



Our first two babies had been conceived with the help of Clomid, a fertility drug, after much heartache and longing for a baby. When we found out we were pregnant with Jessie without the help of modern medicine, we were truly shocked. Just a month or so before, we'd been taking a walk and discussing whether we were certain if we were ready to take a more permanent step about not having any more children. We were getting older (I was 35) and knew our risk of having a child with Down syndrome was higher at our age. That, combined with the fact that my husband wasn't certain he wanted to start over with the baby stage again....our children were 4 and 6 years old, finally past the sleepless nights and colicky baby stage. While we walked and talked trying to reach a decision, what we didn't know was at that moment I was already pregnant! Before our 1st baby was born I'd had 2 miscarriages; I had gestational diabetes with our 1st baby, and some late pregnancy bleeding problems with our second baby. So, although we were surprised and worried, we were amazed at what a miracle this baby was.

With this pregnancy, we chose not to have the AFP test just as we had done with our first two babies. With each pregnancy I asked my doctor if there was anything life threatening that would be detected that we wouldn't find with ultrasound. Each time after discussing it I felt reassured that anything life threatening (a severe case of spina bifida) that could be prepared for at birth would likely be discovered on ultrasound. Other than that, what the test would look for was Down syndrome. We had talked about that if the AFP results were abnormal, an amniocentesis would be recommended, which has a 1% risk of miscarriage. Even that small risk we didn't want to take. I don't at all regret our decision not to know beforehand. It was the right decision for us. For some the knowledge beforehand enables them to prepare mentally for the task that is to come. I, on the other hand, am a worrier. Although my heart desires to always trust God, I know that the rest of the pregnancy would have been overshadowed with worry of all the possible things we might or might not have to face in the future. I am thankful that when we were trying to adjust to the knowledge that she had Down syndrome, and all the health issues that could come with it, that I was able to hold my baby that I already loved.

Jessie continued to be in the breech position in the last weeks before my due date, so we had a C-section scheduled for 39 weeks. The night before Jessie was scheduled to be born my other two children wrote Baby Jessie a note in her baby book about how they couldn't wait to meet her and how they had gone to the doctor with me during pregnancy and to a sibling class to learn how to help take care of her. They were so excited about having a baby sister. The morning of the c-section my husband and I added our notes to Jessie that we couldn't wait to meet her and how we loved her so much already.

When Jessie was born I only got to see her for a second before they whisked her away to check her out. In that second I noticed something about Jessie's eyes, but I couldn't place what it was that was bothering me. It seemed as if they kept her over there for such

a long time compared to how it had been with my other two babies. I thought maybe it was because she was a c-section baby. My husband followed them to the nursery snapping pictures right and left while they took me to recovery. Some time later, I heard my husband's voice outside of my room and when I called him in I could tell that he'd been crying. I was overcome with fear that our baby had died. When I was told, "We think your baby may have Down syndrome", as scary as that sounded to me, I felt such a relief because seeing my husband upset I had thought something worse. I think the way we each learned about Jessie having Down syndrome greatly affected how we dealt with it in those early weeks. I was relieved that although she could be found to have some serious health problems later, for now she was alive and seemed o.k. For Julian, he had been happily taking pictures and had no suspicion of anything wrong when they told him; he was so taken by surprise he felt as though he'd been punched in the gut. (His words!) We all have our own way and time table of grieving and learning to accept the way things are. I had really grown in my relationship with God in the couple of years before Jessie was born, learning to trust Him more, and I know now in many ways he was preparing me for things to come. In those first days I held on to what we had known from the beginning, that the way this baby came to be was such a miracle for us, that she was meant to be here exactly as she was.

Our pediatricians had immediately told us our greatest concerns in the first days were to watch for any signs of heart or intestinal problems. We could hardly close our eyes those first few days for fear she might stop breathing while we were sleeping. I was never so relieved to see baby poop, so we could know there wasn't intestinal blockage.

While we were in the hospital we began reading the book "Babies with Down Syndrome" that our pediatricians had given us. For me the greatest fear is always the unknown. I wanted all the information I could get. There were aspects of reading it that were comforting to me and others that scared me to death. There were many serious, and some not so serious, health problems that our daughter could face. We were so scared, wondering in those early days and weeks what this really meant for all of us. I knew it was kind of like the information sheet you get from the pharmacy with all the possible side effects, that they wouldn't ALL apply to us, but all the possibilities of what could felt pretty overwhelming. When I read about all the therapies, etc. that could be helpful I thought how are we ever going to pay for all that?!

It seems odd now, the fears that were so all consuming when Jessie was born. I can remember when Jessie was a newborn wondering what does "some mental retardation" really mean? Would she be able to feed herself? Would we be able to go out to eat as a family in a restaurant? Our other children were doing t-ball and dance lessons. How would this new baby with special needs affect our ability to continue with those activities? How would we ever know how to discipline Jessie – how could we know what she understood? As Jordan and Evan got older, how would they feel about having a sister with Down syndrome? In general, would life EVER resemble normal again?! When Jessie was still just a baby we met some other families who had children with Down syndrome and that was such a huge help! I can't tell you how much that helped us and put many fears to rest.

When Jessie was 2 weeks old our pediatrician heard a heart murmur and the next day the cardiologist found that she had two holes in her heart called ASD and VSD. We learned she would need to have open heart surgery by the time she was 6 months old. Although as heart defects go we were told this was a better one to have, more easily repaired, it was a scary time until surgery was behind us. Suddenly, any more distant future concerns took a back seat and we concentrated on getting Jessie to gain enough weight to be ready for surgery. Our lives seemed to revolve around getting Jessie to take in enough calories to gain weight. Eating burned up more calories than she took in a feeding. Jessie had open heart surgery when she was 3 months old, sooner than expected. She did so well with surgery and we couldn't believe how well and quickly she recovered.

Jessie started in early intervention when she was just a few weeks old. All of the therapies (physical, occupational and speech therapy) were time consuming and in our every day lives that was the biggest adjustment. While our other babies went through each stage so quickly you almost missed it, with Jessie, we had to learn how to teach her new things. Sometimes we'd seem to work on the same thing forever; then suddenly she could do that thing and 2 or 3 other things as well. I can remember every step of teaching her to pull up to stand, and how she worked so determinedly to do it. When Jessie learns something new it's like a party at our house! We all enjoy her every accomplishment so much. Jordan and Evan used to argue over who got to call Daddy at work to tell him what



new thing Jessie did! Now that Jessie is 7 and loves to talk on the phone she insists on calling Daddy herself. Just this week she called Daddy to recite every word of John 3:16, making her Daddy quite proud.

When Jessie was a baby and toddler most of the time I was fine with the fact that she did things on a slower schedule than other kids. There were days though, where it was so obvious that other children did things effortlessly that she had to work very hard to do. I would have a little reality check and cry for a day or two and feel sorry for the both of us. After a day or two I was usually able to shake it off and get back to the business of life. This would usually happen after I took a turn in the nursery at church or our homeschool coop. It truly wasn't about the delays, it was the realization that she would always have to work harder at things.

At seven Jessie is learning to sight read before learning to read with phonics. She is a very visual learner and has an excellent memory for things she sees. For her AWANA class at church she has been learning Bible verses. She is learning to write her letters, can write her first and last name, recognizes most #'s to 100, counting to 10. She can swim short distances under water, is taking gymnastics and just started a "Special Steppers" tap dance class. It was a very difficult decision initially for us to decide whether to homeschool Jessie or for her to go to school. Although our 1st two

children have always been homeschooled, I felt very intimidated by the challenge of being her only teacher. Although it is challenging, it is equally rewarding, as I see all that she can learn when it is presented in a way that works for her. I only mention the specific things that she can do because it was so encouraging to me when she was young to read the accomplishments of other children with Down syndrome.

I thought a lot before writing this about what I really wanted to know when Jessie was a newborn, what was helpful to me. You of course know, that there will be difficulties and challenges, and I don't want to gloss over or minimize that they are real. There are things that are different, and in some ways more difficult, about raising a child with Down syndrome. What I want you to know is that even though that is true we wouldn't change Jessie if we could. Of course we would change the health issues if we could, but the core of who Jessie is, is in part due to Down syndrome.

It is not all of who she is but is part of what makes her who she is. Many, many times I have thanked God, that in giving us Jessie, He met His expectations and not ours. We wouldn't have chosen to have a child with Down syndrome and in not having her we would have been cheated of an incredible blessing. One of the biggest blessings that Jessie has brought to our life is the way our whole family looks at things differently now.

Having her has caused us to reevaluate and remember what is really important in life. At 13 and 15, Evan and Jordan are her biggest advocates. They both have tender hearts for all children with special needs. They each were "Buddies" in our Miracle League season this past spring and helped at Camp Smile the past 2 summers. Whether it is a career choice or volunteering, I know they will always be involved with people with special needs. We are richer as a family because of Jessie and the experiences she has brought into our life. Whereas in the beginning, I wondered would our life ever be "normal" again, now I am so thankful it is not.



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