

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 looks, 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 said proudly. 'Boeing 727, 747, 777 and Airbus, 320'. 'Well done' Nick replied. (Nick is very particular about their names). 'You know that your daddy was born with the same thing as you, a 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 what I do and one day you can do the same thing if you want too, Ok!'. Joshua happily nodded his head and we all went to the park to play 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. The 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 and we want to make sure that they will be able to overcome any hurtful comments. 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 held him for the first time there were tears of happiness seeing our beautiful baby with lovely big eyes. The first few weeks when he was born were hard and I was very tired and exhausted, as feeding was taking a long time and I didn't have much time to rest between expressing the milk and feeding Joshua but I was determined to give Joshua the best start in life, mummy's milk and with the support from the feeding advisor and my speech therapist I managed to express the milk until he was 5 months old.

Originally when they told us at my routine ultrasound scan that the baby will be born with a cleft we were very upset and scared, as we didn't really know what to expect; how will we cope and what care is available for the babies born with this condition. Nick called Addenbrooke's and spoke for the first time to a lovely lady Ms Sue Burgess, the cleft Network Co-ordinator, who was wonderful and very helpful. She asked us if we would like to meet the surgeon before the baby is born, as he will be able to tell us more about the surgical procedures and what can we expect. Ms Burgess also arranged for Dr Anne Harding-Bell, Specialist Speech and Language Therapist, 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!). After speaking to Dr Anne Harding-Bell and seeing Mr Per Hall, Consultant Plastic & Reconstructive Surgeon for the Cleft Team at Addenbrooke's we felt so much

happier and less anxious and for the first time we approached the forthcoming birth with less apprehension. We really appreciated the support given to us by the Cleft team and our local NHS staff, even before his birth and since.

Joshua is now seven and already has had four surgeries. His first was when he was only 4 months old, this was on his lip and when 9 months on his palate. More recently he had an operation on his fistula and just a few months ago a surgery to improve his speech. It always amazes me about the surgeons' (both Mr Hall and Mr Ahmad) skills and knowledge to perform those surgeries and they will do their utmost to do the best repair for every child. Though I was very apprehensive and upset every time Joshua had surgery as I didn't want to see him in pain and was scared about possible risks, I trusted the medical team fully and I knew that he was in the best place. The team is very passionate and dedicated to improve the cleft care in the East Anglian Region and we can always talk to the team if we have any concerns and questions. Today Joshua is doing great, is a healthy and mischievous boy, full of life.

We would like to say a very special thank you to; his surgeon Mr Per Hall for all the repairs and care given to Joshua, Dr Anna Zeffertt, Consultant Clinical Psychologist who helped Joshua with his fear before his last surgery, as well as helped us with our apprehension about the surgery, so that we were able to make the right decision for him and Mr David Sapsford, Consultant Anaesthetist, who monitored Joshua during all four surgeries as well as used gas induction before his last surgery. Also a very special thank you to ALL the other medical professionals in the Team; Mr Tariq Ahmad Consultant Plastic, Reconstructive & Aesthetic Surgeon, ENT Surgeons, Ward D2 Nurses, Recovery Room Nurses, Orthodontists, Audiology Specialists, Paediatrician, Speech therapist, Clinical Nurse Specialist and our local GP Dr D Fenske, and his dentist Dr A Nash. All of them are equally important in providing an excellent medical care for children born with a cleft. They are the real heroes who make a real difference in a child life.

Today I'm actively involved with the Cleft Lip and Palate Association – (CLAPA), Cambridge Branch and am proud to be part of other volunteers who support children and their families that are affected by a cleft across the East Anglian Region. We provide (free of charge) a 'starter pack' to every new born baby in the East Anglian Region. Each year we have two main events the 'Summer' and 'Winter Wonderland' Parties that are supported by the Cleft Team at Addenbrooke's, who always find the time to come and talk to children and parents informally. Both children and parents get a great deal out of meeting other families, talking to members of the team and in generally having lots and lots of fun. Lastly thank you for all the kind donations from the many individuals as well as our local community's businesses that enable us to raise valuable funds for the Cleft.Net.East Network based at Addenbrooke's that provides a centre for excellence for the region's cleft lip and palate patients. If you would like to find out more information about our activities please don't hesitate to check our web site (www.clapa.com) or you can speak to Dr Anna Zeffertt, Consultant Clinical Psychologist who is also our valuable member on 01223, 596 092/ 596 265, Mary Newbold nm.newbold@ntlworld.com (01234) 308 101