I am number 17
Lucinda and Nola's experience

Nola started to have seizures just before she was three months old, however at the time it was unclear to us that they were actually seizures. We took Nola to A&E but after checking her over we were turned away as Nola was seen as well. I was assured I was probably worrying about nothing but was advised to record videos of the odd episodes she was having. It was only after I showed video footage of Nola having a seizure to my GP the next day, that Nola was urgently referred to the paediatric department. So, we waited for an appointment.

Over that week Nola was experienced a lot of seizures, so we went back to A&E after sending videos to my old boss who is a paediatrician.

Investigations began and after an MRI scan, benign tumours (called tubers) were discovered in Nola's brain. The probable diagnosis was tuberous sclerosis (TS); however, this was not confirmed until we received genetic blood test results, which was around five months later. After more investigations we found out she had benign tumours in her heart and eyes too.

Receiving Nola's diagnosis was a really difficult time, as you don't expect your child to be diagnosed with a rare condition. It was also a very lonely time. When we were discharged with that probable diagnosis, we were not told any information about TS; we were unsure how this was going to impact our lives.

I was very open about sharing Nola's experiences, right from the start, when investigations into her condition first began. The only thing I didn't mention was that the probable diagnosis was TS as it hadn't been confirmed. By sharing my experience and opening up to the social media world, it almost felt like therapy.

You just don't know who out of a crowd could be living with a rare condition. People may appear to have no medical issues however, they might be living with a rare condition, you just don't know.

It would be brilliant if there was more awareness of rare diseases and an increase in public understanding. I used to be one of those people; I was unaware. However, when you experience things for yourself, it gives a difference perceptive on life and how people with lifelong conditions face multiple hurdles.

I know everyone's journey is different, people receive different diagnosis times, or may never find out their exact condition.

It can be frustrating at times as access to treatment and support to help conditions like Nola's can be a complete post code lottery.

I feel it is vital to raise awareness for all rare diseases and I am really excited to be a part of this campaign. It is important to get the word out about rare diseases, as they affect 1 in 17 people.

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