

Charity Number: 1024547



## National Epilepsy Awareness Day - Thursday 26th March

Thursday 26th March is National Epilepsy Awareness Day.

To help us mark this important day, we invite all children attending pre-school on this date to wear something purple in support.

This day is very close to our hearts, as we have two very special children with epilepsy who attend our setting. We kindly ask you to take a few moments to read the stories shared by Ernie and Lacie's parents below.

We are very much looking forward to celebrating these wonderful children while also raising awareness and understanding of epilepsy within our pre-school community.

Thank you for your support



Charity Number: 1024547



Hi Everyone,

Our names are Shauna & Stephen the proud parents of Lacie who has been attending St Charles Pre-school since August 2024 and thoroughly enjoys herself there.

We are writing this as we would like to share something that you may not be aware of, concerning Lacie.

As of 11th June 2025, Lacie was diagnosed with a neurological disorder called **Myoclonic Astatic Epilepsy (also known as Doose syndrome)**. This is a childhood form of epilepsy that typically presents between the ages of 2 and 6. Around two-thirds of children outgrow this condition; however, some do not.



At the onset of this condition, Lacie experienced very frequent daily **Myoclonic Atonic Seizures**. These seizures involved sudden muscle jerks, which at their worst caused Lacie to fall or drop whatever she was holding. The high frequency of these seizures contributed to developmental delays, behavioural changes, and communication difficulties. Her doctors explained that these effects are common in children with this condition due to the intensity and frequency of the seizures.

Lacie takes three different medications twice daily, in the morning and evening, administered orally via syringes. After several months of adjusting medications and increasing doses, her seizures are now finally under control. However, the medications do have side effects, including tiredness and behavioural changes. To help manage these, we allow Lacie to sleep in longer in the mornings and sometimes have an afternoon nap, ensuring she stays happy, healthy, and ready for each day.

Lacie's development is improving now the seizures are under control, however, Lacie's communication skills are still delayed and may be behind those of her peers; however, both we and her pre-school are working closely together to provide as much support and guidance as possible to help her continue to develop and improve in this area.

During the process of stabilising Lacie's seizures, Stephen and I underwent genetic testing, and we are still awaiting the results, as we have been advised that Lacie's condition is likely genetic. The purpose of this testing is that if the specific gene responsible for Lacie's epilepsy is identified, her medical team will be able to tailor a more suitable and effective medication to help keep her stable.

Charity Number: 1024547



Currently, our focus is on raising awareness about epilepsy, as it is a significant part of Lacie's life and the lives of many others.

The purpose of **Purple Day** is to raise awareness, challenge stigma, and ensure that people living with epilepsy know they are not alone and that they are understood and supported.

Below are some resources if you wish to learn more about epilepsy as there are many different forms of epilepsy.

- ♥ Epilepsy Action
- ♥ Epilepsy Foundation
- ♥ [www.youngpilepsy.org.uk](http://www.youngpilepsy.org.uk)
- ♥ [www.epilepsysociety.org.uk](http://www.epilepsysociety.org.uk)

Stephen, Lacie and I would like to thank you all for taking the time to read this. We would also like to take this opportunity to thank Theresa and the team for everything they have done, and continue to do, for our beautiful daughter, Lacie. We are truly grateful.

Thank you for reading our story

Lacie, Shauna & Stephen

X

Charity Number: 1024547



## Ernie's Epilepsy Journey

Ernie was born in 2022, a healthy little 6lb 3oz baby boy. Everything was completely normal — until one day, just after his second birthday, he suddenly collapsed in his bedroom. He was completely lifeless. An ambulance was called, and doctors said it was a suspected seizure. We were told that if it happened again, we should try to film it.

Six weeks later, it happened again. This time, I managed to capture it on video, which led to a quick diagnosis of epilepsy.

The following six weeks were horrendous as we waited for an MRI scan to try and find a cause. As a mother, your mind always goes to the very worst possibilities.

Thankfully, the MRI came back clear.

However, Ernie then experienced two more life-threatening seizures, each lasting around seven minutes.

Ernie is now on daily medication to control his seizures, and thankfully it seems to be working. He also has emergency medication in case of any future seizures. With treatment, Ernie is now able to live a relatively normal life.

As parents, though, we are on constant alert. We don't know the cause or the triggers, so a seizure could happen at any time. It has definitely changed our whole family's life, but we are so grateful that his condition can be managed.

The one small blessing is that Ernie doesn't remember anything when he has a seizure.

We are learning every single day. The more people who are aware of epilepsy, the better.

Paula (Ernie's mummy) x

