



### Belinda's DDH Story:



Abby was diagnosed at 8 weeks old. She had an ultrasound because we have a strong family history (Mother, Auntie & Uncle were all braced as babies) & at my insistence, as I work as a sonographer and part of my job has been to work scanning for hip dysplasia. Through my work, I was already well aware of babies who have been told they were clinically normal but turned out to have severe DDH on imaging.

The day after Abby had her scan and we discovered she had bilateral severe dysplasia, we went for our routine MCHN check. The nurse did the usual weight, length and hip checks & informed us all was going well - when I told her that Abby's hip were in fact not fine, she was anything but surprised. Her lack of reaction did make me question further how well these clinical checks are being carried out. However, when we met with the Orthopaedic Surgeon the following week, after examining Abby and the imaging, he informed us that she is a tricky case as she does not clinically feel as concerning as the imaging showed. This again highlighted to me the inadequacy of the clinical manipulations, & that even when the clinical tests are carried out correctly, the results can be misleading.

With all this in mind I am so grateful for my family history and for the knowledge I have gained in my career, as it would have been so easy for Abby to slip through the net & miss early diagnosis. Given the severity of her dysplasia, we would have certainly headed straight to invasive surgery had she been diagnosed later.

Abby adapted to her brace wonderfully. She was so determined! She learnt to roll & crawl whilst braced. I on the other hand struggled, but eventually adapted.



Breastfeeding was tricky but manageable with pillows for support; we couldn't use our brand new double pram as it was too narrow; we needed a new wider car seat; she had to move from her bassinet to a cot because it was too narrow; clothing never really fitted properly as it needed to stretch over the brace; she could no longer be swaddled properly, so we transitioned her to a Grobag; she couldn't have a bath for the first 8 weeks, as the brace stayed on 24/7; nappy changes were an art form, again because they had to be done with the brace in place.

My biggest sorrow was that squishy newborn snuggles were taken away from me, because she always had the hard brace on and it was impossible to hold her in the traditional, cuddly way. But, missing out on those moments is a small price to pay for healthy hips and with the wonderful support of the DDH Facebook community we got through it.

Abby was given the all clear with a normal x-ray at 10 months old. After 8 months of bracing the brace came off for good.

She has just had her 6 months post-bracing x-ray & check up with the surgeon and unfortunately there has been some regression. The x-ray shows she now has mild bilateral dysplasia again. We are in no-man's land. The current plan is to wait another 6 months & re x-ray her, by which time her hips will either improve or worsen and we could then be looking at surgical correction. Abby is a rare case; Regression is uncommon. If caught early & treated appropriately, the outcome is usually favourable. And in fact even if caught late, it is still a readily treatable condition. Unfortunately the interventions required become insurmountably more extensive & difficult the older the child gets.

There is more of our journey to come - for both Abby and myself. Whilst Abby was being treated, I myself at 32yo began to have groin pain. After x-rays and an MRI, I was re-diagnosed with hip dysplasia. I was braced as a baby, after being born breech with bilateral hip dislocations. Unfortunately the only cure for an adult with hip dysplasia is a rather brutal, bone breaking operation called a Pelvic Osteotomy or to wait until osteoarthritis sets in and have a hip replacement. But whatever the future holds for us, eventually we will both have healthy hips - whatever it takes.

Written April 2015.