



## the muir maxwell trust

HELPING UNCOVER EPILEPSY

### **Ben's story**

The youngest of three boys, Ben Holmes goes to Donaldson's School for the Deaf because of its highly regarded communication clinic. "Although he's six years old, Ben only has three words – mama, dada and hi," explains his mum, Jane. "It was a real battle to get him in there, but Donaldson's have been really good at dealing with Ben's seizures and getting the appropriate training."

Ben has recently been diagnosed with Lennox Gastaut Syndrome – one of the most severe forms of epilepsy with poor prognosis when it comes to controlling seizures. From having his first seizure in a remote holiday cottage in the Highlands before his third birthday, Ben's epilepsy has evolved to include just about every type of seizure. He can have up to seven tonic-clonics a night, absences when he zones out, up to 150 'drops' in a day when he loses his whole body tone and collapses, and head nods. But no-one can say why Ben is like he is. "They've done an MRI scan and it's normal. We've been to Great Ormond Street, where they have a better scanner, and it's normal," says Jane "so they think it's a genetic syndrome." But there's absolutely no history of epilepsy in either of Ben's parent's families. In fact, like many parents of children with severe epilepsy, Jane knew nothing about the condition before this. "If you told me back then that I'd deal with what I deal with now, I'd say no I couldn't, but you do."

Ben's sleep, in particular, is horrendous and very disturbed. Having suffered so many seizures at night, he has reached the stage where he tries to keep himself awake. "That's not good for him because tiredness triggers seizures," says Jane. "It's a dreadful cycle, with seemingly no light at the end of the tunnel. When you feel ill, sleep is often the only relief you get, but Ben doesn't even have that."

Despite all this, Ben has a great joy of living. "He wants to get out and enjoy himself," says Jane "but many days he wakes up feeling rubbish because he's had tonic-clonics during the night." But still Ben gets up in the morning and goes to school. "He's an amazingly resilient wee boy and really tries to enjoy life whenever he can," says Jane proudly.

An epilepsy alarm provides some practical support and Ben has tried the Ketogenic Diet through a Muir Maxwell Trust funded clinic. He's on the waiting list for a vagus nerve stimulator implant – Muir was the first child to get one in Scotland thanks to Ann's

perseverance. In an effort to get to the bottom of Ben's genetics, the family has also been through to Glasgow to see Dr Zuberi and hopes to benefit from the DNA Sequencer at Yorkhill Children's Hospital. "It's a case of exploring all the options and seeing what we can do," says Jane. "It's reassuring to know that there's someone like Ann out there doing these things. It makes you feel that things can be done."

In recognition of this, Jane has raised money for the Muir Maxwell Trust for the last couple of years by organising an Arts Fair at the Bonham Hotel. Last year they managed to raise over £5000 and Jane and her Gallery Girls pals will be doing the same again this year. Together with her husband, Jane is also in training for the Edinburgh Marathon as part of the Muir Maxwell Trust team.