

## Our Miracles

We are the parents of 2 beautiful and wonderful daughters who were both born with a profound hearing loss. Sade, now 6 years and Topaz, now 4 years old.

Remarkably Sade passed her hearing test at 8 months old at the local health clinic and we were still blissfully unaware of her hearing problem. It was when Sade was approaching 1 year old that we began to have concerns about her hearing. She was a very bright, happy and attentive baby and had made up for her hearing loss by being very visual, this is one of the reasons why we later experienced such problems with our local services, audiology and ENT. We raised our concerns to the health visitor, who referred us to our local ENT and audiology department. After waiting endlessly for an appointment we went only to be told that Sade had '*selective hearing*' and hears what she wants, a phrase that haunts me to this very day. Sade was at this point 18 months old and not attempting to say any words. Naively we believed the so-called '*professionals*' and left the hospital relieved but not quite satisfied. They agreed to see her 3 months later for another hearing test and again told us the same '*selective hearing*' by now we were not standing for this diagnosis and were sure that Sade was not hearing us. We requested for her to have different tests, hoping to get a more accurate result, we were told that she would have to see a paediatrician first to confirm that she had no other problems or delays, although we insisted she did not. We checked the post everyday for an appointment, time ticking on, valuable social skills being missed and Sade's second birthday fast approaching.

We waited, eventually after pressure from us we got an appointment, to be told Sade was a bright child with no other delays than an obvious hearing loss. Finally after another hearing test our local audiology unable to give us any answers referred us to Southampton University, where we were fortunate enough to meet Kevin Munroe he gave us a clear and definite diagnosis. This was the day our nightmare came true, they confirmed that Sade had a profound hearing loss and had not heard for the first two years of her life. Our world was turned upside down, the nursery rhymes we had sang to her everyday had not been heard, the stories I had read her had not been heard, she didn't know our voices, she had lived in a silent world. We knew that she had a hearing loss of some degree, but we still clutched onto the hopes that it was something like glue ear that could have been corrected.

Then everyone's attention turned to Topaz, now 2 months old, is it possible that she too could not be hearing. Topaz was tested and the nightmare turned into the worst day of our lives, she too had a profound hearing loss and we were devastated, words cannot describe the feelings of heartbreak, we cried and cried and grieved for what we thought our girls had or should have. It was a difficult time, we had no experience of deafness and had no history of it in our families. Our heartache soon turned to anger at how unfair life could be, why should our girls have to deal with this??? We turned to sources of information the Internet, people we trusted and found out everything we could about deafness.

The girls were both fitted with hearing aids shortly after their diagnosis and we stumbled across, The Elizabeth Foundation in Portsmouth, we visited them and discovered a group of people that offered the girls and ourselves a huge amount of support and advice. We continued to visit them twice a week for a year, travelling the 3-hour round trip, determined that we were going to give our girls the best possible chance to learn to listen and talk. We did not want our girls to be forced to live in a bubble. Our lives were completely taken over, all we did was travel around to different appointments, trying to get the best for our girls. It was an exhausting emotional rollercoaster that I would never wish upon anyone.

We thought that we were doing everything possible to help our girls when we were recommended to see Jacqueline Stokes at Oxford AVT. We decided that we should visit her, just to prove to ourselves that she could not offer us anything more than what we were currently doing. On our first visit with Jacqueline we knew that we **HAD** to see her again, she had got Sade making sounds in her first hour session that she had never made before. We continued going regularly to see Jacqueline and Sade started to say words, It was wonderful to hear her sweet, lovely little voice and the day she called me Mummy I will never forget. Sade had a cochlear implant in July 2002 at 3yrs 2months. We stopped going to The Elizabeth Foundation and with my Mother, sister and support from Jacqueline I started my own pre-school for all children. I used the knowledge I had gained from The Elizabeth Foundation and

Jacqueline to create an ideal environment for my girls and other hearing impaired children, to socialise and achieve their potential along with their peers.

Topaz was fitted with a cochlear implant at 2years 7months and had been seeing Jacqueline and Elizabeth at Oxford AVT since she was tiny. She had built up a good vocabulary before her implant. Both girls have achieved amazing results with their cochlear implants, they have beautiful voices and are happy confident girls. They both started mainstream school at 4 years old and joined reception class like any other child. They both had age appropriate language and understanding and both *graduated* from AVT before they started school. They have 15 hours of support each at school, they use a personal radio aid and the school is fitted with soundfield systems. Whether this amount of support is necessary we are not sure, but while they are young we believe that they should have as much support as possible to be reduced as they grow older and more independent.

When people meet our girls now and we tell them that they have a hearing loss they do not believe us, they **cannot** believe it. 'But they talk just like any other kid' they say and we just smile, what better compliment can they give us?

We know that the amazing results that our girls have achieved are down to the commitment and hard work we put in right at the beginning. We will be endlessly grateful to everyone who helped us achieve this, particularly Jacqueline Stokes. She showed us how to communicate with our girls, how to play with our girls and how to bond with our girls. That got results, excellent results. AVT is not rocket science, don't be surprised if you end up dancing around the room with a bucket on your head! It's fun and it gets results. Our girls loved their sessions with Jacqueline and Elizabeth and talk about them with affection. We recommend any parent of a hearing impaired child to waste no time and visit AV<sup>UK</sup> ASAP .

Many professional people (not JS) are unable to tell you what can be achieved for fear of reprisals, fear of the emotional anguish for parents if they do not achieve the achievable so they don't take the chance, they don't tell you that you could do more, they don't push you, they encourage small gains when so much more could be achieved. Jacqueline employs tough love she tells it to you straight, tells you what you need to hear she won't allow you to stay at the "comfort zone hotel" of doing ok. We always left her feeling focused and energised and **wow** do you get results, our reality now contains no worries about Sade and Topaz's speech and language. Our nightmare has finally gone and our girls are flying, we know that we will most certainly hit a few bumps in the future, but we have survived the hard part and are enjoying living with the most fantastic, chatterboxes! in the world.

Most people pass through life never really achieving anything out of the ordinary. We were given the chance to achieve two minor miracles. Having faced all the challenges, all the emotional upset, travelled all the miles, attended countless appointments, carried all the worries we look upon two miracles each and every day. Two miracles that might (according to some professionals) have some awareness of environmental sounds like a car horn or maybe answer to their name, **not our miracles** they enjoy and respond to every aspect of a world full of sound. We have travelled a journey that has made us (personally) stronger, more insightful, more focused and more successful in life, we were given the opportunity to shine..... and (judging by our girls) we buffed up OK.

Steven & Victoria Oram  
**Parents of Sade & Topaz xx**