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ENERGY TOP-UP SAVING KIDS FROM SEIZURES

One of the exciting topics at this year's Annual Queensland Epilepsy Symposium Thinking outside the box is 'New dietary treatments for epilepsy' being presented by Associate Professor Karin Borges who is the Head of Neurological Disorders and Metabolism Laboratory at the University of QLD.

A drug developed in the USA is helping to reduce seizures in Australian children with epilepsy, according to a University of Queensland clinical trial. Almost 50 per cent of children involved in the trial at the Lady Cilento Children's Hospital showed a reduction in seizures while taking triheptanoin.

UQ School of Biomedical Sciences Associate Professor Karin Borges said energy was needed to prevent and recover from seizures.

"If you have less energy in your brain cells, you are more likely to have a seizure and you will find it harder to recover," Dr Borges said.

"Once metabolised, triheptanoin enters the brain and helps with energy production.

"Patients did not experience any of the typical side effects of anti-seizure medication such as tiredness, behavioural disturbances or severe rashes.

"This indicates the drug could be safe and tolerable in children."

Epilepsy is the most common brain disorder in children, and is especially debilitating and hard to

treat.

"Approximately 45 per cent of children experience uncontrolled seizures despite the availability of a variety of medications," Dr Borges said.

"Even on medication, 30 per cent of children will find no seizure relief at all."

Current treatment for epilepsy involves following a strict ketogenic diet, which is high in fat, low in carbohydrates and controls protein intake.

"People following this diet are required to weigh their food and restrict their caloric intake, leading to side effects including hunger and lack of energy," she said.

"My team wants to find a straight-forward approach to managing this illness, so patients do not have to follow such a restrictive diet."

Triheptanoin was originally developed as a treatment for rare metabolic disorders such as fatty acid oxidation disorders.

Dr Borges said larger trials of triheptanoin were needed to find out which types of epilepsy responded best to the treatment.

The research is published in the European Journal of Paediatric Neurology (DOI 10.1016/j.ejpn.2018.07.014).

The study was funded by the Thrasher Research Fund and supported in part by Ultragenyx Pharmaceuticals. The trial involved researchers from the Neurosciences and Dietetics Departments at the Lady Cilento Children's Hospital in Brisbane.

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!

MY HEALTH RECORD - IMPROVING CARE FOR CARERS & THEIR LOVED ONES

Meet Donna. She's a public health professional, single Mum and carer to daughter Marnie.

"One afternoon, my youngest daughter phoned me to say Marnie's collapsed – she can't walk. After Marnie's brain haemorrhage, she spent nearly three months in intensive care. She had the base of her skull removed and a tracheostomy placed because the implication was, if she survived, it was going to be a very long journey," Donna said.

An important element of Marnie's care was that she had a My Health Record.

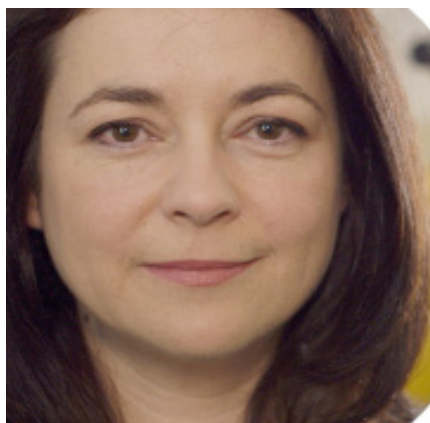
"With others participating in Marnie's care, if I'm not around and if they need to take Marnie to the doctor, or if she is hospitalised, the information is there for her," said Donna.

"At the age of 16 or 17, most people don't consider having a My Health Record. But sometimes, things happen unexpectedly.

"For Marnie, she's been a complex case – we've had a number of interactions with the health system and visited hospital over 400 times. In that period, the procedures and blood tests she's had are numerous. My Health Record provides me with the security and confidence that Marnie will be managed appropriately by all healthcare professionals."

General Practitioner, Clinical Professor and Chief Medical Adviser at the Australian Digital Health Agency, Dr Meredith Makeham, believes that a My Health Record is an important system to keep provider, carer and patient information together.

"One of the frustrations for people who are carers for loved ones or other people is they just don't have access to that person's health information. If we could all see the same health information, we can work much more effectively as a team and support the person who we are trying to care for."



Dr Meredith Makeham



Donna and her daughter Marnie

My Health Record can contain a summary of an individual's information such as medications, medical conditions, pathology and medical imaging results, immunisations, hospital, specialist, GP and allied health visits. In emergency situations, it has allowed treating doctors to provide the appropriate treatment quickly. It also gives healthcare providers a more detailed picture to make decisions, diagnose and provide treatment.

My Health Record provides many valuable benefits for carers. It:

- supports and assists carers and those they care for to ensure better connected care;
- gives carers better oversight of healthcare services being provided;
- gives carers and their dependents the ability to see their prescribed medications and test results;
- gives carers the capacity to upload important health information including allergies and adverse reactions;
- and enables the carer to share the dependent person's health information with their healthcare providers.

The My Health Record system has multi-layered security processes and strong safeguards in place to protect your information. It adheres to high level Australian Government security requirements and privacy regulations.

By the end of this year, all Australians will have a My Health Record created for them, unless they choose to opt out by 15 November 2018.

To find out more about being a nominated or authorised representative, or for more information on how to opt out, go to www.myhealthrecord.gov.au or call the help line on 1800 723 471.

NDIS - UNDERSTANDING THE STRUCTURE OF YOUR FIRST NDIS PLANNING MEETING

Epilepsy Queensland have been supporting people at various stages through their NDIS journey including attending the NDIS Planning meeting with individuals and their families.

Below is an overview of the experiences of these meetings:

- The meeting will start with introductions, so that you get to know the planner, and they get to know you.

Tip: It has become known that not all planners have good knowledge of epilepsy, or various syndromes associated with epilepsy. A suggestion - spend the first few minutes educating the planner – as this will help them with further assessments and conversations.

- You will be asked various questions about the level of functioning aligned to 6 core areas – cognition, mobility, self-care, social interaction, self-management and life activities – such as work, school, volunteering etc.

Tip: Consider the question in totality, for example, 'can you dress yourself' – if the person can do all of the steps to dress themselves, then YES, however, if they are unable to identify the correct clothing for the day, ensure it is on correctly, poor fine motor skills for buttons etc. – then the answer is NO. Please note – some answers are yes and no, others you may be asked to comment on a rating scale e.g. all of the time, through to none of the time.

- There will also be questions that relate to outcomes and risk assessment.

Outcomes – this discusses where you are now, and where you want to be in the future – and considers various life stages, such as, home, work, health & wellbeing, daily activities, community involvement etc.

Risk assessment – this conversation draws out risks to the person that need to be taken into consideration with the planning, e.g. no money understanding, limited stranger danger awareness, if leaving home by themselves, can the person find their way home, risk of informal support break down etc.

- Participant Statement! This is all about you, where you live, who you live with, who supports you etc.

Tip: We strongly encourage people to have this section already prepared before the meeting. It is one less thing to have to think about in the meeting

Tip: When considering informal supports (family, friends etc.) only discuss those that provide supports, as it may be interpreted that they provide more supports than they actually do.

Your Goals

Generally, the NDIS plan will have 2 short term goals (goals for the duration of the plan, which is typically 12months) and then identification of longer term goals. The wording and focus on these goals is important, as the funding that you get will link back directly to the goals, and will determine how the NDIA can assist you to achieve them.

Tip: Try to keep the goals broad, but also specific as needed.

E.g. instead of 'to continue to participate in swimming classes' a better goal may be worded as 'to explore social and recreational activities that will enhance my overall wellbeing and enhance my independence. Various assistive technologies may be required to keep me safe and enhance my independence. (the specific statement that will enable an OT to identify relevant assistive technologies.'

Your planning meeting will usually be between 2-4hrs.

Tip: The planners are coming with varied backgrounds and may not understand your disability/needs. If you feel uncomfortable about the planner understanding your needs, please know that you have the right to request to stop the meeting and request another planner. This may delay the meeting, but it may be beneficial for you.

If you have any questions or seeking support at any part through your journey, please contact us on 07 3435 5000.





What's On . . .

A REMINDER for your SCHOOL - 2019! BOOK IN NOW!

Does your school need to update its Epilepsy Awareness training?
Does your school need to update the Administration of Midazolam for your child?

We can offer these trainings
*Understanding Epilepsy
*Administration of Midazolam
(all tailored to individual needs)

It's easy! Simply download a 'training request' form from our website (epilepsyqueensland.com.au) or call us on 07 34355000 or 1300 852 853 (toll free) to discuss a training package and a suitable date and time.

'UNDERSTANDING EPILEPSY' and the Administration of Midazolam WORKSHOPS BRISBANE

monthly workshops at the Woolloongabba office on:

18 OCTOBER (9.30am - 12:00pm)
& (6:00pm - 8:00pm)

15 NOVEMBER (9.30am - 12.00pm)

'UNDERSTANDING EPILEPSY' and the Administration of Midazolam WORKSHOPS GOLD COAST

14 NOVEMBER (11:00am-1:00pm)

Position Available

We are currently seeking new staff to join our team of Lifestyle Support Workers for clients in Brisbane and Ipswich. If you are seeking meaningful work with an organisation committed to a vision where our team and our clients thrive, we'd love to hear from you.

For further information contact:

Leonie Hogarth

lhogarth@epilepsyqueensland.com.au

or

P: 07 3435 5000

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po box 1457, coorparoo bc qld 4151
phone 07 3435 5000 • 1300 852 853 (regional queensland)
fax 07 3435 5025
email epilepsy@epilepsyqueensland.com.au
www.epilepsyqueensland.com.au
ABN 42 025 269 961

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