

The Fragile X Society

This article was first published on the Jeans for Genes website in 2006.

Ewan and Harry's Story



Ewan is 6 and Harry is 4 years old, they live with their mum, dad and baby sister Tessa

Both Ewan and Harry were born with a genetically inherited condition called Fragile X Syndrome. Fragile X causes varying degrees of learning disability and developmental delay, it affects both boys and girls and is often accompanied by autistic-like behavioural traits.

Although Ewan and Harry both have speech delays and they learn things slowly, they are totally different characters to each other. Ewan adores Brother Bear and Manny from Ice Age and his life revolves around these fictional characters. He watches them on DVD, plays computer games of them and takes them everywhere he goes! Ewan is a friendly, timid and affectionate little boy who likes routines and predictability.

Harry on the other hand has a totally different outlook on life. Harry is larger and louder than life! He likes to be in the absolute thick of the action, he does everything at top speed and with boundless energy and enthusiasm.

This is their story told by their mum, Liz:

When Ewan was about 18 months old, I started to notice that his overall development was on the slow side. He combat-crawled at 12 months but only if we placed a line of chocolate buttons just out of reach for encouragement and reward! He walked at 18 months but if he fell down he couldn't get back up and at this point he was only beginning to say a few words. So we were duly referred to a paediatric consultant and as I had already found Fragile X on the internet and there seemed to be some alarming similarities to Ewan, he agreed to do a Fragile X DNA test.

The timing for Ewan's diagnosis was less than perfect. Harry was 6 days old when my husband, Stu, collected us from the hospital. I was oblivious to the news he was hiding from me until we got home and he said with tears in his eyes that he had something to tell me. He recounted the paediatrician's phone call saying Ewan was Fragile X. We cried and cried as I looked down at this new baby in my arms not yet even a week old and with a 50% chance of also having Fragile X.

The next big question on our minds of course was Harry. Was he or wasn't he? Harry was tested on that very memorable day, September 11th 2001. I remember watching the planes flying into the twin towers and not even registering the significance of these events. Stu again answered the dreaded call. Our geneticist simply said that there was no doubt - Harry was Fragile X.

So in the space of one month our lives had transformed from having a seemingly perfect family to a very different scenario, with the realization that we had a whole lifetime of responsibility in a way we just couldn't imagine for our little boys.

After the boys' diagnoses we started to think positively about their future and we started to put into place all the help they would need in order to get the best out of life. We contacted the Fragile X Society and through them we have met a whole new group of people. The Fragile X Society keeps us up to date and informed about all that is going on in the world of Fragile X through their wonderful conferences and newsletters.

Both boys currently attend our local primary school, which they love. They are well supported by the teachers, the pupils and they have their very own learning support assistants. They use symbols and pictures to bring on their speech and they follow a 'sensory integration' programme which helps with their varied anxieties. It would be hard to say which boy has the busier life. Ewan loves swimming, he attends Beavers and has also started Riding for the Disabled. Harry loves anything musical, soft play and he never misses a party. Harry loves a party!

Life with Ewan and Harry is always interesting and brings each of us new challenges and opportunities every day but also it makes our family life full and rewarding. The boys now have a little sister called Tessa who does not have Fragile X. It has taken them a bit of time to get used to her arrival but she adores them, Harry loves playing with her and Ewan admires her albeit usually from a distance.

Read also:

Liz's talk to the Fragile X Society's Scottish Family Conference "Starting School" – accessible from the Society's website at www.fragilex.org.uk and click on 'Fragile X families'

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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