



the muir maxwell trust

HELPING UNCOVER EPILEPSY

Evie's story

14-month-old Evie Phipers had her first seizure at just 12 weeks, followed by another one a few weeks later. Both were attributed to febrile convulsions so, while Evie's mum and dad, Alex and Jason, were surprised by what was happening, they didn't think too much more of it.

That was until two months later when Evie had the worst seizure of her life. Alex had taken Evie and her older sister, Amy, swimming at the local pool. They had all been enjoying themselves when "BANG – it was as though Evie had had an electric shock," says Alex. She remembers hesitating for a moment, but as Evie turned from red to very pale, she got the lifeguard to call 999.

Even more alarmingly, Evie suffered a respiratory arrest in the ambulance to hospital, but the paramedic managed to get her breathing again. Tests, including an ultrasound of Evie's brain, revealed nothing and the Phipers were discharged none the wiser.

It wasn't until Evie had suffered another seizure, lasting 30 minutes, that doctors started talking about epilepsy and she was referred to a paediatric neurologist. From then on, Evie's seizures became more frequent and severe. She started having generalised tonic-clonics lasting up to 25 minutes, up to 30 or 40 absences a day and jerks. Specialists began to suspect Dravet Syndrome.

Alex and Jason were distraught. "It felt like the world was ending," says Alex. "Thank God for the Muir Maxwell Trust." Like many parents, they had been given this devastating news and then very much left to get on with it. Two pieces of advice the neurologist did offer were: don't research Dravet Syndrome on the internet because it's frightening; but do look up the Muir Maxwell Trust.

Alex spoke to Ann-Marie that same day: "She was just fantastic and helped us come to terms with what was happening." After a fortnight grieving, Jason and Alex came to the realisation that they have to live each day as it comes, enjoying the times when Evie is well and dealing with it when she's not. "Because epilepsy is so unpredictable," says Alex, "you

never know when the next fit is going to happen. But if we sit there waiting for it, literally staring at her, we're missing out on all the positive days."

The Muir Maxwell Trust has provided emotional support and a greater understanding of Evie's rare condition ever since the Phypers contacted them. "They've helped immensely," says Alex and "given us some real hope with Evie." At the moment, Evie's development is absolutely fine – she's hitting all her milestones. After such an early diagnosis, it's hoped Evie will receive treatment that will reduce her seizures in the future. "A lot of children's epilepsy goes undiagnosed, so can't be treated," continues Alex. "We have to be very thankful that Evie was diagnosed so young."