

Media Release

Knowledge reduces fear of epilepsy

Joanna and Chris Hulland know only too well the feelings of shock and fear that often accompany a diagnosis of epilepsy after being told their son Ryan, at just nine months old, has the condition.

Now four and a half, Ryan has also been diagnosed with Dravet Syndrome just two months ago, a rare and serious form of childhood epilepsy that means he will have ongoing seizures.

Ryan has a range of different seizures. According to Joanna, “Some seizures are mild, where he will firstly hallucinate, then start screaming and slowly lose consciousness with a very mild shaking and jerking. Others are quite violent with no warning where he’ll go flying backwards with a violent tonic clonic type of seizure where Ryan ceases breathing for a minute or two.”

Unlike many children with Dravet Syndrome, Ryan has no intellectual or physical disabilities. However, the impacts on him, his parents and his older sibling, six-year-old sister Sarah, have been enormous and are continuing to affect the family’s ability to lead a normal life. Joanna has now given up work due to the pressure of coping with Ryan’s constant seizures.

“Ryan’s development slowed for about eight months when he was about two and during the last four years he has had periods where his development has stalled for a couple of months,” Joanna explains. “Then we have had a rapid increase in development since he turned four.”

“When he was first diagnosed we didn’t know much about epilepsy. It was hard and you do deal with a fair bit of stigma because people don’t understand it.”

“There was a fear of what the future might hold and it was a major disruption to our whole work and family life. It has taken five years before it has taken a physical and mental toll on me. I gave up work because I am close to breaking point.”

“We are on edge, expecting seizures almost on a daily basis. For example, Ryan had a seizure on a slide a few weeks ago. Sarah grabbed him at the bottom of the slide, whereas if he had had it on the top of the slide he might have fallen on his head and really hurt himself.”

“We have also had issues with Ryan’s social interaction with other children, particularly if he is ‘spaced out’, whether that’s drug related or from the Dravet Syndrome, and where his development ebbs and flows, as kids pick on him. There was a time when he should have been learning how to interact with other children but he missed, out so he still struggles with that.”

Joanna describes her daughter Sarah as a “mother hen” but says Ryan’s epilepsy has also had an effect on her development. “Sarah had toilet training issues and she gets really clingy, even now, which is related to her need for attention. She is fabulous with Ryan and very supportive through a seizure but it has had and will continue to have a major impact on Sarah’s life – she has missed out on a part of her childhood.”

Joanna says the Epilepsy Foundation of Victoria has played a big part in helping her and Chris deal with Ryan’s epilepsy. “I was very slow in thinking that I needed any services, but once I opened that door the Foundation has been fabulous,” she says.

“The biggest support service I have had was when Ryan started preschool. We made application to receive funding to have another set of eyes in the playground. The application was fairly demanding so we did that with Lisa Rath’s help. Lisa came up to the preschool and offered support to the school and the teacher and she will also do that with the school that he will be attending next year.”

“When you are dealing with teachers and schools that are just not used to epilepsy – they all want to be helpful but they are just not sure how – the Foundation’s service has been huge.”

This week is Epilepsy Awareness Week (11-17 May), an opportunity for people like Joanna and Chris to tell their stories and raise awareness of epilepsy.

“There is not much awareness of epilepsy in the community and there needs to be more,” says Joanna. “Most people just don’t know what to do. There are still people who believe that you need to get a person’s tongue out of their mouth or shift their tongue. There are a lot of old wives tales still out there.”

“It’s important for more people to know what to do if someone is having a seizure. Epilepsy is not something to hide and they can still have a normal interactive life, but it covers all walks of life and is different for every individual.”

Graeme Shears, chief executive officer of the Epilepsy Foundation of Victoria explains the condition. “Epilepsy is a disorder of brain function that takes the form of recurring seizures. Our every thought, feeling or action is controlled by brain cells that communicate with each other through regular electrical impulses. A seizure occurs when sudden uncontrolled bursts of electrical activity disrupt this regular pattern,” he said.

“Epileptic seizures can range in type and severity from seizures where, for example, a child might simply appear vague or distracted for a short time, right up to the more commonly-held perception of seizures where a person might fall to the ground and experience severe body spasms, known as tonic clonic seizures.”

“However, for 80 percent of people with epilepsy, medication controls their seizures well, and they are able to live normal lives and work, drive a car, swim and do all the normal things.”

It is estimated that up to 104,000 people in Victoria will have epilepsy during their lifetime. Surprisingly, many older people will have their first seizure over the age of 65, so our ageing population means many more people are likely to experience epilepsy in the future.

The Epilepsy Foundation of Victoria provides services including counselling, support, information and advice, as well as advocacy and research, and wants to raise awareness of epilepsy to reduce the stigma in the community.

“Our services are about working with each individual to help them manage their epilepsy better in the way that matters most to them – whether that means ensuring they are seeing a specialist neurologist to get the best treatment, providing up-to-date information and counselling support or linking families with other people who also have epilepsy through our family camps.”

“We also consult with teachers and principles in schools that might have a student with epilepsy, so they understand the condition better and know what to do when the child has a seizure. We do the same in businesses where an employee might have epilepsy.”

“A large part of our work is about raising awareness of epilepsy and reducing the social stigma attached to it, so that people have a better chance of being accepted in the community and getting on with life in a more positive way.”

People with epilepsy or their families can call the Epilepsy Foundation of Victoria for assistance on 9805 9111 or the National Epilepsy Helpline 1300 852 853 for the cost of a local call, or visit www.epinet.org.au

Epilepsy Awareness Week will take place from Monday 11 May to Sunday 17 May 2009. The aim is to raise awareness of epilepsy and seizure first aid and to reduce the stigma in the community.

Ends

For further media information contact:

Julie Stephens, Stephens Public Relations
Tel: 03 9391 4603 0413 119 673

Graeme Shears, Epilepsy Foundation of Victoria
Tel: 9805 9111
Email: gshears@epilepsy.asn.au

20 April 2009