

# The fight for Lewis' Education!

By Helen

While Lewis appears to be affected minimally by mosaic trisomy 18 and in many respects he is, it became increasingly apparent to us that he started to struggle once he entered school in September 2006. Initially we were not unduly concerned as the school had been briefed. However during his 3<sup>rd</sup> term in school it was obvious to the untrained eye that there were problems which were being ignored by trained staff!



*Lewis with a pet rabbit*

In September 2007 we became concerned. Not only was Lewis unable to count beyond 10 and recognise numbers up to 10, but he was unable to read any of the high frequency words that children are usually managing during their reception year. Lewis was also unable to tell us what school he went to or even where we lived. The homework the school were sending home was totally inappropriate and when I commented in his book, my comments were brushed aside. I was effectively accused of not getting him to try and was told that he could do it. We also noticed that Lewis was becoming increasingly distressed about going to school and he used to come out at the end of the day and kick me round the ankles. In November 2007 I had to attend the scheduled parents evening alone as we had no one to look after the three children. Lewis' teacher asked me initially if

there was anything I would like to ask, which is strange as they usually leave that bit til last. I asked outright if she thought Lewis had a problem or was he just not trying. The answer was the latter, but it was admitted that he was struggling so I suggested that reading with him for 10 minutes each day would be appropriate. She said they could manage 5 minutes and as I had requested they would document this in his reading record so that if I was able to persuade him to read at home we could see what he had done and not repeat the same pages!

Following the parents evening I noted that nothing was being documented. I raised the issue again and after a further week of nothing being done I went straight to the SENco (Special Educational Needs Co-ordinator). My chat with her was quite positive and she was going to observe him in class the following week. Once this had taken place I went into school for a meeting with her and the classroom assistant, although it really should have been the class teacher. I should add at this point that the SENco was also a teaching assistant and not a qualified teacher! They had decided that Lewis was struggling in the area of literacy and they were planning to implement a reading scheme called Toe by Toe, but first they had to get approval to buy the book for him. I even offered to buy it ourselves just to speed up the process but was told no they would get it, but not until the New Year!

During the Christmas break it was distressing that Lewis, usually the most solid sleeper in our house, was disturbed by us just walking into his room. My suspicions were further raised when they returned to school in the New Year as he was increasingly distressed

each day. My ankles were also black and blue again. It was a fight everyday to get him dressed for school and it took both Nick and I. We virtually had to pin him down and if you let go he would strip himself of his uniform and hide. The walk to school involved pushing a pram and dragging Lewis kicking and screaming. I cannot believe we were so blind! We were assured it was separation anxiety and he was fine once I had left but I doubted this. One lunchtime, I witnessed Lewis sat on the bench in the playground huddled up in his coat, hat, scarf and gloves, all alone and near to tears. I obviously stopped and spoke to him but that just made matters worse. The lunchtime supervisor ignored me talking to him and when I later questioned his class teacher she knew nothing!

Shortly after this Lewis saw his general paediatrician. He had gained virtually no weight in the preceding 3-4 months, he looked pale and was so miserable his whole character had changed. I rang the Community Paediatrician for an early appointment. Mark Hunter was fantastic and saw us the following week and immediately saw we had a very unhappy little boy and asked what I wanted...“I want him formally assessed”. He agreed and said he would write to the school suggesting this, tactfully! The schools response to him was “it was not warranted”. Mark and I had also had a frank conversation in his office that day and so I continued to look for an alternative school for the boys. The school put in an extra review for Lewis in the March and it was not a satisfactory meeting. We were given no copy of his IEP (Individual Education Plan) and there was no evidence that this was being used in the classroom. The SENco, not a qualified teacher, reiterated that it was not worth getting the Educational Psychologist in to assess Lewis as nothing would be done until

he was 4 years behind his peers! I knew that this is wrong and I decided to request the Educational Psychologist to assess him.



One morning Lewis had a hospital appointment in Oxford and I asked him if he would like to look at another school. He was hesitant but agreed, so I rang the primary school in the neighbouring village and they said we could go round but the Head was not in that day. We were shown round the school by the SENco who was a qualified teacher and taught in year 1-2. Talking to her I knew that this would be a more positive environment for Lewis and Ryan also! After the Easter holidays communications with their school broke down irretrievably because they failed to support either Lewis or myself each morning and ignored the fact he was kicking, screaming and hysterical in the classroom. They were both ill on the Friday but recovered on the Sunday enough to go off to an open day at a secondary school in a neighbouring county. My faith in education was restored when a teaching assistant spent time with Lewis and supported him in making a pig out of “junk”. Unfortunately the next day both boys were ill again, and by Tuesday Lewis' temperature was sky high and he had rash, one that looks typically like Meningitis but I knew that it was to do with his platelets. Following x-ray's, bloods and detailed examinations it was deemed that it was an infection and they would give him antibiotics. While the boys were ill we contacted the school in the next village and had a positive meeting with the

Head and the SENco, and the boys went to the school for the day on the Friday. What a change in Lewis as he went straight off and loved it! Ryan was more of a problem but the Head rang later and told me both boys were settled. We talked to the boys over the weekend, and Lewis certainly was more positive so we contacted the school and said we would see them the following Monday!

I won't say it was all plain sailing after that but the difference was that not only did all the staff support the boys, but I was supported too. While we had been in Jersey, the E.P. (Educational Psychologist) had discussed Lewis and a decision was made to continue what had been started at the original school, but more importantly they had to gain his confidence and trust and then he would be seen in the Autumn term. This is exactly what they did. Occasionally Lewis would not want to go into school but it was always swiftly dealt with by staff and there was a difference in how he acted at this time and more importantly I no longer got kicked each day when I collected him. We then noticed, his appetite increasing, his hair growing again and he was in a deeper sleep!



At Helmdon, Lewis had one to one support from the classroom assistant and formed a fantastic relationship with her. The staff were always happy to discuss any progress or problems and learnt how to handle Lewis very quickly! In November 2008 the momentous day arrived when Lewis saw the E.P. I could have cried as she told us I had been right all

along and the poor little chap had got severe learning difficulties along with speech, language and comprehension and attention problems! Nick and I sat in that office and along with the E.P. and the SENco we wrote Lewis' I.E.P. which would be reviewed in February. The plan was that we would have enough evidence to request a "Statutory Assessment" with a view to getting a Statement of Educational Needs for Lewis, which would mean additional funding for the school, however even without the funding Lewis was receiving one to one support.

February came and while Lewis had made a lot of progress it was clear he needed support to maintain this. I wrote our evidence and reasons for wanting an assessment and the school made their report and this alone was accepted so after Easter things moved at a rapid pace. The school had to submit their evidence along with further input and assessments from the E.P. who was thrilled by the progress Lewis had made but still maintained that he needed the additional support. Lewis was also assessed medically by the school nurse, who could not believe how much he had grown since she had seen him, and Mark Hunter was thrilled to see that Lewis was so much happier.... and that I was too! I will admit that all the hassle we had with the old school had a detrimental effect on my health and resulted in a breakdown during the summer holidays, ironically once things had settled down! It was an agonising wait from May until July. I rang the Department and what a relief, we had got it! It took a few more days to get the proposed Statement and make sure all was correct. Eventually I was happy so it was sent to school to wait for the actual statement to be produced, but there was no time! On July 16<sup>th</sup>, school and I agreed Lewis' targets for the following year and how we were going to achieve them and discussed the provisions

they were putting in. The provision will be in place when they return on September 7<sup>th</sup>!

The relief that this has brought to us is immense. It is not easy to write reports about your child highlighting their problems and in turn reading reports where you realise how behind your child is. To give you some idea Lewis, being 7 and about to enter Key Stage 2, should have attained level 2's in reading/writing, numeracy and science. Lewis has not even managed to achieve level 1 as he is still at "W" which in the case of children with additional needs is further classified into P levels, he is at P7 – P8 so he is almost there at level 1 but a long way behind his peers.

Some may be asking how is Lewis now? Well, he still has his moments going into school but if you look closely he has a grin over his face, he loves to please, and he runs off to speak to his friends. I have watched him and rather than being huddled on his own he is in the thick of it. He is more observant and eager to talk but he is still shy and while he can tell those he knows his name and where he lives/goes to school, when out of his "comfort zone" he clams up which would cause a problem if he were to get lost while out shopping or on day trips! He can now ride a two wheeled bike, previously he lacked confidence, tries to read books and we hear less of "I can't do it"! Lewis always has and

always will prefer practical based tasks such as drawing, painting and constructing with Lego over reading and writing but at least he will be supported in reaching his full potential.

Our advice to those of you struggling to get professionals to listen to you is you know your child best. Do not let anybody put you off fighting for your child's rights and don't be intimidated by them. I allowed myself to be intimidated by a 28 year old Head Teacher, which made me lose faith in the Education System. Having since dealt with mature Heads (for the last 2 terms we have had an Interim Head) and staff that understand children with needs, we will never look back and now know what to look for in the next stage of Lewis' education at Secondary school. Ryan moves in September 2010 so we are already looking into what is available for him and whether it will suit Lewis, and if the school we pick for Ryan can provide for Lewis. One of the most important things to remember about any stage of a child's education and care is that the professionals should work in partnership with the parents. Life with a child who has Special Needs is tough enough without being made worse by a lack of communication. Thankfully we have had a happy outcome and I would like to thank Christine Rose for her invaluable advice during some very trying months.



*Facepainting fun for Lewis, Ryan and Shona!*

