

Football, Skiing, Basketball, Athletics, HED and James Turvey

James was born at 5.28am 9/9/99. I was over the moon as any new Mum would be; my first-born was here safe and sound. A beautiful, perfect, healthy baby boy!

However at 10 Months old we found a small lump on James' arm, to cut a long story short this turned out to be Fibrous tissue. He was sent to the London Hospital for it to be removed; by this time he was 17 months old.

It was whilst we were there, that I mentioned to the nurse I had concerns over James' teeth as they had come through pointed and widely spaced, Just by chance the nurse had come across HED before and thought she recognised this in James.

At this stage I was expecting my second baby any day. The nurses pulled my husband Adrian aside and showed him pictures of children affected by ED. Adrian agreed that the resemblance to James was unbelievable. The nurse was very considerate and said she did not want to stress or worry me as I was about to give birth. Adrian assured her that I would welcome any discussions with the doctors, as I had spent a stressful couple of months going round in circles trying to find out what was wrong with James' teeth. The dentist told me "not to worry his second teeth would be ok, and it was probably lack of calcium." The doctor had referred me to the dentist, and the health visitor didn't have a clue! The hospital arranged an appointment for the following week, if I hadn't gone into labour! It was at the hospital appointment that the doctor was able to give James a full diagnosis.

Looking back James had all the signs of HED but as a first time Mum I was not aware that the monster secretions coming out of his nose were not normal, and I can recall a few very hot days when James just would not settle, whatever we tried to do.

I am sure that my friends and family thought I had gone nuts as I called them all with the good news that James had HED. I say good news; I finally had a name for James' condition, as a mum you know when things are not right, and I knew James was not 100% Ok. I then did what we have all done and took to the Internet and scared the living daylights out of myself! I read everything I could on ED. This wasn't all bad as it was through the Internet that we found Diana Perry and her truly wonderful support group. I can honestly say without them at that time I would not of known what to do.

My second child was born on 31/3/2001 a beautiful baby girl. We have since been genes tested and have the good news that I do not carry the ED gene, so Georgia therefore is not a carrier.

Life carried on for us all as a family, James started a wonderful nursery that was fantastic in

listening and understanding his condition. As a family we tried not to make a big deal out of it, but just made people who needed to know fully aware of the condition.

James was under Miss Goodman at the Eastman Dental Hospital who was fantastic. We had lots of visits to the hospital just for James to have a ride up and down in the chair and a chat to Miss Goodman. At the time I was thinking is this really necessary, but our patience was well rewarded as when the time came to start work on dentures, we had no problems with James, he happily sat in the chair to give impressions etc. We did have a small reward system as advised by Diana, so depending on the extent of the appointment James was rewarded with a small toy etc.

James started our local primary school "St Peters" in Sept 2005. Diana was a godsend helping me to get things

into place. I have to say it wasn't easy, the first school I visited was very negative about James' condition, they told me that he wouldn't be able to go inside in summer months if he got too hot as they could not give up 1 member of staff just for James. They also told me having a fan in the classroom would prove difficult, as the lead would be dangerous, etc etc. I left that school in floods of tears, thinking he will never start school.

However, St Peters were the total opposite, I also left that school in floods of tears, but these were happy tears as they were prepared to do just about anything I asked to accommodate James. He started school with his "new teeth" in place and fitted in just like all the other children, we had a couple of occasions where he was upset but nothing major, children are just inquisitive and a few couldn't understand why James' teeth were able to go in and out of his mouth. Once the teacher explained a few things the kids got used to it and nothing more was said.

He has got on really well with his dentures, although he finds it difficult to keep his bottom ones in especially when he is eating, as he has very little bone on the bottom jaw to keep them in place. As a result of this, the teeth have turned up just about everywhere! On one occasion the Headmaster phoned me after a school disco to ask if James had his teeth, after checking we discovered that he didn't, and the headmaster said they had been found in an empty crisp bag! James managed to look after them all week when he went on his year 6 school trip; the teacher said she had them in a bucket when they were on the beach rinsing them, and had reminded him to take them out of his pockets etc. They survived all that and then he lost them on the coach coming home!

That was June 2011, and we are still going back and forth to the Eastman Dental Hospital to have fittings for a new top & bottom set. I am going to tie these ones round his neck!

James started secondary school last September, and once again has settled very well. He earned his place at the school that is not in our catchment area due to his sporting ability. He was one of 19 children out of 400 odd selected for sports.

HED has never stopped James trying anything, he seems to have been more determined to succeed in whatever he does. He left his Primary school being the fastest runner, captain of the football team, and a key member of both the basketball and athletics team. He plays football to a high standard and has been with Tottenham Hotspur Elite for over 4 years. He has also been invited to trial with other premier ship teams. He participates in just about any sport he can. The only sport he is not so keen on is swimming. He absolutely loves Skiing and as a family we go once a year, we have never had any major problems with James and the cold.

Secondary School certainly is so different to Primary; I was worried that with so many children in one school, James may get overlooked. But the pastoral care is fantastic and the teachers are fully aware of James' condition.

I say all the above not only because I am proud of the way James copes with HED and what he has achieved but to assure everyone reading this article, that ED certainly has not held James back and therefore should not have to hold back any other affected child. I will also add that James is mildly affected compared to some children, but nonetheless he has the condition and copes. We have had a few instances along the way where he has got too hot but with the right cooling devices to hand it's soon overcome. As a toddler he would cool himself on the Kitchen tiles, this was before we even knew of his condition - children are so resourceful! We carry a 'Wickes' fence sprayer in the summer filled with ice-cold water and all the children welcome a blast of fine cold water sprayed over them!

Our thanks go to Diana Perry and her fantastic team, they do a stirring job. It goes without saying that we as a family have had tremendous support from other family members and friends alike, James is blessed to have grandparents who are a very important part of his life, and also wonderful Godparents, Charles and Keely Cook who have played a big part in helping us too fundraise for the ED Society. The saying goes you can't choose your family but you can choose your friends- well "The Turveys" have certainly chosen well!!!

I hope in reading this article anyone who had any doubts about their child's future with ED can now be reassured. Best Wishes to you all. Justine Turvey