Poppy’s Story

Poppy had her first seizure at 6 months old, I had never seen a fully grown adult have a seizure let alone an infant. To say it was the scariest day of my life is an understatement.

Kia ora, My name is Emily and I would like to share my epilepsy journey.

I have a daughter with epilepsy, her name is Poppy.

Poppy had her first seizure at 6 months old, I had never seen a fully grown adult have a seizure let alone an infant. To say it was the scariest day of my life is an understatement. Her first seizure lasted about 5 minutes. It was her brother who noticed something was wrong. He was 9 and started shouting “Something is wrong with her! Something is wrong with her eyes!”. We called an ambulance as we couldn’t get her to respond to us, her body had gone completely limp and blue, and she was having difficulty breathing. After several hours at A&E, she was diagnosed with a BRUE, or “brief resolved unexplained event” …. Great! an unexplainable event that made absolutely no sense to us; our only comfort was they said … “. unlikely to happen again”. So, you can imagine our distress when 24 hours later she had another seizure (we were not calling them seizures at this time as we genuinely had no idea what they were). We were admitted to the hospital for 5 days to monitor her, and the doctors hoped she would have another event, so they could better understand what was going on. Poppy did not have another seizure, and we were discharged feeling none the wiser, but now more anxious than ever. After this, she began having seizures roughly every two weeks; then weekly, this progressed to two or three times a week. At this stage, the doctors had decided to begin medicating her, initially on a broad-spectrum medication as these medications treat a wide variety of seizure types, as they didn't yet know what type of seizure she was having.

After six months her seizures had increased to daily seizures, sometimes multiple times per day, during this time I had to video the seizures each time, to get better observational video images; which we hoped would give the doctors a better understanding of what was going on.

Finally, her neurologist diagnosed her with non-familial self-limiting epilepsy and put her on her 5th type of medication. Her new medication, Tegretol, has been so effective that while she has been on it, she has had no seizures at all. We attempted to wean her off the medication on her 2nd birthday, however, after 6 days with no meds she had another seizure, so she went straight back on her medication.

We will attempt to wean her off medication every year until hopefully, it works. We know we are the lucky ones, that in theory, she will grow out of this, but it has opened our eyes to the world of living with epilepsy, and the many precautions we take/took to ensure she is safe in all her environments.

SELF LIMITED FAMILIAL AND NON-FAMILIAL INFANTILE EPILEPSY

"Seizures are often frequent and intractable at the onset but spontaneously resolve. The child is expected to have normal developmental progress. Familial and non-familial forms of infantile epilepsy are identical except for the presence of a family history."

From www.epilepsydiagnosis.org