

## Article

*Epilepsy Awareness Week 11-17 May 2009*

### **Romy's Story: living with Dravet Syndrome**

Romy Parks-Earl was a baby – just 4 and a half months old – when she had a severe seizure. She was admitted to hospital for a week to undergo various tests, which found no explanation for the seizure. Just four weeks later Romy had another seizure, which was followed by constant seizures.

“We had no idea of what the seizures were. At the time, we were seeing a neurologist and our own doctor. We then consulted a paediatric neurologist who specialises in epilepsy. At 11 months old Romy was diagnosed with Dravet Syndrome,” says Romy’s mother, Dannielle Parks.

Dravet Syndrome is a severe form of epilepsy which usually appears in the first year of a baby’s life and generally does not respond well to antiepileptic medication. Dravet Syndrome is also known as Severe Myoclonic Epilepsy of Infancy (SMEI). Most of the children will have varying degrees of intellectual disability, physical difficulties and require ongoing care.

Romy’s seizures were severe and unpredictable. “It was frightening. For over six months, it was ambulance trip after ambulance trip. Every night I packed a bag and slept in my track suit so I was ready to just go ... it was terrible, terrible,” are Dannielle’s memories of those few years.

“When Romy was diagnosed with Dravet, at least we could put a name to her medical condition. But we know through genetic testing that Romy carries the SCN1A gene which means that this condition will be with her for life,” she says.

Anyone who knows anything about epilepsy can tell you how distressing it is for parents to see their young child experience severe tonic clonic seizures. “I can only explain the tonic clonic seizures that Romy has as being ‘full-on’ convulsions,” says Danni. They last on average 25 minutes, sometimes up to 80 minutes. She goes white; her lips turn blue; her little body stiffens; her back arches so badly, you think it will break. For anyone not used to it, it is a frightening experience. I look back and wonder how we survived.”

Last year, despite some initial reluctance, the Parks-Earl family spent a weekend at the Epilepsy Foundation of Victoria Family Camp. “I remember Jean Ewing, our counsellor from the Foundation, ringing me to invite us to come to the camp,” says Danni. “I told her it’s easier to stay at home. But then she said ‘This is one time when you don’t have to apologise for your child’s behaviour’. That was good enough for me.”

“It was just fantastic, especially to have a siblings program. We didn’t see Jack all weekend – he had a ball. It was such a sense of relief for Scott and me to know there were so many other people in the community living our life.”

This year – 2009 – Romy has started school at a local mainstream Catholic school. For Danni and Scott, it is a great milestone for their daughter to reach. “I was a wreck at the thought of Romy going to school, but we have had great support from the principal and teachers,” says Danni. “It was important for us to have a nurturing environment, and that’s what the school provides.”

“One of the Client Services team from the Epilepsy Foundation visited the school before Romy began and ran a session for teachers explaining Dravet Syndrome,” says Danni. “She then followed that visit up a few weeks later which made the staff feel much more confident about dealing with any situation with Romy. That sort of support is irreplaceable.”

While Romy has some behavioural issues which are common in children with Dravet Syndrome, the hope is to keep Romy at mainstream school. Later this year, she will have a neuropsychological assessment to assess her learning development.

Dannielle and Scott say that it is probably only in the past twelve months that they have really come to terms with Romy’s condition. “We accept that nothing is going to change, and that this is our life. All of us, including Jack, have roles to play in dealing with Romy’s seizures and development, and we just get on and do it.”

**This week is Epilepsy Awareness Week (11-17 May)**, providing an opportunity for people like Dannielle and Scott to share their story and help to raise awareness of this debilitating condition.

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 things they usually would.”

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 principals 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](http://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**

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