

Our Story: Baby Kylie

We knew our future baby would be a blessing to us when we found out that I was pregnant on my 29th birthday. We had just started trying for our second baby the month before and had trouble conceiving our first, so it was a great and unexpected surprise!! Just as our first pregnancy, we were cautious about everything. I started prenatal vitamins months before I became pregnant, took calcium, ate healthy, was the correct weight, didn't paint, and I made sure not to carry around my 2 year old as much as I could. We were sure that we would have a healthy, perfect, little second baby!!

We were so excited to go into our 19 week ultrasound and to find out the sex of our new little baby so we could start preparing his or her room just as we did our first. Little did we know that our life was about to change forever. As we entered the room, we made sure to let the technician know that we wanted to find out the sex of our baby and breathed a sigh of relief every time he spoke about the different parts of our baby and measured them to see if they were normal. We found out that we were having another little girl and we were so excited and overjoyed!! Now our little girl would have a sister. As our ultrasound continued though, we could see they kept going back to her feet. The technician then said he couldn't get a good look at her feet, so he went to get another technician to take a look. At this point, I knew something was wrong and my stomach turned and heart started to ache. The second technician also looked at her feet and took more measurements. My husband and I were frantically asking questions that could not be answered. They just told us they needed to take a better look at her feet and escorted us to a waiting area. They told us to wait here and they were going to go speak with the doctor.

The next few minutes felt like hours as we waited to find out what was happening. When the technician finally returned, he escorted us to the doctor's office where we again waited to speak to our doctor. She cared for us for my first pregnancy and I regularly saw her, so we felt confident she would clear up this situation. As she entered the room, I will never forget her words, "As you have probably figured out by now, something is wrong with the baby." I immediately started crying and panicking as my husband tried to remain calm and strong. She then told us that our daughter has bilateral clubfeet and explained this is a birth defect. My head was spinning and I had no prior knowledge of what a clubfoot even was. I was shocked and in disbelief. How could something like this happen to us who had done everything exactly like we were supposed to? What was going to happen to this child? Were kids going to make fun of her? Would she walk? How would this affect our first daughter? Would her life ever be the same again?



Then, I started questioning my doctor. I asked if this is for sure and not just a chance that they made a mistake. She told me they were positive and we would be sent to Mayo Clinic to see a perinatalogist to make sure she only had the clubfeet and that there was not an underlying larger problem. She explained that clubfoot can be corrected, but did not know a lot about it. She

thought possibly surgery and explained that her feet would be turned inward. She would still have toes and feet similar looking to ours; they would just be turned inward and facing the wrong way. I was completely devastated.

As we returned home, I felt hopeless and depressed. I was still crying as we went inside our house to my mom who was watching my little girl. We told her the news and she hugged me and told me she was sorry. I hugged my daughter and felt more thankful than ever that we had one healthy child. I was not sure how we were going to get through all of this and I was frightened that our life would never be the same again.....

Now at present day, our life is almost back to normal. We are so thankful that we have our second daughter, Kylie, and would not trade her in for anything or our experience with clubfoot either. Everything that has happened has made us stronger, both individually and as parents. It surprisingly has not affected our first daughter as badly as we had originally thought it would. She understands we are fixing her feet and doesn't notice her differences.

Our sweet baby girl is now 9 months old and her feet are perfect!! She still wears her braces (shoes and bar) for 14 hours in a 24 hour period. This means that she wears them from 7 am to 7 pm usually and a 2 hour nap. Most people do not even know that she was born with clubfeet unless we tell them or they are close friends or family that has stuck through it with us!!!

I did A LOT of research on clubfoot for the remainder of my pregnancy. I met with a pediatric orthopedic surgeon before my daughter was born. I searched websites and read anything about clubfoot that I could get my hands on. In the end, my research and diligence paid off. We decided to treat my daughter with the Ponseti method at Mayo Clinic (where we lived at the time). We had a great orthopedic surgeon there, Dr. McIntosh. She started seeing Kylie just days after she was born. Kylie had 7 sets of casts on her little feet and legs. We would go in every week to have her casts sawed off and watched as Dr. McIntosh moved and manipulated her foot before she put the new cast on. We watched our daughter cry and feel pain, but kept our eye on the end result and how much better her life would be in the end. We

watched her tenotomy (where they cut their heel cord so that the foot will release like normal) and were again excited when her final cast was put on.



Her casting was successful and she moved onto bracing for the next 3 months. We moved after casting and now see Dr. Morcuende, who is also excellent, for Kylie's clubfeet. He handles all of her bracing and encourages us to continue with the bracing as it is a success in ensuring that her feet don't move back. Most likely, Kylie will remain in her braces as she is until she is between the ages 2-4 year old. We are hopeful and optimistic that her feet will remain corrected and she will live a normal, healthy life. At 9 months, she has met every milestone on time and is now pulling to a stand and bearing weight on her little feet!!!

What I wish I would have known as a pregnant/new parent of a clubfoot child.....

This will all pass!! Do what you have to do for your child to be treated with the Ponseti method vs. surgery if at all possible. Life will eventually return to normal.

There are still a lot of doctors that treat clubfoot with surgery or other methods that are not as effective as casting and bracing (the Ponseti method). It is worth the traveling and inconvenience of possibly being apart from your family for a few months so that your child will be able to walk normal!!! We have seen many children in the waiting room coming back at older ages because their feet have regressed or turned back. A lot of these kids started off being treated in some way besides the Ponseti method!!! The few months of discomfort and the inconvenience of bracing afterwards is a small price to pay for your child to have the same advantages as other children for the rest of their older childhood and adult life!! Things are almost normal now and most people don't even know our daughter was born with clubfeet. The only difference is she needs her braces put on for nap and nighttime and we have appointments every 6 months with her orthopedic surgeon.

He/she will be a little fussy and needy after each casting. If possible, arrange for someone to take your other child/children so that you can give needed attention to your clubfoot child for the rest of the day after a casting.

Your baby will be tired from crying and sore for the rest of the day and sometimes for the next day after casting. His or her foot is being manipulated to go a different way than it was formed to go. I would compare the fussiness/tiredness/eating for comfort to be that of a sick baby. You will want to give your baby the comfort that he or she needs and wants after you see them

going through the casting. We never wanted our other child to feel less important or deprived of attention, so we always arranged for someone to take her for the rest of the day after casting if possible. Since you know a week ahead of time, it usually can be planned and just makes everything go smoother!!!

Always bring a bottle and pacifier to casting. If you live in a cold climate, bring a blanket and towel also.

Surprisingly, our baby loved the saw and vibration of it. Our doctor said a lot of babies do, but your baby will cry during casting. It helps to have a bottle for comfort and a pacifier for distraction. When you leave a casting, their cast will still feel wet, so you can bring a towel or washcloth so the plaster doesn't get on your car seat and if you live somewhere where the temperatures are cold, you might want to bring an extra blanket as well. It does take a couple hours for the plaster to fully dry each time even though it gets hard almost instantly!!!

How will this affect my other child/children?



Surprisingly, not much. This was one of my greatest fears when I found out that we were having a clubfoot child. When your other child sees that you don't treat him or her different, they will adjust. Our daughter even started explaining to other people why she had casts on or why she wears her braces. Kids are resilient and if you don't make a big deal of it, neither will they. We always told our daughter that we are fixing her feet so that she can walk just like you!! That seemed to always be a

good enough answer for her! She did ask questions about her casts and liked to feel them and touch them, but after a few minutes, usually went back to playing and "her own" things.

How will people treat my clubfoot child?

Well, this depends on the people....most people have a good heart and are just curious. This is what my husband and I always assume when we are answering questions or get into a conversation about our daughter's feet. It seems people are most curious when they see casts on a tiny little infant. Most people are concerned and worried about how this happened. They will probably say things like, "What happened to her?" or "Ouch, she must have had a bad accident, huh?" It took us a while to not take it as a judgment on ourselves as parents. Once we adapted the attitude of "who cares" it became a lot easier to inform rather than defend ourselves. Towards the end, I tried to always smile and answer questions politely and kindly instead of rolling my eyes because this was the 5th time I had answered the question since we

had been out that day. As time went on and goes on, we have learned that answering nicely is giving people knowledge and knowledge is power. A lot of times you just want to move on with what you are doing and go through places in peace, but as you are answering, you may be giving someone knowledge who needs it or empowering a relative to pass on the knowledge for another parent who may eventually have a clubfoot child.



What am I going to dress my clubfoot child in??

During casting, we dressed our daughter in sleepers that were one size bigger than she would wear normally and just rolled up the sleeves that were too long. During the summer months, your baby could wear shorts, skirts, etc. Even with the casts on, regular clothes and socks (the same size they would normally be in) will fit (even leggings) because their little calves and feet are just made smaller because of their clubfoot condition!!!

For bracing, you will need a bunch of sleep n plays without feet. Carters sells these in the fall at the Carters outlet, Target, and Walmart. We stocked up in every size (from 3 months to 12 months) and used them for PJ's and clothes. If you or someone in your family is handy and can sew, you could just cut the feet off of regular sleepers and hem them.

When they are in full time bracing, button crotch pants and sleep n plays are easiest because you can get the pants off without taking the shoes and bar off each time you change them. If you are buying clothes ahead of time, you will probably want to look for separates because their legs (calves) are just made smaller because of their clubfeet. We always bought one size smaller pants than top.

After full time bracing, they can be dressed just as any other baby!! Yah!!! We still use Sleep n plays without feet for bedtime or after the size 12 months most stores sell footless pajamas with a top and bottom that also work!!

Your baby will develop normally and meet milestones on time even with wearing his or her casts and braces.

This was something that was hard for me to believe when I heard. How can this be possible? I always thought that Kylie would be slower than our first daughter. However, she has been faster on some things and has met every milestone either the same or faster than our first child. Those huge casts and braces give those babies a lot of strength as long as you give them a lot of floor time to play!!! She is in many ways stronger and more willful than our first child. It did take her a little bit of time to build up her leg muscles to crawl once the casts/braces were

off, but she could always kick like a star!! Just beware that those braces and casts can be weapons when they kick, especially to siblings and furniture that are in their way!!

She/he will still be happy and fulfilled and develop normally.

I was so worried that my little angel would not be as happy as my first child because of all of the things that she has had to bear and go through. She is, in fact, happier. She really does not have any clue that she is different than any of us. Once she was free of the casts and braces during the day, she is as happy, if not happier, than any baby I have ever seen!!

Your baby's calves and feet will be smaller than they would have been if they did not have clubfeet. Their feet are also very sensitive, especially after getting out of casts.

All clubfeet children have smaller calves and feet than other children their age and they will remain smaller for the rest of their lives. My daughter's is not extremely noticeable since she had bilateral clubfeet (both feet), but it is noticeable in the summer when she wears shorts and skirts. Her feet are extremely small and at 9 months she is still in a size 2 baby shoe!! My first daughter wore the same shoes at just a couple months old!! Also, my daughter doesn't like her feet touched a lot. They are more sensitive than usual and they were especially sensitive for a month or two when she had her final cast removed.