

NATIONAL EPILEPSY AWARENESS MONTH

Statement

HON COLIN de GRUSSA (Agricultural — Deputy Leader of the Opposition) [5.20 pm]: I rise to make some comments during National Epilepsy Awareness Month, following on from Hon Kate Doust's comments last night around epilepsy. In a similar vein, I want to talk about my own experience, with my eldest stepdaughter Amelia having been diagnosed with epilepsy early last year, at 14 years of age, after first having a tonic-clonic seizure in November 2021. Some members in this place will be well aware of that because, ironically, we were in a hearing with St John Ambulance at the time that she was put in the back of an ambulance and ferried off to Perth Children's Hospital. It has been quite the journey for her from there, and for her family as well. I want to take the opportunity while I am speaking to give a bit of a shout-out to the ambulance officers and the amazing staff at PCH, in particular Dr Peake, Dr Silberstein and Nurse Julie, whom Amelia still sees regularly and gets the help she needs from. It has been quite the journey.

Obviously, with epilepsy, one of the critical and hard things to do is to get a diagnosis in the first instance, because they have to observe the seizure happening when doing an EEG to confirm that it is in fact an epileptic seizure. That was quite tricky, although we did get referred to an organisation called Seer Medical, which provided an at-home EEG. It is one that the patient wears for five days; it comes with a little suitcase-sized computer that sits in the corner of a room with a camera on it that monitors the patient for five days and sends all the data back to Melbourne, so that they can see what is happening. That was fantastic, because it gave her the opportunity to have a relatively normal home life for five days, but at the same time get the diagnosis she needed. It is quite an impressive bit of technology, which was developed, I believe, in Melbourne. From there, it has been a matter of adjusting—doing the treatment and getting used to the different drugs. I have to say that the first round of seizure medication she took turned her into a suicidal maniac. That was harrowing for a little while—until we changed medication, basically. It was to the point of physical self-harm as a result of the medication. It was quite an experience for her, and obviously for us as parents as well. One of the complicating factors with Amelia is that she also has a similar illness called functional neurological disorder, which in fact causes seizures but they are non-epileptic seizures. Learning to identify which is which has been a challenge, but we are getting the hang of it now.

I want to acknowledge the organisations that work in the space of epilepsy. Obviously, we are all wearing the badges today for Epilepsy WA, which is 60 years old. As Hon Kate Doust said last night, the Purple Walk 4 Epilepsy will be held on Sunday. Unfortunately, I will not be in Perth, but I am happy to make a donation to the organisation anyway. This sort of advocacy and support organisation is incredibly important in whatever people are dealing with. Epilepsy WA has been a fantastic resource for us.

I am also very excited by a story that came out earlier this week about Monash University receiving funding for a world-first trial of a drug treatment that could potentially cure epilepsy. It is a potentially curative drug. In fact, they are starting clinical trials on that this year, after having done some testing of this drug on mice. That is very exciting for the about 150 000 Australians who suffer from epilepsy, more than 27 000 of whom are in WA. It is exciting that an Australian organisation is doing those trials and may potentially end up with what could be a curative treatment for epilepsy after six months, which would be amazing. Again, I want to take the opportunity to acknowledge the organisations that do work in the advocacy space for epilepsy. I have also committed to fundraising for epilepsy and will attempt my first half-marathon in May, which should be fun. I am not yet sure whether I will cross the finish line but I will keep trying. If anyone wants to donate to support epilepsy —

Hon Dr Steve Thomas: It's whether you're standing up or lying down when you do, that's the question.

Hon COLIN de GRUSSA: That is right. If anyone wants to support me, I would be very grateful for that. Of course, we have lots to look forward to for Amelia. When she turns 16 early next year, of course she will be trying to get her licence, which again is a challenge for those with epilepsy. We just hope we can keep her epileptic seizure-free for enough time to have that opportunity and to do all the things that young people want to do.