician in neonatal said he was a miracle. He told us that the name Felix means 'lucky'.

After four days, we were able to bring Felix home to begin our lives together. He is the source of so much happiness to us and to others. We are thankful every day to have him as part of our family.

~ Kylie, Felix's mum; 39; Australia

Blogging @ http://felixsmum.blogspot.com.au/

{Luke}

I held on tightly and pushed my head in between my hands as I gripped the steering wheel of my parked car. I was sobbing and my body was shaking. I couldn't catch my breath. My eyes were pouring tears, and they stung from the salt. Just moments ago, I'd been in the store buying supplies for my son's first birthday party tomorrow afternoon. While I was shopping, I'd seen two brothers chasing each other, playing. I wondered if my boys would play like that some day? I managed to maintain my composure, but when I was checking out, I caught a glimpse of a man with a disability greeting shoppers as they entered, and it was too much. Would my son be able to hold a job some day? I completely lost it. The cashier didn't know what to do with me. I shoved my money at her, exited the store amidst the heat and humidity of mid-August, and ran to my car.

I was 21 weeks into my second pregnancy, and I'd gotten the call earlier that morning. Our doctor contacted me to let me know that the results of our MaterniT21 test had come back "consistent with Down syndrome". We'd been waiting seven days for the phone call; however, when I saw the caller ID that morning list the name of my doctor, I still felt butterflies in the pit of my stomach. My husband, Dustin, and I had spent the last

week preparing for this moment. The test was just a formality; our doctor had already found so many indicators.

It all started with my choosing to complete the quad marker screening, a blood test that is drawn at 12 and again at 18 weeks gestation to look for neural tube defects and genetic abnormalities. Quite honestly, I hadn't put much thought into agreeing to do the blood draw. I'd completed it during my first pregnancy just a year ago, and the assurance that came along with knowing my baby was normal and healthy felt great. I was looking forward to having the same results this time around, too. My results came back normal for the quad marker at 12 weeks. Our next "big" appointment was our anatomy scan at 18 weeks gestation. We learned that we were having another boy, and I spent the remainder of our ultrasound dreaming about how, with our boys only being 16 months apart in age, they would play sports together and rough house on the living room floor. I thought about how since they'd only be one grade apart, they'd even share a junior/senior prom!

"Ma'am, are you sure about your dates?" The ultrasound technician, Roger, broke me away from my thoughts. He explained that the baby's heart didn't seem mature enough to be 18 weeks yet, and that he thought it looked to be closer to 17 weeks. I told him I was sure of when I became pregnant, and I was confident that I was 18 weeks along. He reminded us that a lot of development takes place even in a day's time, and that he'd like for us to come back a week later when the baby was more developed, so he could get another look. Before we left the clinic, I took a seat in the oversized green vinyl chair, and made small talk with the phlebotomist as she drew my blood for the quad marker follow-up test. That was a Friday. I spent the next three days dreaming about the future in store for the wonderful family Dustin and I were creating.

On Monday afternoon, just before leaving work, I had a call from my doctor. She was new at my clinic, and for the first time in my life, I had a doctor who appeared to be about my age instead of someone gray, wrinkled, and full of experience. Nonetheless, she seemed confident. Although I wasn't an established patient of hers, when I went into labor with my older son, Matthew, she was on call, and stuck with me for the first 15 hours. Even after she went off call, she came to my room to let me know that she'd be around doing paperwork for a few more hours, and if the baby were to come during that time, she was going to see my delivery through since we'd been together all night. In the end, Matthew didn't come quickly enough, and I ended up with one of her partners for my c-section. Because of her awesome bedside manner, I sought her out for my follow-up care, and when I learned that baby number two was on the way, I wouldn't have considered anyone else. On that Monday afternoon, she was calling to let me know that the results of my quad marker had come back abnormal, showing a 1:85 chance for Down syndrome. As my mind began reeling, she reminded me that the screening was known to show a high rate of false positives, and that I shouldn't get too concerned yet; however, she was recommending that I come in later in the week to see a maternal-fetal medicine (MFM) specialist who had an opening on Thursday for what she called a level two ultrasound.

We had a different ultrasound technician later that week. She was young and blonde, and told me that she'd spend the first 30 minutes or so completing the ultrasound, and when she was finished, the MFM or perinatologist, as I later learned was the appropriate title, would come in to look at the pictures she'd taken. She told me that together, they'd take more pictures, and that he'd likely narrate to me as they surveyed the baby. The monitor was connected to a wall-mounted, flat screen TV and we could

watch as they examined our little guy. When the perinatologist came in, he was polite and kind, but I was quick to notice that he didn't narrate. He concentrated hard on the monitor, asking the technician to review some of the baby's body parts two and three times. When they were finished, the technician left the room and the doctor spun his stool around to the counter behind him, found a piece of scrap paper and began drawing. Dustin and I exchanged a look. We knew that if he needed to draw a diagram, there must be very important news coming our way.

When he spun back around, I noticed that the diagram was of a heart. Somehow, even though our anatomy scan had been less than a week earlier, I didn't make the connection of the immature heart that the tech had mentioned and the diagram in front of me now. The words started as a blur, but eventually, it sunk in that he believed that our baby had a congenital heart defect known as Atrioventricular Canal Defect, or AV Canal for short. He showed us on his pencil-drawn diagram that there appeared to be a hole between the bottom two chambers of the baby's heart, known as a VSD or Ventricular Septal Defect, and another hole across the upper chambers, known as an ASD or Atrial Septal Defect. This man, a doctor who would become a very important figure in my life, also shared that our baby had a shortened femur and a six millimeter thickness of skin on the back of his neck, which, when combined the with heart defect and the abnormal quad marker screening results, led him to believe that our baby had Down syndrome. I didn't cry right away -- honestly, I didn't really know what to think. I pushed the doctor to tell us what he believed to be the "odds" of our baby having Down syndrome based upon the new findings, and he shared that although the quad marker had indicated 1:85, he believed our odds were actually higher than 1:2. Before leaving,

we made a follow up appointment to see him the following week to complete an amniocentesis.

That night, my regular obstetrician called me from her home. I was struck that she trusted me with her personal cell phone number. We talked for about an hour, and during that time, she solidified my trust and respect for her as one of my medical providers. We talked about what it meant to have a diagnosis of Down syndrome. We talked about the emotions that were going around in my head. We even talked about abortion. I was confident that I could never terminate the life of another, especially a being who was growing inside my own body, but at the time, it felt important for me to be educated about the option, and the physical process of terminating a pregnancy this far into the baby's development.

The day came for us to complete the amniocentesis, and I was terrified about the possibility of miscarriage related to the amnio. We'd had a hard time conceiving our first child, and I couldn't imagine what it would be like to lose this pregnancy, especially due to us making the choice to complete the procedure. The nurse had me sign the paperwork that stated I understood the associated risks, and she got me prepped so I was ready for the amnio when the doctor entered our room. When he joined us, however, we validated that we were not going to terminate based upon the results, and because of that, he suggested that we do the MaterniT21 test in its place, which was a simple blood draw instead of an invasive procedure.

We'd waited seven days for the results, and they arrived the morning before we were set to celebrate Matthew's first birthday. We didn't want the news to take over Matthew's special day, so we kept it to ourselves, sharing with just a few important

people when the party was over. In addition to keeping appointments with our perinatologist, we also began seeing a pediatric cardiologist, who we'd follow with for the remainder of the pregnancy to monitor baby's heart as it developed. Additionally, we'd meet with medical genetic counselors to learn more about Down syndrome. I spent a lot of time researching, trying to learn what to expect. Eventually, we accepted our diagnosis. As I continued to feel baby stretch, kick and roll inside my belly, I soon regained excitement about the pregnancy, and once again, became eager to meet our baby boy!

My official due date was January 9th, 2013, but because I was having a repeat cesarean, my scheduled delivery date was the morning of January 2nd, 2013. I had spent the month of December preparing for Christmas with our sweet Matthew, while also getting ready for baby's arrival. In anticipation of baby, I was completing tasks like sterilizing my nursing supplies, and working on getting our nursery together in the final few weeks of the pregnancy. I was thoroughly surprised when I went into active labor early on the morning on December 22nd, 2012. The delivery went off without a hitch, and my perinatologist even came in on his day off to deliver me. Luke William arrived at 11:44 AM, and weighed in at six pounds, eight ounces, was 18 3/4 inches long, and had a head circumference of 12 inches. His APGARs were eight and nine. The nurses cleaned him up and allowed my husband to hold him, while I lovingly gazed on as my doctor continued with the surgery. We snapped a few photos, and Luke was taken to the NICU, where he was evaluated by the cardiology team soon after birth.

The next time I saw Luke, I was being wheeled into the NICU on my way from recovery to the general nursing floor. The nurses pushed my bed in next to Luke's isolette and the first thing I saw were his feet. During the delivery, as our doctor lifted Luke from my

body, I'd questioned if he could tell that the baby really had Down syndrome, and his response to me was, "It's often difficult to see physical signs immediately after birth, but rest assured that your son is beautiful."

Finally, I would get to see my baby! As my bed passed his, I saw those toes. As if it was my maternal instinct kicking in, I saw the first physical sign, a wide space between his big toe and the next one: the sandal gap. As I held him for the first time, and inspected each of those toes and his ten little fingers, and his nose, eyes and ears, my heart began to melt. The fears, anxieties and worries that I'd been carrying for the previous months began to fade. I was in love. Down syndrome didn't seem like such a big deal after all.

One of the hardest parts about Luke's arrival wasn't that he had Down syndrome; it was that he arrived just three days before Christmas, and because I'd had a c-section, I was to be admitted for four days, not to be released until the day after Christmas. As my pregnancy had been considered high risk due to Luke's heart defect, we delivered in a large hospital about an hour and a half from our hometown, which meant we hadn't seen Matthew since we put him to bed on the night of the 21st. I was aching to see my big boy, and was so sad that we wouldn't all be together for our first Christmas as a family of four. Not short of a miracle, the hospital actually granted us our wish that day, and made a special exception for us to allow our boys to meet in a private room for the first time on Christmas Day, 2012. Those short 35 minutes will forever stand out as one of the most precious memories of my lifetime.

That was nearly nine months ago, and our lives have changed as we've grown into a family with two small children, not unlike any other family in our circumstances. It may

come as a surprise to some, but my life feels remarkably normal. We all play together, read books, sing and dance. My husband and I go to work, cook, clean and do laundry. We give the boys their baths before bed and dress them afterwards in cozy jammies. My life feels good! My perspective on Down syndrome has evolved from what it was just one year ago. I am not sad for Luke; he is who God designed him to be before we ever knew he was planned for our family. It's a privilege for all of us to be a part of his journey. I am not sad for Matthew; he has been blessed with a little brother – one that he adores. I know that he will learn lessons throughout his life; because of Luke, he will learn a love and compassion that many never experience. I am not sad for my husband, although I'm not sure he ever felt much sadness himself. He has been a rock and on many days, he's been a great source of strength for me. He is such a loving and involved father, we are all lucky to have him in our lives. I am most certainly no longer sad for myself; however, I'd be lying if I said there wasn't a short period of time when the reality of our situation rocked my world. I have become more than I ever knew I could be before Luke entered my life. The emotional obstacles I've overcome have led me to being more confident in my role as a mother, and also as a woman.

I don't believe all of our challenges are in the rear view yet. In fact, a big one is still looming in our future, as we are currently awaiting Luke's open heart surgery to repair his AV Canal. We are expecting the operation will take place sometime when he's around 15 months old. We know there are other medical issues that could present themselves, and obviously due to the presence of that 47th chromosome, we are expecting that Luke might have to work harder than others to achieve throughout his lifetime.

I'm not letting myself worry too much about what the future might bring. For now, I'm working hard to live in the present and enjoy our young family. When Luke smiles, his entire face lights up, and when I see him smile, my face lights up, too. The joy his soul emits is radiating and consuming, and it reaches me in a way that no other individual has ever touched my heart. The thought of him not being a part of my world is devastating. While there was a time when I questioned if I was really cut out to be the mom of a child with special needs, I can now say with complete honesty that I would go to the edge of the earth for both of my children – regardless of their "special child" or their "typical child" needs. Throughout this journey, I've been surprised by my own ability to stretch and grow and learn about a world that I'd never been exposed to before Luke. I am inspired in different ways by both my children, and I am confident they will make their own individual contributions to our world!

~ Kristin, Luke's mom; 31; Ohio, United States
Blogging @ www.luke-bringeroflight.blogspot.com