

## **The Fragile X Society**

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### **Fragile X Families**

#### **Rose's Story**

I'll start first by telling you a bit about us. In our family there is myself, Rose, my husband, Ian, and our children, Marshall (5) affected, Ellen (2) not affected and Libbie (1) not affected. We live in Hartlepool, and we have had Marshall's diagnosis since June 2007. Marshall is a cheeky, loveable little lad, with a caring and sensitive side that is so endearing. One time I described him as 'able to charm the birds out the trees one minute and able to make a saint swear the next'! I can't imagine him being any other way, I wouldn't want to, his character makes up a big part of our family. Ellen is the bossy and noisy one, she's like a bull in a china shop, but she helped Marshall to begin to interact with other children. When she was about 6 or 7 months old she decided that if he was here he would play with her, so she kept chasing him in her walker till he did as she wanted. They have a wonderful relationship that now Libbie is also included in. Marshall has started to change some of the games that he and Ellen play to include her, but that's the kind of lad he is, he loves to make everyone happy. We consider ourselves to be very lucky, we think that we have a wonderful family.

We had known for a while before we received our diagnosis that there was something different about Marshall. We had always thought that his problems were due to the problems he had had with his ears as a baby. His ear drums popped on numerous occasions when he had 'glue ear' (middle ear infections) and he had an operation when he was two to remove the build up in his ears and to fit grommets. Before his operation they did an electronic hearing test and his hearing came back at 2 out of ten, but after his operation it came back as 7 or 9 out of 10 which is average. I always thought that he had just needed to catch up on the first two years of his life.

Marshall goes to Barnard Grove Primary School, a mainstream school, and they have been absolutely fantastic. They have always treated Marshall as an individual, made allowances for his difficulties (before and after diagnosis), all the while helping him to progress and develop and always giving him 110%. They are willing to try new approaches to benefit Marshall while also trying to keep him doing what the other children in his class are doing, and trying not to single him out, while making sure that his needs are met. They made allowances for Marshall almost straightaway. School policy was usually that children must be fully toilet trained before attending nursery, but at that time Marshall was still having the odd accident, and using a potty rather than the toilet. The school allowed this and also bought some steps to encourage him and to make it easier for him to use the toilet, they had also arranged one to one support for him in nursery. I was developing a close relationship with the staff at Barnard Grove and we worked together to help Marshall to progress. Within a short time Marshall was using the toilet, hardly ever having accidents and starting to talk a lot more.

By the time we got Marshall's diagnosis, he knew his numbers, colours, shapes and much more. His behaviour had improved and he was starting to interact with his classmates, not very well but before that he hadn't interacted at all. He had developed an excellent relationship with his support worker and he thoroughly enjoyed nursery.

When I got Marshall's results, I, like most people had no idea what Fragile X was or what it meant. My Mam went on the internet at work and printed off some information from the Fragile X Society for me. When we read it, we felt that a lot of what was said did describe Marshall perfectly. I gave the information to Barnard Grove and the staff read it as soon as they could. We made changes in the way we were behaving towards Marshall and put plans in place to help him straightaway. One major change we made was to stop trying to encourage him to make eye contact, it did feel weird at first trying to talk to him without expecting him to look at us and also knowing that he would still understand. But as we got used to it Marshall started giving more eye contact voluntarily as he felt more relaxed.

When Marshall started reception class, his support worker came with him, but due to him having full time support he also needed to have another worker, which is when he was introduced to his second support worker. Barnard Grove had previously arranged sessions in nursery so Marshall had met her and the transition would be easier for him. He had also met his teacher while he was still in Nursery so there wouldn't be many new faces for him.

Since Marshall started at Barnard Grove he has thrived and progressed in ways that I hadn't thought were possible. When he started in the reception class he started to come on even quicker. He prefers the structure of school, and learnt the routine really quickly. He enjoys sitting on the carpet for register and his favourite parts of his day are dinner time, playtime and assembly. I knew he would love dinner time as Marshall loves being fed. He eats more than I do most days, but I am lucky that his preference is mainly for fruit and vegetables, although he wouldn't say no to a packet of crisps! When he raids the fridge, he leaves the chocolate and biscuits alone, but the cherry tomatoes are never safe! I never thought that playtime and assembly would be fun for Marshall, I was afraid that he would get the mickey taken out of him by the other kids and that assembly would be too long for him to sit and be quiet as he should. But he as usual surprised me, he is really popular with the other kids, though how – I'm not always sure. Sometimes kids say hello to him and he just tells them to go away, or leave him alone. I shouldn't have worried about the other kids, they just accept him the way he is. He received a mountain of Christmas cards, and is always getting invited to parties. And with assembly, he just does what all the other kids are doing and sits there, joins in with the songs and comes home to tell me that assembly was fantastic.

The SENCO (special education needs co-ordinator) at Barnard Grove arranged for himself, Marshall's teacher and his two support workers to take a morning to spend at a 'special' school in Hartlepool, where they observed how the TEACH program works and gathered ideas for how they could implement the programme to work for Marshall at Barnard Grove. An outreach worker from the special school came to Barnard Grove for two weeks to work with the staff and Marshall. She introduced changes to benefit Marshall and showed us all how to approach Marshall and how to speak to Marshall to get the best reaction. With the outreach worker's help Barnard Grove introduced a separate work station for Marshall, which has no distractions and enables him to complete some tasks that the other children aren't doing but also to reinforce what he has learnt with the other children.

Even after the short time that the outreach worker spent with Marshall and the staff, the help that she has given us all has helped Marshall to improve again and still he is doing really well, he knows all

his phonics and is beginning to learn to read simple words, I couldn't have imagined him being able to do all this six months ago yet here we are and he can do it. With the encouragement and support that we all give Marshall, he wants to learn it all, he loves to get his Well Done stickers and was absolutely over the moon when he got a 'Superstar of Learning' certificate, he couldn't wait to show me, and tell me how he got it in assembly. We were so proud and so was he that we have put it up on the front room wall and it is still there now.

I went to the special school and spoke to the teachers there and they are going to arrange with the school when Marshall and some of his classmates can go to the special school and use some of their facilities. It will mainly be the light room and the soft play, although they have also offered, once Marshall has had the all clear on his grommitts, to give Marshall swimming lessons.

My sister has a friend who is a primary school teacher, and we arranged with her to come and see Marshall at the weekend. She spends an hour each weekend with Marshall to help him with his writing, but she also contributes greatly to helping him to focus and concentrate. She didn't realise this at first and she told me she didn't think she was doing very well as she only managed fifteen minutes full concentration from him. I nearly fell over! I asked her how she had managed to get him to sit for that long and joked that she must have tied him to a chair and gagged him to get his attention for that long. As she hadn't come across any other children with Fragile X she didn't realise that for Marshall that was a huge achievement.

Due to all the help that we receive, from Barnard Grove and the excellent staff there, and from the special school, the local education authority, the private tutor and last but not least the Fragile X Society, everything is going really well for us. At the moment there are no plans to take Marshall out of mainstream school and he can join in with the other kids, which is what, on top of Marshall being happy, we wanted. I am now determined that although I thought my world had ended when they told me there was something 'wrong' with my son, that we will still get there – the road is just going to be bumpy and a bit longer than the road everyone else uses. Who wants to be run of the mill and boring anyway!

*Membership of the Fragile X Society is free to fragile X families and carers living in the UK. The Society also welcomes as associate members those with a professional interest in fragile X and families living outside the UK join as overseas members.*

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