

The First Years with Josh

When Josh was born it appeared as if he had a layer of skin missing from the top of his head all the way down his shoulders and back. He was taken straight away to the Special Care Unit. No-one was sure what was wrong with him or how to treat him. Eventually his skin cleared up to a satisfactory standard and he was allowed home after 10 days.

Josh though was very difficult to feed. It would take a good hour to feed him his bottle and he appeared clingy as he would fall asleep in our arms, but as soon as we put him down he would wake up screaming. When we were winding him he would have milk coming forcefully out of his nose. However, as Josh was our first child we weren't sure what to think especially as our health visitor told us this was normal for some babies. After 7 weeks we had to take Josh to the doctor as it seemed he would wriggle around while feeding as if he was struggling to breathe. The doctor wasn't sure what was wrong but told us to keep a check in case he would start fitting. A week later we had to call an ambulance as he was struggling to breathe and his lips were turning blue. After feeding him at the hospital he was x-rayed and it was discovered he had reflux. We noticed great improvements now as we knew to change him before eating and to prop him up while sleeping. He was very much more settled. After a year we were referred to a genetic specialist who diagnosed Josh with Hypohidrotic E.D. We were relieved to have a diagnosis and were referred to various specialists. We also discovered the ED Society who were such a help with any queries we had and where we could read more information about this condition.

Josh made all the usual baby noises and made good attempts at making proper words. He started nursery and though he was making progress he saw a Speech Therapist. He was lucky as one worked with him once a fortnight in his nursery and gave us activities to complete at home. When he started school he was kept in this programme but worked with a different Therapist. She noticed Josh had a very good comprehension along with a good knowledge but still struggled with the clarity of a lot of sounds. She asked about how he fed as a baby and then referred him to The Royal Hospital in Belfast. The Speech Therapist there swept her finger around his mouth and felt a notch at the top of his mouth. She referred him to meet a plastic surgeon. Again he did a finger sweep and explained that all his muscles were gathered together and were in the wrong places so that's why Josh couldn't use them correctly. The reflux as a baby and the fact that a lot of Josh's sounds were very nasally were as a result of Josh's palette not closing over enough. It was diagnosed that he had a sub mucus cleft palette.

Within a few months Josh had his operation. Although we were concerned, we knew this was best for Josh especially at his young age. He was very content in hospital and the staff were fantastic. There was a lovely atmosphere around the ward and Josh made friends. He loved his Surgeon as he knew how to talk to Josh at his level and explained exactly the procedure he would perform. It was explained to us that there were 2 possible procedures. One was less intrusive and it was hoped this would be enough to benefit Josh. When the Surgeon opened Josh's palette he was able to re-arrange Josh's muscles and this was enough to hopefully cure the problem. Josh coped very well after the operation. After a few days Josh was eating and drinking and was back chatting to everyone as usual.

Josh has been to see the Surgeon at various appointments and he is very pleased with the progress Josh has made. The scar has healed well although there will still be some sensitivity for a while around that area. Josh completes Jolly Phonics work in school and at

therapy. Before the operation Josh was beginning to become very negative toward any sound work as he was struggling and was beginning to try to refuse completing it. We had to attack it in short bursts and finish when he was having some success. Now though everyone has noticed such improvements with his speech. He still struggles with his 'c' 'k' sounds but other than that he has the majority of his sounds. He does not sound nasally and his confidence is soaring. He loves participating in show and tell in front of his class and his teacher has written some lovely notes home about how well he has done. Josh's reading is now one of his favourite activities and he is catching up to a standard where he should be. Hopefully he will continue to make good progress.

We now have a little girl who is 2 and she is perfectly healthy. This made us realise how hard some things were for Josh. He has gained a lovely personality though partly because of being around so many unknown people from such a young age. His sister is very lucky to have such a kind brother.

I hope this information will be of use to others.