

THANK YOU ADDENBROOKE'S

One day Joshua came home crying because some older children, (not from our street) were making fun of him because of his speech and his look, while they were playing football in the park, just few yards away from our home. Our first reaction was to go out and speak to them, and to tell them off for hurting his feelings, but there wasn't enough time as Joshua was upset and we just wanted to give him a hug and talk to him. His dad, Nick took him into his arms and said. "Now, tell me what does your daddy do"? Somehow, those words grabbed his attention as he was getting less upset and was thinking about his answer. 'He is a pilot', Joshua said with an excitement. "That's right' Nick said. 'Tell me what type of aeroplanes has daddy flown.' Joshua gave us a smile and with a bit of thinking mentioned all types of aeroplanes Nick flew. 'Well done' Nick replied. 'You know that your daddy was born with the same thing as you, cleft lip and a palate and his nose is very similar to yours, even though I think your nose and lip are really nice, as Mr Hall who is a very nice man, did a fantastic repair. You also know that your daddy used to speak so much like you when he was little, but look at me now, my speech is very clear and you will speak just like me, (with a bit of practice). So, next time if somebody teases you just remember that. Joshua happily nodded his head and we all went to the park and played football. When we got to the park the boys who teased him earlier were still there. Nick went to them and explained how Joshua was hurt by their comments and how they should never make fun of anybody. Boys apologised and we all had a good game of football.

At that time Joshua was 6 years old and this was just one of the incidents that many children born with a cleft lip and/or a cleft palate will face in their life. Joshua knows that he can always come and tell us if he is hurt and that we'll try everything we can to help him, but we are also aware that as much as we want to protect our children and fight the battle for them, there is going to be a time when they will need to do it for themselves. Nick talks to Joshua about his own experience and what he went through when he was growing up, how determined he was to overcome any unkindness and hurtful comments and how he achieved his goal to be a pilot. Today he has over 25 years of flying behind him and have very special bond with his son who is also very proud of his dad.

Joshua was born with a cleft lip and a cleft palate, and we can only praise the care given by the medical professionals both in Bedford and Addenbrooke's Hospital, Cambridge. When we were told at the ultrasound scan that our baby will be born with a cleft lip and possible cleft palate it was very hard to take in everything medical staff was saying. I was really upset at the time and my husband who was with me was trying to be strong for both of us. The next few days I cried a lot and lots of questions were going through our mind; how will this little baby cope with the surgery, who will operate, how will I feed him, how will I cope with having a baby with a cleft, will I bond,?

Few days after the scan we spoke to a lovely lady Ms Sue Burgess, the Cleft Network Co-ordinator at Addenbrooke's Hospital who was wonderful and very helpful. We felt assured that everything will be OK. Ms Burgess arranged for one of SLT to call us and tell us more about feeding and what type of bottles and teats to get, as babies born with a cleft usually experience difficulties with feeding, because the hole in roof of the mouth makes it hard to suck and soft squeezable bottles and orthodontic teats should make it easier. (That was just before the clinical nurse specialists were appointed to advise about feeding!). Few weeks after the scan we saw Mr Hall, Consultant Plastic Surgeon, who explained to us about the cleft care, showed us some pictures of pre and post surgeries and told us about other team members who will be involved in the care of our baby. It was really assuring to know how the cleft care is set up and that the team is very experienced and caring. For the first time we approached the forthcoming birth with less apprehension and more excitement.

We told all our family and friends that the baby will be born with a cleft and I started enjoying my pregnancy. We started looking forward to our new arrival.

When we held our baby for the first time, there were tears of happiness seeing our healthy baby with lovely big blue eyes and a wide, big grin across his beautiful little face. We felt enormous love and protection towards Joshua and we knew that he will be Ok. The first few weeks after the birth were hard and I was very tired and exhausted as feeding was taking a long time I didn't have much time to rest between expressing milk and feeding Joshua . It took us few days to learn how to feed him properly with specialized soft bottles and I managed to express the milk until he was 5 months old.

Joshua is nearly 10 years old and recently had a bone graft, what was his 5th and hopefully last surgery. Surgeries are not easy but we trust the medical team fully and we know that he is in the best place. Surgeons are great at their job, very caring for their little patients and the whole team is passionate and dedicated to give the best care for each patient. We know that we can always talk to them if we have any concerns and questions. Everyone in the team is equally important in providing medical care for children born with a cleft.

We will always appreciate excellent care given by the team and how they have looked after Joshua throughout numerous appointments and surgeries. For us they are the real heroes who make a huge difference in a child life. Today Joshua is doing great, his speech is very good and he is a very confident and bright boy, full of life.

I was inspired to join the branch after the meeting (Nov. 2004) where Dr Anna Zeffertt, Consultant Clinical Psychologist and Mr Per Hall, Consultant Plastic Surgeon talked about the branch and how we can get involved. It's fantastic to be part of volunteers who support children and young people born with a cleft across the East Anglian Region. Our Summer and Winter Wonderland parties are great events where children have lots of fun and families have opportunities to get together, meet other families and share their own experience. It is always nice to see members of the cleft team supporting our events and meeting families more informally.

The kindness and generosity of many individuals towards our work is enabling us to continue support families across the region and the cleft team at Addenbrooke's Hospital. We are ever so grateful for your support!

If you would like to speak to me or other mums or dads on our committee, please do give us a call or if it is easier send us a text or an email. It would be lovely to hear from you. We are here to support you, most of us have been through similar experience as you are going through now. We are looking forward to meeting you at some of our annual events. *(Please do check out our website for further information)*

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