

KIRSTY AND HANNAH

Our story so far...

Hannah was born in January 2008 at 27 weeks and weighing just 2lb 6oz. Her arrival came as somewhat of a surprise, I'd been working the day before! I realised something wasn't quite right during the day as, very unusually, I hadn't felt her kick at all. Luckily my in-laws were staying with us at the time so we were able to leave our older son Ollie in their capable hands as we traipsed off to Southmead Hospital in the middle of the night. After several hours on a monitor I was asked to stay overnight and be seen by a consultant in the morning.

A scan revealed that something had gone badly wrong and Hannah had lost a lot of blood. The decision was made to deliver her early. She needed a LOT of medical intervention and altogether spent 14 weeks in the Neonatal Intensive Care unit at Southmead, coming home on oxygen. During our time in the unit we noticed that Hannah didn't seem to respond to loud noises at all and we were not overly surprised when she failed the Newborn Hearing test. We were reassured that many babies did not pass this test and it could be due to the background noise in the unit or how tiny she was.

We were given a follow up appointment at Children's Audiology. Again Hannah failed this test and the following ABR test and we were told that Hannah was profoundly deaf. Even though I knew what the results would be I still cried all the way home. I knew nothing about deafness, knew no one else with a deaf child and had no idea what the future would hold. We were contacted by the Sensory Support Service the following day and met with our Teacher of the Deaf within a week. It was such a relief to know that there was support out there for us. We also contacted the NDCS and got as much information as we possibly could. I think we accepted Hannah's hearing loss quickly because we had come so close to losing her at the beginning, but I was still occasionally blindsided. I remember receiving a leaflet from the NDCS about home technology – alarm clocks that vibrated, door bells that flashed etc. For some reason this made me dissolve into tears – I think it was the impact that simple things that I'd always taken for granted would have to change for Hannah.

We appreciated the support that the Teacher of the Deaf gave us, but wanted to meet other families with deaf children. The sensory support service at that time held New Parents groups before parents could join the Acorns group held at Elmfield House. We had to wait a couple of months before the next new parents' groups were organised and for us that seemed like a very long time. I didn't know anything about the Family Centre and we were not given any information about it, which seems a real shame.

Eventually Hannah, her big brother Ollie and I were able to attend Acorns and at last here were other parents who understood exactly what we were going through and had advice and support from 'real' experience. The talks from professionals, including Sign Language Communication advisors and Speech and Language therapists were invaluable and I was able to heave a huge sigh of relief – I now understood that although our family had changed, it wasn't going to be a change for the worse - just for something different.

As we had expressed an interest in Sign Language, our ToD arranged for a deaf adult to come to our home on a weekly basis to give us basic signs to use in the home. Both Rik and I attended, along with my parents and other members of the family. Eventually Ollie joined in too and when Hannah was old enough she became part of the group. I was also told by another parent at Acorns about The Family Centre and their parent sign language classes. I quickly joined this class and this gave me the confidence to start a BSL Level One course at Filton College, along with my mum. We followed this with a Level Two course organised by The Family Centre and I have just passed Level Three.

It became obvious very quickly that Hannah wasn't receiving any benefit at all from her hearing aids and we began the process of assessment for cochlear implants. For us, this wasn't a particularly difficult decision to make as Hannah had never responded to sound during audiology tests, apart from one raised eyebrow at a tone that apparently was the equivalent of an aeroplane taking off in her ear! We knew that implants would be the only way that she would ever be able to access sound and although the Implant Team were very careful not to give us any guarantees we agreed that implants were the way forward. Hannah was implanted in 2009 and very quickly responded to sound.

When we made the decision to go forward with cochlear implants, our ToD advised us to stop signing with Hannah, however I disagreed with this and we have continued to use BSL with Hannah as well as speech. Hannah is and always will be deaf and there are times and situations when signing is a far easier mode of communication. We also wanted to give Hannah the choice when she is older; she may not want to use her implants on a daily basis and may prefer to rely more on sign. The whole reason for us agreeing to cochlear implants was to give her more opportunities and more choice, I didn't want to deny her the opportunity of learning sign.

As Hannah is getting older, the Family Centre events are a way for her to meet and play with other deaf children. When she starts school next year and we no longer go to Acorns, these events will ensure that all of us continue to have contact with other families with deaf children. I think this will be important for Hannah to have a deaf peer group – kids she knows well who know exactly what she's talking about, important for Ollie to have contact with other siblings who know what he's talking about and important for Rik and I to know other parents who understand when we have a moan, commiserate when we have setbacks and celebrate when we have successes.

Through Acorns, NDCS and Family Centre events we have met lots of families with lots of different stories. We all have our deaf children in common but we have very different journeys, some have chosen an oral-only route, some a sign-only route, some choose to mix speech and sign. Some families come to nearly every event and some to only a few. I think we have been incredibly lucky to meet all these families, to hear their stories and to share ours. We have received so much support, sometimes at the really difficult times that all of us encounter, sometimes in shared commiseration at the difficulties of keeping hearing aids on small babies! I think Ollie's words sum it all up though: "Mummy, I'm really lucky that Hannah is deaf, not everybody gets to have a deaf brother or sister."

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