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MUSTER PERSONAL STORY

Not knowing what is wrong with your child and where to turn is one of the hardest challenges a mother can face. When Maria Harms' son, Charlie, started having "strange turns" at the age of two, she had no idea that it could be epilepsy.

The Harms journey through diagnosis was not an easy one. Like many people, she turned to Google and was even more frightened when she read about Sudden Unexpected Death in Epilepsy (SUDEP). It was two months of extreme difficulty, culminating in an emergency trip to Brisbane after a particularly bad cluster of seizures.

After a period at the Royal Children's Hospital in Brisbane, the Harms family returned to their home in regional Queensland but found that there was little follow up or support available in their local community. Maria wished there was someone to help them navigate the system and help plan for when they got home. She wished she knew about Epilepsy Queensland back then.

By the time Charlie reached 14, he had never met another young person who lived with uncontrolled epilepsy. Epilepsy was having such a major impact on his life every day. Charlie was affected at school so often that Maria had started home schooling him. For Charlie it looked like he would never be able to hold a driver's license or a full-time job due to his frequent seizures and the side effects of medications.

Charlie's little sister Milli wanted to do something to help, so she organised a Purple Day fundraiser in 2017. This success led to a conversation around the dinner table, about how the family could make a bigger difference for people living with epilepsy in regional Queensland. The idea of "The Great Elders Cattle Muster" was born.

The Harms' and the other wonderful families that assisted with the Muster, raised funds to establish a service on the ground in regional Queensland. Stay tuned for more information on this service as we continue to raise funds.

At the age of 14 Charlie had epilepsy surgery. The future is now looking much brighter for Charlie, but it has come with a lot of hard work. Charlie is now able to attend school every day and is doing well. Maria was thrilled to let us know that Charlie has been seizure free 20 months and now has his learner driver's license.

A highlight of the Muster for Charlie, was meeting the other young people living with epilepsy who were involved in the event. When he met Tayler Kenny and Georgia Sherry, it was as if they could "truly see each other". Amongst the dust, the cattle and the spirit of helping others doing it tough, the three teens were no longer alone in their battle with epilepsy.



EARLY-LIFE SEIZURES PREMATURELY WAKE UP BRAIN NETWORKS TIED TO AUTISM

Antiepileptic Drug May Keep Synapses ‘Silent’ Longer So Brain Can Develop Normally, Penn Study Suggests

A study from researchers at Penn Medicine published recently online in Cell Reports and detailed in Penn Medicine News suggests early-life seizures prematurely switch on key synapses in the brain that may contribute to further neurodevelopmental delay in children with autism and other intellectual disabilities.

The study shows that an existing targeted therapy may keep those synapses “silent” after seizures to allow the brain to develop normally during a critical time in a person’s life. “Silent” synapses become active with experience, and removal of the reservoir of these synapses due to seizures results in a decreased capacity to engage these synapses in later learning.

Seizures from epilepsy early on in life have been linked to autism and other disorders—up to 40 percent of children with autism have epilepsy, for instance. However, mechanisms behind that relationship have been less understood. What is known is that early development of the brain involves a series of “critical periods” where synapses tied to learning and language skills are gradually activated. Seizures can lead to learning and cognition issues, past research has shown, but how they affect the critical periods of development remained unknown until now.

According to recent estimates from the Centers for Disease Control and Prevention, about one in 60 children in the United States has autism. Up to 40 percent of children with autism and intellectual disabilities also suffer from epilepsy, and approximately 35 percent of children with infantile spasms develop long-term intellectual disabilities, including autism.

In preclinical studies, the team discovered that following induced seizures “silent” thalamocortical synapses in the auditory cortex containing only NMDA receptors switched to “unsilent” synapses with both NMDA and AMPA receptors. Thalamocortical pathways are the main route of sensory information to the cerebral cortex, and the NMDA and AMPA receptors play important roles in learning and forming new memories. This premature activation of the synapses with the additional AMPA receptor is what created a disruption in the auditory synapses days later during the critical period of development in mice, they found.

The researchers induced seizures in mice with pentylentetrazol, or PTZ, injections and used voltage-sensitive dye (VSD) imaging to monitor, measure, and visualize brain activity in the auditory cortex.


Researchers believe this is proof of principle that synaptic plasticity is a dynamic target for the treatment of autism and intellectual disabilities that accompany early-life seizures. Researchers hope further exploration will not only gain more insight into the etiology and treatment of autism, but also other neurodevelopmental disorders.

The new findings reveal a mechanism for the relationship between seizures and later-in-life cognitive impairment, as well as a much-needed potential treatment avenue to pursue.

The information above was reproduced from: <https://www.pennmedicine.org/news/news-releases/2018/may/early-life-seizures-prematurely-wake-up-brain-networks-tied-to-autism>

Ninth Annual

Queensland Epilepsy Symposium



Thinking outside the box !

Save the date
Tuesday 30 October 2018
State Library of Queensland

Join us for some stimulating dialogue...

www.epilepsyqueensland.com.au**Bookings essential!**

SAFETY - MEDICATIONS

For many people living with epilepsy, taking medication is a daily part of their routine. Antiepileptic medications, commonly referred to as AED's, help to control brain chemicals that send signals to nerves around the body, in turn reducing seizure activity. Therefore, it is vital that medications are managed & taken carefully to ensure effective seizure management. Things to consider include:

Administration

- Always follow doctors instructions
- Do not reduce your dose or stop taking your medication unless your doctor tells you to do so
- Aim to take your medication at set times each day
- If you forget to take your medication:
 - If it is almost time for your next dose, skip the dose you missed & take your next dose at the usual time
 - Otherwise, take it as soon as you remember & then go back to taking your medication as you would normally
 - If you are unsure, contact your doctor or pharmacist for advice
- If you take too much medication:
 - o Immediately contact your doctor or the Poisons Information Centre (phone 13 11 26) for advice or go to your nearest Accident & Emergency Centre

Prescriptions

- Always ensure you have enough medication by filling prescriptions before your supply runs out & having a repeat prescription available at all times
- Do not change brands of medication. Whilst the active ingredients in branded & generic medications are the same, non-active ingredients (fillers, coatings, colours etc.) may differ. Therefore, swapping and changing brands can affect blood levels of your medication & in some people can lead to breakthrough seizures.
- Tell your doctor or pharmacists if you are taking any other medications, even over the counter medications & vitamins

Storage

- Most AED's should be stored below 25° C & kept away from light
- Do not leave medications in the car, on window sills or in the bathroom as heat & dampness can destroy them
- Keep medication in its original packaging until it is time to take it

Side Effects

- Report side effects to your doctor – these may be more severe in the beginning but may subside as the body gets used to the medication
- If experiencing serious side effects tell your doctor immediately or go to your nearest Accident & emergency Unit. These may include:
 - An increase or change in seizures

- Major changes to mood including strange, unusual or suicidal thoughts
- Changes in vision or hallucinations
- Sudden signs of allergy - skin rashes, hives, itching or swelling of face, lips or tongue
- Respiratory changes – difficulty breathing, wheezing etc.
- Changes in mobility including gait (walking style) or loss of balance

Travel

- Take enough medication in its original packaging to last your holiday
- Carry an extra prescription if travelling in Australia & a letter outlining your diagnosis, medications & dosages if travelling overseas
- Always carry medications in hand luggage in case your main luggage is lost or delayed
- When travelling long distance & changing time zones, discuss with your doctor to develop a plan to manage medication timing

For more information on how to safely & effectively take AED's or medication side effects, contact our Services team on 3435 5000 or 1300 852 852 (outside Brisbane).

Children's Health Queensland Hospital and Health Service

Learn the life-saving skill of CPR

CPR Awareness Program

Friday, 28 April
Friday, 26 May
Friday, 30 June
Friday, 28 July

2pm - 3.30pm
Level 7, Seminar Room 2

Book by calling **3068 4600**
or **3068 1770**

A gold coin donation
to the Queensland
Ambulance Service
is appreciated

All families
welcome



Developed in collaboration with:





NDIS - TIPS AND HINTS

With many regions now live with the NDIS, and many others becoming live from July 2018, now is the perfect time to consider the information below as part of your pre-planning.

At a minimum, we recommend that all people with epilepsy have the following items within their plan. A suitably qualified and experienced team member from Epilepsy Queensland can provide these services:

Capacity Building: Improved Daily Living (Therapy Supports)

- Epilepsy Needs Assessment - Assessment of the person's unique epilepsy related needs, particularly where the epilepsy is complex or unclear. This includes assessing the person's ability to self-manage at home or in the community and identify safety and risk management support needs – such as monitoring equipment etc.; (~4 hrs – depending on the complexity + travel)

An outcome of the Epilepsy Assessment above, may be recommendations for the purchase of specific aids or equipment. As some providers for this equipment may not be registered with the National Disability Insurance Agency (NDIA), you may need to consider this section of your plan being Self-managed or Plan Managed. For more information on this, please refer to <https://www.ndis.gov.au/participants.html> or contact Leonie Hogarth at Epilepsy Queensland who can explain this further.

- Developing an Epilepsy Management Plan, +/- Midazolam Plan – documenting an individualized epilepsy management plan in an easy to understand format, that provides information on the type of seizures, how the seizures present, triggers for the seizures, and specific first aid and emergency management; (~3hrs – depending on complexity and availability of information + travel)
- Training for families/carers and support staff – this is essential for the persons support team - this provides necessary information for families, carers and support staff in relation to identifying and responding to the persons

needs and the safe administration of prescribed medications (~2x sessions per year – to manage staff turn over, at 2.5hrs p/session)

A few other tips that we have come across, that may be relevant to your pre-planning:

1. If your loved one would benefit from any low-risk, low-cost assistive devices, such as modified utensils, non-slip mats, external continence aids (one off/short term supply of washable briefs; pads; bedding protectors etc.) - then these should be identified, and trigger the funding allocation for this in the plan - I think it is about \$1500 now
2. On page 29 of the Price Guide, it mentions that Service Providers providing 'Assistance with Social and Community Participation' - "If arranged in advance with participants, providers may charge up to 4 hours for each plan period to document the process and expected outcomes." We would recommend articulating that this needs to be added to the hours in the plan, so it doesn't come out of direct service delivery
3. Some families choose to self-manage some parts of their plan – as it gives greater flexibility to choose which providers you use, as they do not need to be registered with the NDIA. A common area that people self-manage is the transport funding (if eligible) and the consumables – which incorporates incontinence aids – as it may be easier to purchase items when they are on sale at the local shops than through a service provider.

We have a range of other factsheets and pre-planning workbooks, so if you would like additional information or support with your pre-planning, or any other stage of your NDIS journey – please do not hesitate to contact us on 07 3435 5000, we are here to help.

What's On ...

Understanding Epilepsy Workshops Brisbane

19 July (9.30am to 12.00pm)
16 August (9.30am to 12.00pm)
13 September (9.30am to 12.00pm)

Understanding Epilepsy Workshop Brisbane

25 July (11.00am to 1.00pm)

Save The Date

30 October
Ninth Annual Queensland Epilepsy
Symposium

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