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## DRAVET SYNDROME AND SPIDER VENOM RESEARCH

Epilepsy Queensland was thrilled to welcome Professor Glenn King to present at the recent Queensland Epilepsy Symposium. Professor King's topic, 'Can venomous animals help us develop medicines for epilepsy?' explored research into Dravet syndrome and spider venom. Dravet syndrome which is resistant to traditional drugs may have met its match in spider venom.

Professor King and researchers from The University of Queensland and the Florey Institute of Neuroscience and Mental Health have discovered a peptide in spider venom can restore the neural deficiencies that trigger seizures associated with Dravet syndrome.

UQ Institute for Molecular Bioscience (IMB) Professor Glenn King said the study in mice could be an important step towards better therapeutic strategies for the rare and life-threatening type of epilepsy developed by children in their first year of life.

***"About 80 per cent of Dravet syndrome cases are caused by a mutation in a gene called SCN1A,"*** Professor King said.

***"When this gene doesn't work as it should, sodium channels in the brain which regulate brain activity do not function correctly.***

***"In our studies, the peptide from spider venom was able to target the specific channels affected by Dravet, restoring the function of the brain neurons and eliminating seizures."***

Professor King said the discovery, made in collaboration with The Florey Institute's Professor Steven Petrou, was the latest to demonstrate the unique effectiveness of spider venom in treating nervous system disorders.

***"Spiders kill their prey through venom compounds that target the nervous system, unlike snakes for example, whose venom targets the cardiovascular system,"*** he said.

***"Millions of years of evolution have refined spider venom to specifically target certain ion channels,***

***without causing side effects on others, and drugs derived from spider venoms retain this accuracy."***

***"This latest finding may help develop precision medicines for treatment of Dravet syndrome epilepsy, which has been difficult to treat effectively with existing seizure medication."***

Research in Professor King's laboratory at UQ is focused on development of venom-derived pharmaceuticals to treat epilepsy, chronic pain and stroke. His laboratory maintains the most extensive collection of venoms in the world, which includes venoms from more than 600 species of venomous spiders, scorpions, centipedes and assassin bugs. Professor King shared many pictures of these venomous animals with the audience at the Queensland Epilepsy symposium and we thank him for his time and expertise.

Source: The University of Queensland News (August 2018) and Epilepsy Queensland Inc.



Professor Glenn King  
presenting at the 2018 EQI Symposium

# QUEENSLAND EPILEPSY SYMPOSIUM 2018

The ninth annual Queensland Epilepsy Symposium: Thinking outside the box was held on Tuesday, 30th October 2018 at the State Library of Queensland in Brisbane.

The theme this year was, 'What's in the pipeline?', with experts from overseas and throughout Australia presenting on a range of topics including autoimmune epilepsy, the changing landscape of paediatric epilepsy surgery, new dietary treatments for epilepsy and transitional care for adolescents.

The annual Scientific Meeting of the Epilepsy Society of Australia (ESA) was held in Brisbane this year, around the same time as the Symposium, and Epilepsy Queensland appreciated attracting a number of visiting international, interstate and local medical specialists who gave generously of their time, to speak at the Symposium.

We were thrilled to have Professor Sean Pittock as a keynote speaker. Professor Pittock is a consultant in the Department of Laboratory Medicine and Pathology. He holds the academic rank of professor of neurology, Mayo Clinic College of Medicine. In 2006, Professor Pittock set up the Autoimmune Neurology Clinic at the Mayo Clinic, the first dedicated clinic of its type in America.

At the Epilepsy Queensland symposium Professor Pittock presented on Autoimmune Epilepsy: From Biomarker to cure.

*"It is believed that some forms of epilepsy may be autoimmune and caused by antibodies that attack different proteins in the brain. This form of epilepsy may not respond fully to standard antiepileptic drugs (AEDs) and might require a different treatment strategy."* Professor Pittock said.

*"Knowing at the time of diagnosis whether a person's epilepsy is linked to autoimmunity would help to ensure they received the right treatment promptly".*

Dr Stephen Malone, Paediatric Neurologist and Epileptologist, Queensland Children's Hospital, presented on the changing landscape of paediatric epilepsy surgery. Dr Malone helped establish the first dedicated Paediatric Epilepsy monitoring

unit at the Royal Children's Hospital in Brisbane. This allowed Queensland children local and timely access to important services previously only available in Melbourne and Sydney.

In his presentation Dr Malone looked at advances in surgery & pre-surgical assessment for paediatric epilepsy overtime, stating, **"Surgery options are not used as much as they should be or as early as they should be. Surgery works with improvement of quality of life."** He discussed the expansion of paediatric surgical services in Queensland, giving hope that epilepsy surgery will become more common into the future.

Professor James Wheless is Chief of Pediatric Neurology and the Le Bonheur Chair in Pediatric Neurology at the University of Tennessee Health Science Center in Memphis. At the Symposium Professor Wheless presented on Transitional care for adolescents.

In his presentation Professor Wheless discussed the Three C's of Transitional care: capability, communication and continuity of care. Several practical steps were discussed, as were the ages at which transitional processes should be shared and implemented.

Professor Wheless discussed work done in the area of transitional care and looked

at various approaches including the American Academy of Pediatrics Algorithm (2011) and the recommendations of the Ontario Epilepsy Taskforce: Epilepsy Transition (Canada 2017).

This transition addresses three main areas:

1. Diagnosis & management of seizures
2. Mental health & psychosocial needs
3. Financial, community & legal support

These recommendations also suggest transition is an ideal time to:

1. Rethink the diagnosis
2. Repeat diagnostic testing where indicated (especially genetic testing)
3. Repeat/Update screening tests (video-EEG, EEG, MRI)

Feedback and evaluation of the event was positive and planning for the tenth annual symposium is underway.



EQI Client Service team: Jenny, Trish, Donna, Leonie

Thank you to our sponsors:



# NDIS - UNDERSTANDING THE STRUCTURE OF YOUR FIRST NDIS PLANNING MEETING

From mid-November 2018 a new planning process was introduced for goals, with a focus in the planning meeting to identify what supports are required to achieve the participants goals. Whether you are yet to have your NDIS planning meeting, or have this in mind for your next meeting, this information will be helpful to you.

The new planning process requires a goal to be identified, and then the planner will work with the participant/nominee to identify what supports are required to meet that goal. We have been informed, that you can have more than 2 goals, however this needs to be within reason. Instead the planners may work with you to combine some of your goals, if this is appropriate and will achieve the same outcomes.

Listed below are a few examples of goals and some points underneath to think about what supports may be needed to achieve the goal.

## Examples

### Goal 1.

To develop my confidence and independence in learning to improve my daily living skills and personal care including my emotional and mental wellbeing.

What is required to assist me with this goal:

- 1-1 assistance to develop my independent living skills – such as age appropriate chores – cleaning my bedroom, dishes etc.
- Small group (no more than 2 people) activities aimed at capacity building in the areas of emotional and mental health wellbeing
- Epilepsy Assistive Technology (AT) assessment to identify relevant AT that will keep me safe and enhance my independence
- Epilepsy training for my support team
- Epilepsy management plan, to ensure my support team have the necessary information to promote my safety and wellbeing
- OT assessments to develop relevant learning programs
- Psychology sessions – to help me develop skills to manage and regulate my emotional and mental wellbeing
- Positive behavior support to develop a plan that will help me to develop my skills in learning to adjust to different settings and how to regulate my emotions; this includes training for my support network
- Speech therapy – support to learn the skills needed to communicate my needs and wishes effectively; assessment of alternative communication device

### Goal 2.

I would like to increase my confidence and

independence to engage in social activities and community groups of my choice.

What is required to assist me with this goal:

- Assistance to access the community (combination of 1-1 sessions and small group sessions)
- Speech therapy – to help me improve my communication skills and articulate my needs and wants
- Psychology sessions - to help me develop skills to manage and regulate my emotional and mental wellbeing
- Transport allocation
- Epilepsy Assistive Technology (AT) assessment to identify relevant AT that will keep me safe and enhance my independence
- Epilepsy training for my support team
- Epilepsy management plan, to ensure my support team have the necessary information to promote my safety and wellbeing
- Continence management (sufficient aids/support to ensure safety and dignity)
- Mobility aids – wheelie walker, wheelchair, walk belt etc. (don't forget maintenance in your plan or any aids/equipment)
- Other?

### Goal 3.

I would like to access short term accommodation to maintain and continue developing my independency in different social settings. (think of this as what was previously called “respite”).

- Access to short term accommodation to meet my needs
- Staff have training in epilepsy management
- Portable equipment to take during the short term accommodation stay – e.g. epilepsy monitoring equipment, anti-suffocation pillow, sensory items etc.

### Long term goal

To have the necessary supports, aids and equipment to enable me to develop my independence and access a range of recreational, social and other services to meet my needs.

For more information about NDIS support please call Epilepsy Queensland on 07 3435 5000



# Watch this space

## Purple Day for epilepsy QLD

Purple Day Celebrations 2019



Epilepsy Queensland 50th Anniversary Celebrations 2019

### 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?

It's easy! Simply download a 'training request' form from our website ([epilepsyqueensland.com.au](http://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 and Gold Coast

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