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QUEENSLAND EPILEPSY SYMPOSIUM 2017

The Eighth Annual Queensland Epilepsy Symposium was held at the Princess Alexandra Hospital on 26th October 2017. With an audience made up of members of Epilepsy Queensland, people living with epilepsy, education and medical professionals a diverse number of topics were covered. A presentation by Ruth Blackburn, a Psychologist working as a researcher with the Lambert Initiative focused on current issues surrounding Medicinal Cannabis and provided an update on the Paediatric Epilepsy (Lambert Initiative) Cannabinoid Analysis (PELICAN) Study. An important part of this study is speaking with parents about their opinions towards and/or experience with cannabis products used in childhood epilepsy. For parents currently using cannabis products, the PELICAN study can analyse your product for cannabinoid content with the option available to receive individualised feedback. To find out more about the PELICAN study visit <https://sydney.edu.au/science/lambert> or phone (07) 3069 7014.

“Epilepsy and Spirituality” was the title of the presentation from Professor Cecilie Lander. It provided a fascinating perspective on health-spirituality research and the journey some people living with epilepsy have taken to find acceptance and resilience. Other presentations included Genetics in Focal Epilepsy, by Dr Piero Perucca; Stereo EEG, by Dr Sasha Dionisio; Causes of Epilepsy, by Dr Lata Vadlamudi; Non-Epileptic Seizures, by Professor Harry McConnell & Dr Rian Dob; Epilepsy Medication, by Dr Dan McLaughlin; and finally the NDIS and Epilepsy. With the NDIS being phased in across the state, Epilepsy Queensland is able to work individually with people and their supporters and Leonie Hogarth, Services Development Officer for Epilepsy Queensland explained the process to the audience at the symposium. A range of factsheets and other information and resources about the NDIS is available, please contact the Services Team at EQI on (07) 3435 5000 or 1300 852 853 (outside Brisbane) for further information.



L-R Trish, Donna, Jodie, Jenny, Alison, Leonie



Psychologist Ruth Blackburn

MyTime Support Group

Epilepsy Queensland Inc. is excited to partner with Playgroup Queensland to host MyTime groups in 2018. MyTime is a free information and support group for parents, grandparents or anyone caring for a child up to the age of 16 years with a disability, developmental delay or chronic medical condition. A Play Helper will be available to provide activities for children up to the age of 5yrs old, to enable parents and carers to attend and engage with the support group. Stayed tuned about this exciting opportunity in 2018!

EARLY CHILDHOOD EARLY INTERVENTION – HOW THE NDIS MAY BE ABLE TO HELP YOUR CHILD.

If your child is aged newborn to 6 years, and has a disability, or if there are concerns with their development, they may be eligible to receive support from the National Disability Insurance Scheme (NDIS).

A child's early years are very important as they set up how they will learn and develop later in life. It is widely accepted that early intervention for a child with developmental delay or disability is critical to achieving the best outcomes, reducing the possible need for longer term intervention and supporting them over time to lead an ordinary life.

The Early Childhood Early Intervention (ECEI) approach has been designed to identify the type and level of early intervention supports your child needs to achieve their best outcome in aspects of their life. This approach also seeks greater inclusion in mainstream settings and builds the capacity of the child and the family unit.

What are Early Childhood Partners?

The National Disability Insurance Agency (NDIA) partners with local providers in the community to give assistance, advice and access to early intervention and support for your child. These partners are called early childhood partners. Details of your childhood partner or interim arrangement will be available on the NDIS website when the NDIS is available in your area.

What is the ECEI Process?

1. Connect with an Early Childhood Partner

Contact the Early Childhood Partner for your region. Information on the regions and Partners are available on the NDIS website, or by phoning the National Disability Insurance Agency on 1800 800 110.

2. Receive relevant information

The Early Childhood Partner will provide you with information and guidance that will assist you to make decisions about the right supports and services for your child.

3. Identify support needs

The Early Childhood Partner will help you to identify what supports and services are available to you to help your child meet their goals. As each child is

unique, the supports and services will be different for each child depending on their circumstances.

This support may be:

- Information and linkages
- Short term intervention supports
- Or access to the NDIS

Our experience has shown that often, the Early Childhood Partner will approve funding for the family to undergo further assessments to identify options to best meet the child's needs and goals.

4. Accessing the NDIS

If your child will be best supported with an NDIS plan, the Early Childhood Partner will work with you to request NDIS access and once confirmed, develop a plan and support you to connect with providers of your choice.

5. Monitoring and review

Whatever supports your family receives, your child's progress will be monitored against the goals you set. Your Early Childhood Partner and Service Providers will work with you towards improving your child's independence and participation in everyday activities.

How Epilepsy Queensland can assist you?

Epilepsy Queensland is an approved registered provider with the NDIS, and can assist you in many ways including -

- Information and support about accessing the ECEI supports;
- Information about the NDIS;
- Completing epilepsy monitoring assessments, and identifying aids and equipment that may assist your child;
- Developing /reviewing epilepsy management plans;
- Delivering training to teachers, support workers and families
- Providing supports in the home and in the community – aligned to individual goals

For a personalised conversation about how we can support you and your family, please contact us on 07 3435 5000.

Daelle, lives with epilepsy, but takes on each challenge of her late teenage years with a smile on her face. She has absence and focal seizures every day and two to three difficult tonic clonic or atonic seizures a week. After some of these seizures, Daelle has difficulty maintaining her airway and one time even broke her leg. Epilepsy Queensland is here to support children living with epilepsy and their families. With your donation, we can help more children like Daelle to live full lives and let their smiles shine through this Christmas.

Visit www.epilepsyqueensland.com.au/donate-now.



Help put smiles on children's faces this Christmas.

Please donate today.

www.epilepsyqueensland.com.au





SAFETY RETURNING TO SCHOOL

With the summer holidays underway, the last thing most of us are thinking about is getting back to school! To make things a little easier, we have put together a “To Do” list, to help make starting the new year a little safer for your child with epilepsy.

Must do's:

- Ensure your child's needs have been clearly communicated & understood by key staff at the school/kindy/childcare centre;
- Ensure that staff at the school/kindy/childcare centre have completed Understanding Epilepsy & Midazolam Administration Training;
- Ensure the Epilepsy Management Plan has been completed/updated;
- Ensure the Midazolam Administration Plan has been completed/updated, if ordered for your child (we recommend that it should be reviewed 12 monthly);
- Ensure all other paperwork required by the school/kindy/childcare centre (this will vary between facilities) is completed & returned asap, including a letter from their doctor clearing them to participate in activities such as swimming.

If Midazolam is required:

- Check your Midazolam Kit:
 - Check the expiry date of the Midazolam;

- Check that the Midazolam is wrapped in the original foil packaging or aluminium foil;
- Check that the foil packaging is labelled with the date the packaging was opened (Midazolam expires within 8 months of opening the foil packaging);
- Check that your child's name is clearly marked for easy identification;

- Ensure the Midazolam Kit contains:
 - Plastic Midazolam vials (5mg in 1ml);
 - Syringes if required;
 - An atomiser for intranasal administration if required;
 - Disposable plastic gloves;
 - Pen and paper for documentation ;
 - A copy of the Midazolam Management Plan;
 - An ice brick and cooler bag for the kit to be stored in during the hotter months when taking the kit outside;
 - Provide a separate kit for school (This is to ensure the kit is never forgotten between destinations);

How can Epilepsy Queensland Assist?

- Helping you to complete your Epilepsy Management Plan;
- Checking over paperwork to make sure all the important information is clear & concise;
- Providing Understanding Epilepsy & Midazolam Administration Training (contact us for a request form);
- Providing resources & fact sheets on a variety of topics, including:
 - Educational implications for children with epilepsy
 - Midazolam administration
 - Epilepsy & Swimming
- Liaise with family, school/kindy/childcare staff to provide support & information;
- A range of children's books are available for purchase for school libraries etc.

For more information or help with any of the above, please contact Epilepsy Queensland on 07 3435 5000

New handbooks for Lady Cilento Children's Hospital Neurology families.



The Neurosciences team at Lady Cilento Children's Hospital have developed a handbook to help patients and families who are receiving treatment for a neurological condition. The handbook was developed in consultation with consumer representatives and is now available for neuro families who are new to the service, as well as existing families.

How to access the new handbooks?

The new handbooks will be given to families by their child's neurologist or neurosciences nurse at their next

appointment or inpatient stay, as time will be taken to talk through it. Families who are new to the service will receive a handbook at their first appointment. If you would like to see a copy of the handbook before your next appointment, you can download it from <https://www.childrens.health.qld.gov.au/department-service-neurology-and-neurosciences/>

Epilepsy Queensland would like to thank Kirsty Wardle, Hazel Lloyd and Sue Hogan who have worked closely with the neuro team to help make these positive improvements for neuro families.

What's On ...



'UNDERSTANDING EPILEPSY' WORKSHOPS BRISBANE

Epilepsy Queensland is holding monthly workshops in our

Woolloongabba office on:

15 FEBRUARY 2018 (9.30am & 6.00pm)

15 MARCH 2018 (9.30am)

'UNDERSTANDING EPILEPSY' WORKSHOPS GOLD COAST

Epilepsy Queensland holds bi-monthly workshops at Benowa:

7 FEBRUARY 2018 (11:00am - 1:00pm)

7 MARCH 2018 (11:00am - 1:00pm)

MyTime Support Group

Dates to be confirmed

EVENTS

26 March 2018 Purple Day Celebration

For further information on any of the above events please contact Epilepsy Queensland on 07 3435 5000 or 1300 852 853 (Regional Queensland) or email epilepsy@epilepsyqueensland.com.au.

Do we need to update our mailing list?

We hope you enjoy reading the Livewires newsletter. However, if you no longer wish to receive Livewires, please let us know by calling 07 3435 5000 or 1300 852 853 (Regional Queensland) or emailing pr@epilepsyqueensland.com.au.

We would also greatly appreciate being advised if you have received multiple copies at the same household, so we can update our records accordingly. Thank You!



Telling your story is a great way to raise awareness about epilepsy. We are keen to raise the profile of epilepsy and increase community understanding and acceptance of epilepsy every single day. You can help so much by volunteering to tell your story in our publications and the media. Please contact pr@epilepsyqueensland.com.au if you're interested in assisting or just want to have a conversation about what may be involved.

EPILEPSY QUEENSLAND'S UNDERSTANDING EPILEPSY AND ADMINISTRATION OF MIDAZOLAM TRAINING

Epilepsy Queensland proudly conducts monthly in-house Understanding Epilepsy and Administration of Midazolam workshops at our Woolloongabba office and bi-monthly at the Gold Coast. Did you also know that we frequently deliver these training sessions to a range of different organisations, schools, kindergartens and child care centres around Queensland and northern NSW?

Come along...

...to our in-house Understanding epilepsy and Administration of Midazolam training at Woolloongabba or the Gold Coast. In 2018 we will also be offering three after hours in-house sessions. These workshops cover -

- seizure first aid
- seizure recognition
- current treatments for epilepsy
- known causes of epilepsy
- seizure triggers
- administration of midazolam

Download a flyer from our website (www.epilepsyqueensland.com.au) or call to register. We would love to see your family, friends and colleagues there or come along to meet new people.

What we offer...

Understanding Epilepsy

Administration of Midazolam

Epilepsy awareness (tailored to individual needs)

Length - 1.5 hours to 4 hours

How to organise an education session

It's easy! Simply download a 'training request' form from our website (epilepsyqueensland.com.au) or call us on 07 3435 5000 or 1300 852 853 (toll free) to discuss a training package and a suitable date and time.



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