

*"I adore being a mum and feel so lucky to have Daisy as my little girl."*

This is Madison's story - first-time mum to 6-month-old Daisy.



Born in March 2025, Daisy is our first child to my husband Rhys and I, the first grandchild and greatgrandchild for both of our families. She loves Hairy Maclary and swimming in the local pool.



Daisy was a healthy and happy baby for the first few months of life. However, when she was just 3 and a half months old, Rhys tested positive to Influenza B. I knew it could be dangerous for infants, but Daisy had no symptoms and went to sleep well that night.

**At 5am, Daisy woke up quite irritable. She was extremely hot to touch. She then had a tonic-clonic seizure that lasted for 8 minutes!**

As a paramedic, I've seen a multitude of seizures.

We called the ambulance immediately and Daisy was rushed to hospital.

As we waited for tests and answers, I researched "worst types of epilepsy for babies". What came up? **Dravet Syndrome**. I ruled it out as it was quite rare and we had no family history.



Two weeks later our little girl was diagnosed with - yes, you guessed it - Dravet Syndrome. Shock. Disbelief. Devastated. Trying to comprehend the immense changes to every facet of our lives, especially to Daisy. Our lives would now be nothing like we imagined.

There was nothing we could do to change this outcome except mourn the small things... *Will she ever drive? Get married? Be able to have a family? Will she make friends? Will she die young?* Hoping she will walk, talk and all the things we take for granted every day.

It's difficult to comprehend but we know we have to enjoy all the good days that we get with her.

Dravet Syndrome is a rare genetic epilepsy characterised by prolonged and dynamic seizures resistant to medications. It can be quite difficult to manage. Over time seizures can be triggered by such things as temperature changes, water reflections, lights, sun through trees, swimming and many more.

We expect her development to be normal and progressive, for now. When she turns 1 or 2 years old, we may see a cognitive impact of





skill regression, delays in speech or walking. There may be issues with growth, nutrition, behaviour, sleep etc.

And there's the risk of SUDEP (sudden and unexpected death in epilepsy) 1 in 5 children with Dravet Syndrome don't survive past the age of 10 years old.

Knowing this is terrifying and gut wrenching. But we will give her the best life possible each day.

Thankfully, the Epilepsy Foundation is by our side on our journey with Dravet Syndrome.

They've supported us and helped raise more awareness of Daisy's condition. We feel heard - a special thing in a time when there is so much still to process. They do the hard work behind the scenes to support people with epilepsy. They answer all your questions with insight, experience, expertise and compassion. Without them, there's not much voice or power for those living with epilepsy.

That's why I ask, if you can, to please support the Epilepsy Foundation. You'll be helping families like mine learning to navigate Dravet Syndrome - a condition which is part of Daisy and our family's lives, but it does not define any of us.

We have no idea what we will face as Daisy grows up. But we will make each day count filled with love, joy and adventures. She is so deeply loved and every day we get with her is an honour.

*Madison. mum to beautiful Daisy x*

