

## Hello Friend,

Edition 21, 2019

Welcome to Brainwaves!

A couple of weeks ago I attended the International Epilepsy & Treatment Conference in Vienna and I have returned with a sense of positivity.

The things Tasmanians have been telling us in relation to their epilepsy and treatment are consistent with may other first world countries and although we have gaps in the health system and service provision, people in Australia are more fortunate than those in many other parts of the world.

It was affirming to see that although there is much to be done in Australia, we are moving in the right direction in terms of policy and advocacy.

I was also pleased to meet Joey and his wife from Texas in the USA. Joey described his epilepsy as like living in a dark prison cell for twenty years but told a very passionate and positive story of how a neurologist saw him before he saw his condition. Joey had a significant operation on his brain and now travels the world reminding others to look beyond the deficit condition to the person themselves.

I heard stories from families and carers that resonate strongly with what Tasmanian families and carers tell us here and I look forward to progressing a symposium to be held here in Tasmania in the next 18 months.

October is Worksafe Month (among others) so look out for Epilepsy Tasmania's new campaign that will be shown on the WIN television network, social media and the State Cinema throughout the month. We hope to encourage Tasmanian workplaces to become epilepsy smart and would love to know what you think of the advert.

I hope you enjoy this Brainwaves and as always, I welcome your feedback.



Wendy Groot, CEO Epilepsy Tasmania.

# **Health Update**

Last month, Epilepsy Tasmania met with the Neurology Team at the Launceston General Hospital (LGH) to discuss how to better collaborate and provide a comprehensive service to people living with or affected by epilepsy.

Our discussion included current service demands, access, future planning, and the ways Epilepsy Tasmania can provide greater support during diagnosis, ongoing treatment and communities.

We look forward to working closely with the LGH team within the specialised outpatient department and supporting the transition to primary healthcare.

Also – our nurse-educator, Emma, is now attending the Neurology Clinics run by Dr DeSouza and Dr Gilies every Thursday morning within the specialist outpatient centre at the LGH between 9 am and 12 pm.

Feel free to pop in and say hi to Emma and have a chat about how Epilepsy Tasmania can help you.

We are in the process of establishing a presence in the Pediatric Clinic in Hobart.



This month Epilepsy Tasmania had a presence at the SpeakOut Disability Expos in Devonport, Launceston and Hobart and received some heart—warming feedback from many who attended and at all three expos made contact with Tasmanians who are now receiving services and support from us.



Our two recent surveys have shown a lack of understanding around eligibility for the NDIS. To ensure we can help eligible Tasmanians access the NDIS we want to know 4 questions:

- 1. Do you have or have you applied for an NDIS plan?
- 2. Do you have support coordination written into your plan?
- 3. do you have a support coordinator?
- 4. Do you want a support coordinator?

**Answer Now** 

# Interest-free loans to buy health equipment? YES!

People who are registered with Centrelink may be eligible to borrow up to \$3,000 *interest-free* to purchase health equipment such as the LifeMinder, seizure mat, and bed-exit alarm.

Contact us if you would like information on how to apply for the No-Interest Loans Scheme (NILS).

**Email Us Now** 



## Last days to WIN!

Please complete our short Health & Wellbeing survey if you have epilepsy, or know someone who has or is affected by epilepsy.

Your lived experiences, suggestions and ideas will improve the health and wellbeing of Tasmanians affected by epilepsy by guiding new aspirations that will help us communicate with Government, health providers and local communities about issues that matter to you.

Complete our survey before the 30th September and go in the draw to win a \$100 gift voucher.

Complete our survey and WIN

#### **BECOME A PEER VOLUNTEER TODAY!**



# Epilepsy Tasmania is seeking 3 people to become Peer Support Volunteers for Epilepsy Connect.

Epilepsy Connect is a free telephone service for Tasmanians living with or affected by epilepsy, including family members, partners and carers. This free service will connect someone who has been affected by epilepsy with a trained Peer Support Volunteer who has had a similar experience.

An increasing number of people want to be connected to others who have 'been there' and we desperately need more peers!

Volunteers must be willing to listen, understand and share their own experiences and ways of coping; and provide practical information and emotional support to people living with or affected by epilepsy.

If you would like more information, please phone us on 6344 6881

"People will forget what you said, people will forget what you did, but people will never forget how you made them feel."

#### Maya Angelou



Epilepsy Tasmania is a not-for-profit community organisation improving the quality of life of Tasmanians with epilepsy, and those around them, through education, coordination and support.

It relies upon public donations and funding from the Department of Health and Human Services, Tasmania.

#### Epilepsy Tasmania

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Friends of Epilepsy Tasmania enhance its ability to speak for and advocate on behalf of Tasmanians affected by epilepsy.

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