please fix sam

Little Sam McCausland is a lively blue-eyed boy who loves to laugh and play and is adored by his parents.

However, little Sam is not like most kids his age. He was diagnosed with Muscular Dystrophy at the tender age of one. He has a rarer form of the condition called Duchenne Muscular Dystrophy (DMD) which affects boys. At present there is no treatment and no cure.

Muscular Dystrophy is a fatal, progressive muscle wasting disease. In its congenital form the disease leads to severe muscle wasting, causing children to become dependant on wheelchairs at a very early age.

Struggle Against Muscular Dystrophy (S.A.M) is a zero cost charity run by Sam's Mum and Dad along with volunteers. The goal is to raise £500,000 over the next two years.

A huge charity event, the 'Emerald Ball' is planned for 14th March 2009 and Hillsborough Castle will also play host to a fabulous fashion extravaganza on March 26th.

Tracy tells Accent Cosmopolitan her story:

"Sam was born on 24th August 2006, a perfect chubby little baby boy. Four days after his birth Sam started to run a temperature, and it became apparent that he had contracted Meningitis. He spent two weeks fighting for his life in the NeoNatal Intensive Care unit of Belfast Royal Maternity Hospital. We were told to face the possibility that we might lose him, or that he would be left with brain damage. Despite this he won his fight.

Because he had been so ill Sam's development was to be monitored for the first year. At his reviews everything seemed to be right on schedule, with the exception of his achievement of his early gross motor milestones. He was slow to get good head control, reluctant to lift his head when placed on his front. Sam gained good sitting balance at 7.5 months and we heaved a sigh of relief.

At his eleventh month review the Doctor said he was concerned that Sam would not crawl. He had only recently started to roll, but we thought that his reluctance to push up on his arms was nothing too serious. He had started to bottom shuffle at around 10 months.

WITH OUR HELP, LOVE AND SUPPORT HE WILL HAVE THE BEST LIFE.

However, when the Doctor tried to get Sam to put weight on his legs, they felt like jelly. We took Sam to a Physiotherapist who recommended some exercises in an attempt to build his strength. All of Sam's other milestones were being achieved ahead of schedule. By 13 months he had nearly 15 words, and his fine motor skills were superb.

Our older boy, Callum, also has his own share of problems. He was a floppy baby, slow to feed, had no eyesight for the first six months of his life. His eyesight is still monitored but is thought to be within normal parameters. Callum did not sit unaided until he was almost one and didn't walk until he was almost 21 months. He never babbled, was not sociable, and did not show much interest in play. By the time he turned 5, having had 2 MRI brain scans, EEGs, blood tests too numerous to mention, a muscle biopsy and a list of consultants as long as your arm, many dreadful possibilities had been ruled out, including, ironically, Muscular Dystrophy, for which he was tested when I found out that I was pregnant with Sam. Callum still has gross and fine motor problems and unable to communicate through speech. He has a diagnosis of severe Dyspraxia.

I had convinced myself by Sam's 13-month check-up that he too had a milder form of Dyspraxia. At the consultation our Doctor looked worried. Sam was still not putting weight on his feet, still not crawling, and had hardly any strength in his arms. He told us that he did not think that Sam was suffering from Dyspraxia, as his other developmental areas were leaps and bounds ahead. Three hours later I got the call. "Sam's CK count is elevated". I knew what this meant as I remembered waiting for the results of Callum's CK test when they told us that MD was a possibility. We were given an appointment to see the Genetics Professor at Belfast City Hospital, and she explained the grim possibilities in relation to Sam's potential diagnosis. She was certain that it was a Muscular Dystrophy.

Two agonising months went by before we saw the Neurologist at the Royal Belfast Hospital for Sick Children. He repeated the CK test and it came back still extremely elevated. A Muscle Biopsy was scheduled for January 13th 2008. In the intervening period Sam started to cruise around the furniture and began to pull himself up from sit to stand. The biopsy itself was not too traumatic – Sam got over it surprisingly quickly. We got the phone call on a Friday afternoon. I remember dropping onto the floor and howling like an animal.

Armed with a file full of information and a brain about to explode we met with the Neurologist. We are now facing a lengthy wait for results of DNA analysis to determine the precise genetic mutation, which is responsible for Sam's condition. This could take up to a year. There are literally hundreds of mutations, which can lead to muscular dystrophy – some are caused by missing parts of the genetic code on the gene, others by duplications of parts of the code. In other cases a tiny part of the genetic code is affected by a premature stop signal, which causes the DNA to halt the manufacture of a specific muscle protein in which case inadequate or faulty amounts of the protein are produced. It is thought that Sam falls into this latter category. The fact that there are so many different genetic mutations of Muscular Dystrophy makes it a very daunting task for scientists to find treatments.

Sam took his first independent steps on 19th February, aged almost 18 months. Watching this was a joy, but seeing him learn to walk is also tinged with longing and sorrow, as I fear one day it will be taken away from him. Sam's personality is really starting to take shape - he has a glint in his eye and a devil on his shoulder!! I look at him and my heart melts. He has been through so much already in his little life. He is a fighter – he has proved that already, and with our help, love and support he will have the best life."

Tickets for the Emerald Ball can be reserved by emailing info@pleasefixsam.com.