



## JENNY AND THOMAS

### Our story.

We have two amazing children. Thomas who is four, has just started school and is learning to read and write and Ella who is two and very cheeky. Thomas is Deaf.

After a traumatic labour and birth, our son Thomas was born via emergency caesarean and taken to the neonatal intensive care unit at St Michael's hospital.

He was ventilated and had head cooling therapy to reduce any potential brain damage whilst the doctors gave him other medications to stop seizures which allowed him to breathe on his own.

After two weeks he was stable enough to have his Newborn Hearing Screen, we didn't think for a second that there would be a problem, in fact we'd spent the previous two weeks reading him stories and singing songs. Hence we were surprised when the audiologist informed us that Thomas had not passed the screening, though she said not to worry and that lots of babies didn't pass first time around due to the background noise in the ward, something we pinned our hopes on at that time. We were discharged home and a month later returned for another hearing test, again Thomas did not pass, and this time we were told that it might be because his brain was still swollen and we were asked to return in another month. As many parents and grandparents of deaf children do, we did lots of our own hearing tests involving loud banging, and convinced ourselves still that Thomas could hear perfectly well.

A month later it came as a huge shock to us that Thomas was severe to profoundly deaf and although we were hugely grateful that he survived his birth we felt a sense of loss and worry for his future.

We were given a leaflet with a number for the National Deaf Children's Society on it but I couldn't face calling them and acknowledging it immediately.

A Teacher of the Deaf visited a week later and after that I felt that I needed to talk to someone who had experience of a deaf child so contacted The Family Centre (Deaf Children). The Family Centre put me in contact with another mum who was a huge help and from her I realised that even though Thomas couldn't hear me, he could feel me cuddle him and feel the vibrations as I talked or sang.

Thomas was fitted with hearing aids at three months old and then we attended a couple of buds sessions run by the sensory support unit followed by weekly Acorns sessions which were invaluable. Thomas had regular visits from his Teacher of the Deaf and over time it became apparent that he wasn't gaining any useful hearing through his hearing aids, and so the Teacher of the Deaf discussed cochlear implants.

We spent a lot of time talking to people and researching cochlear implants and most of all wished we had a crystal ball to see what life would be like for Thomas in the future or to ask him, but time is of the essence for successful implantation in a child without any hearing or stimulation of the auditory nerve, and therefore we made the decision that Thomas would have cochlear implants.

Thomas was implanted at thirteen months old and switched on a month later.

I've continued to use sign supported English with Thomas and he attends Deaf/deaf group every week for access to BSL and deaf adults and peers, partly this is so that Thomas has an identity and confidence about who he is, and also, so that when he grows up he can make the choice himself about which communication method he wishes to use.

Thomas is just completing his reception year at a local mainstream school with HIRB (Hearing Impaired Resource Base) attached and is progressing really well. It is easy to forget just how far he has come and how hard it can be along the way. Cochlear implants are amazing technology but no magic bullet and a lot of hard work is required from the child and parents.

Thomas is now a confident, happy and outgoing boy with strong friends both in school and from The Family Centre and talks away in long sentences. It is only when we look back we remember that we celebrated every new, hard won word as Thomas had to literally learn to listen and work hard at a skill that hearing children just do. We can see as his Sister learns to talk, that language almost comes for free to hearing children but for Deaf children it is hard work. They do not get the benefit of all those overheard conversations and we often thought that Thomas must feel like we would feel in a foreign country trying to guess the context and what is going on. 'What Mummy?' is still a favourite phrase.

A lot of positives have come from this experience as well, and The Family Centre has been at the core of some of these. We have made lasting friendships with other parents, as has Thomas with other Deaf children. The Family Centre has been a brilliant source of support and information enabling us to learn BSL and enabling Thomas to build a whole group of friends outside of school that we believe is one of the reasons for his confidence.

Looking back we realise that a lot of things we worried about have been overcome. Of course we've found new things to worry about. The feeling has always been 'Will Thomas ever get there?' To start with it was would the implants work, then will he learn to say a word, will he learn to talk in sentences, which school should he go to and now will he catch up with his peers. He has done so well and each of these things he has achieved. So given time the worry is less and we have also come to realise all of the positive things that come from Thomas being Deaf.

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