Raising Jarod

My name is Sharon and I am the mum of Jarod, an 8 year old with Dravet's Syndrome also known as Severe Myoclonic Epilepsy of Infancy (SMEI). Dravet's Syndrome is a debilitating form of epilepsy that effects my son's overall development, and ability to communicate. Dravet's Syndrome is marked by prolonged seizures starting in infancy, which can be extremely difficult to control, especially in the early years. Our journey with epilepsy started with his first prolonged tonic clonic seizure when Jarod was just 4 months old.

Although we are far from the early years of frequent hospital stays and ER visits, the memories of those times are clear in my mind and I've always got the lurking expectation that we'll revisit those days in the future. Epilepsy, if nothing else, is unpredictable as we know! I'd like to share with you some of the strategies and resources we've used over the years that have truly been life savers for us.

When Jarod was about 12months old he started showing his first signs of developmental delay. He had stopped progressing, although he was crawling and talking he failed to progress on to walking unaided. At 14 months, 16 months, 18 months his paediatrician reassured us not to worry, but to us the issues were glaringly obvious. It became apparent that we needed to take things into our own hands. Luckily we found an exceptional early developmental program for children with severe and multiple disabilities, called EDP [**http://slingshot.to/EDP**]. The Early Development Program didn't question my concerns they just acted on them. A one to one program was implemented and we spent the next 3 and ½ years prior to school ensuring Jarod had the best possible start in life. He also accessed the hospitals physiotherapy and speech therapy services until IDSC – Intellectual Disabilities Services Council [**http://www.idsc.sa.gov.au**/] took over and then more recently Novita Children's Services for children with physical disabilities [**http://www.novita.org.au/**]

Our first contact with the Epilepsy Association of SA/NT some 7 years ago provided a great source of guidance. We attended our first epilepsy related retreat that year. What fond memories I have of that time. We established friendships that will last forever. To have the entire family included in the fun and relaxation was just incredible to us. To be able to bond with other families facing similar experiences was such a fulfilling and uplifting experience. To know we where not the only one's facing these demons. To know they understood thoroughly without long winded explanations. To see our daughter bond with other siblings and having such abandoned fun was so amazing to us. I'm just so grateful to have been given the experience. We've been on a few retreats since then, some with the entire family, some with just adults, all serving a different purpose, but all such wonderful experiences it's hard to put into words.

Born from this first retreat was the parent support group that still runs now in Seaton, more recently a Southern parent group has also been established, all filling a need for parents to get together and share their unique experiences, fears and success stories.

Angelica, Jarod's sister has had some great times at sibling events for children with special needs. It's great for her to mingle with other kids who face the same issues. Being a sibling of a special

needs kid is far from easy and for her to have her own set of rewards, her own time with mum and dad and her own specialised events gives her the opportunity to explore her feelings and in general just have fun. For us this has been a really important integral part of our lives.

Jarod now enjoys respite weekends and camps with other disabled children. He gets to do things he might otherwise miss out on. Sure it gives us a break, but it's important for him too. Jarod needs to experience independence from his parents, and I need to know he'll be alright if one day we aren't around for some reason.

Seeking more information about Jarod's epilepsy I embarked on the internet in search of answers. It was here I found the clues that led me to Jarod's diagnosis of Dravet's Syndrome. The internet gave me the freedom to research at my leisure, ask questions, and find some rather interesting facts. As we know not everything on the internet is factual so it is important to be vigilant for inaccuracies, but for the most part the internet has provided a great source of information and encouragement for me. Without the diagnosis we would not now be on a medication regime that is doing a sensational job at reducing his seizures from many a week to one every 4 months or so. Without personally pushing for DNA analysis we would still be wondering what's going on. Without educating Jarod's doctors on our findings life for Jarod probably wouldn't be as wonderful as it is. These clues came to me in a variety of ways from information sites, to obscure forums, but the most impressive pieces of the puzzle where supplied to me by other parents. Other parents I've met through online support groups. I've used many, but there are two I can reliably use for support and guidance, the first is 'Parents of Kids with Epilepsy UK', **http://health.groups.yahoo.com/group/Parentsofkidswithepilepsy_uk/** which gets me in touch with other parents of children with a variety of epilepsy's, but for more specific issues related to Dravet's Syndrome you can't go past the SMEI Yahoo group: **http://health.groups.yahoo.com/group/smei/**

I've been so privileged to have been able to share my issues with such caring, sharing, and well educated parents. If I have a question I just ask, I'm sure to get at least one response within a day or two, try and get that reliably from your doctor. Of course none of this can replace doctor input and guidance, but let's face it some times it's our job to educate our kid's doctors, they certainly don't have the time to pour over books and information for just one child, so that becomes my job.

The other side of this is that some times we have the privilege in helping someone else, to pass on the knowledge we've learnt. Now that can produce an amazing buzz. A community striving together for one common goal, to make our kids lives that little bit better. Born of this amazing group is an International organization dedicated to Dravet's syndrome, called IDEAL (International Dravet's Syndrome Epilepsy Action League), based in the US, who proudly hosted their inaugural conference dedicated to the syndrome in August 2006, the first of many to come.

Although Dravet's Syndrome is not a diagnosis you'd wish on any child, it is certainly an exciting time for research and developments. Five years ago you couldn't get the DNA analysis that can confirm the diagnosis, a few years ago you would be hard pressed to find much information on the syndrome at all. Now there are several research projects underway and new findings are being discovered all the time.

It's quite an amazing journey we've been on, fraught with fear, unexpected courage and an unlikely amount of joy. We have two amazing children, very possibly resulting from the unusual set of circumstances we find ourselves in.

What an amazing life we live!

Sharon Wills

Dravet's Syndrome

FAST FACTS

French psychiatrist and epileptologist, Charlotte Dravet (1936–) first described severe myoclonic epilepsy in infancy (SMEI) in 1978.

Beginning before the age of one with febrile convulsions that are often prolonged, affected children go on to develop a wide variety of seizures. While development is normal prior to the onset of seizures, at about the age of one development usually slows considerably. Most or all children will develop psychomotor retardation and other neurologic deficits. Seizures are difficult to treat and usually involves polytherapy.

SMEI is not associated with previous significant brain pathology. The most probable etiological background is of genetic nature.

SMEI is a rare disease, with an incidence probably less than 1 per 40,000. In 2002 Dravet and colleagues found at least 445 published cases. Males are more often affected than females in the ratio of 2 to 1.

In 2001 the ILAE recognised the eponymous name Dravet's Syndrome instead of SMEI in recognition that not all cases experience myoclonic seizures.

For a description of Dravet's Syndrome by Charlotte Dravet visit **www.ilae-epilepsy.org/ctf/dravet.html**

Other recommended websites:

http://www.kidsepilepsy.com/
A remarkable database to access case histories of children with a variety of epilepsy diagnosis. Add your child's details to the list.

http://idea-league.org/
A newly formed international organization dedicated to raising money and awareness for Dravet's Syndrome.

http://members.optusnet.com.au/shazzas01/smei.htm
A laymen's guide to the syndrome, created by a parent of a child with Dravet's Syndrome, based on Dr Dravet's account of the syndrome.

http://shazzas01.tripod.com
Sharon's personal site. Find out more about Jarod and Dravet's syndrome.