

Harry

It was May 2008 just before Harry's 6th birthday rashes had started appearing on his face and eyelids. I took Harry to our local GP who gave Harry some steroid cream this didn't seem to have any effect. Bright pink rashes then started to appear on his elbows, knees and forearms and he started getting lots of mouth ulcers, sore gums and terrible night sweats.

The following month we went away on holiday. Harry, who was the normal sociable little boy became more withdrawn and didn't want to join in with any activities. He wanted to stay in the shade all the time he just wasn't enjoying himself. We just couldn't understand it!

It was when we were away that the pains started "mummy my arms ache" "Harry struggled to walk any distance without being in a lot of pain. The guilt I feel now making Harry walk and telling him to "stop being so lazy!"

We then went out and bought Harry a new bike for his sixth birthday, the man from the shop brought a new silver bike out into the front of the shop" Harry do you want to ride this bike?" His reply was "no". He showed no interest in it.

He had also started swimming lessons. He had to stop as he was unable to keep himself up out of the water because he was so tired and as I now know it was to do with his muscle weakness.

I remember going to work and speaking to one of my colleagues about Harry. "I just can't get him out of bed in the mornings, he is like a teenager, he is so tired, is your son like that?" (he was of the same age as Harry and I thought it must be a 'faze' he was going through), my colleague reply was "no my sons up bright and early!" something wasn't right!

It was then I returned to the doctors, he advised me that it was probably a viral infection and if it hasn't gone in a couple of weeks to return, during this time Harry seemed to be getting worse.

I was walking the dog down our local beach, I bumped into Harry's class returning on a school trip from the beach, Harry was in tears because of pain and tiredness, my heart broke I just wanted to pick him up and take him home.

It was then that the teacher informed me that in PE Harry was unable to balance and lift his legs on the stilts, something wasn't right so I returned to the GP who then referred Harry to the Hospital.

I waited for an appointment, but heard nothing and during this time Harry's deteriorated, struggled to climb the stairs, we had to lift him into bed and the bath and he was unable to get up from the floor without help. So I contacted our local hospital, we were offered an appointment

the following week.

Going to our local hospital I thought that maybe I was over reacting and all Harry had was a viral infection. But deep down I new something wasn't right!

The registrar saw Harry and then called in the consultant who seemed in some way excited! "Harry could have dermatomyositis", my first question to him was is it curable? Not knowing anything about the disease, his reply was " it is treatable! ". It was then he explained to us how rare JDM was.

He then advised that we have to be referred to GOSH asap. Great Ormond Street is something that you read about or see on TV; you never expect it to happen to your own child.

Over the next four days Harry went down hill quite quickly. We then got a phone call, and were up at GOSH the following day. I was advised that Harry needed to be nil by mouth for the muscle biopsy I just hadnt released what needed to be done to diagnose JDM. I thought that we would only be there for one day, just for a few tests, and then we could come home. I don't think I then realised the severity of the disease. A week later JDM was diagnosed.

He has always been a healthy boy having never been in hospital before and it was a scary experience for Harry.

After a week the doctors went though the medication with us and it was a lot to take in, not just the medication but the fact our son had been diagnosed with JDM.

I remember the doctor telling my husband and I that this could become a way of life! I didn't want it to become a way of life and give my son medication, but I new he needed to have it.

Harry then went to GOSH for rehab with the physios, the exercise made such a difference and made me release just how important exercise is in treating JDM. During this time we found out that Harry had hyper mobility which causes him a lot of pain and discomfort in his legs and feet.

Its almost been 2 years since Harry started showing the signs of JDM and he is doing really well .He is nearly off the steroids but still has methotraxate.I am very grateful that we were fortunate enough to get JDM diagnosed and treated so early, thanks to Dr Pilkington and her team.

Harry can get very frustra rated and tired, as he doesn't have the ability to keep up with other children the same age as him, and still has to use the wheelchair, but I am confident that this will improve in time.

Unfortunately he believes he caught JDM from the swimming pool in Majorca and refuses to go back there!!.

He also struggles with the methotrixate injections and gets very sick even before the injection has been given .I believe this stems from taking the syrup he was put on before he started the injections. This has improved slightly as we are seeing the psychologists at GOSH. When Harry has his bad days, JDM can seem all so new again. I remember a friend of mine telling me that knowledge helps you cope and understand. I believe this, as it has helped me.

When Harry feels good, I feel good as no one wants to see their child suffer in any way.

It is great that this website has now been set up to help support families and their children with JDM in the UK, so families don't feel alone.

It is hard to tell what the future holds with Harry , as a mother it will always be a concern , as with any parent that has a child suffering with this JDM