

#### Hello Friend,

Edition 22, 2019

Welcome to Brainwaves!

October is a month of many ....

Mental Health Week, Anti-poverty week, Carers Week, Seniors Week, Children's Week, and Veterans' Health Week. There are consistent themes through all the weeks that encourage us all to start having conversations to enable more understanding of the roles we play, the connections we make, the importance of enabling healthy communities and equity of access for all Tasmanians.

It is also national Worksafe Month and Epilepsy Tasmania has released a new advertising campaign that will be shown on the WIN television network, social media and the State Cinema throughout the month. We hope it will encourage Tasmanian workplaces to become Epilepsy Smart Workplaces because our recent research reveals that 52% of Tasmanians have experienced discrimination at work or school as a result of epilepsy.

I was speaking to someone who said their purpose in life is to live their life, professionally and personally, that tries to achieve "welcome" for people. This has me thinking about that in my life as well.

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



Wendy Groot, CEO Epilepsy Tasmania.

# NEW Tasmanian Epilepsy Research launched

On the 30th September, Epilepsy Tasmania launched a new report that provides current insight into epilepsy within Tasmania in comparison to Australia and the rest of the world.

This comprehensive research reveals startling new facts including:

- Tasmania has the highest prevalence of epilepsy in Australia.
- Epilepsy is estimated to impose a greater burden on Australia's health system than prostate cancer, and one similar to that of lung cancer and Parkinson's disease.

We hope this report will re-energize and guide government, policy-makers and stakeholders as they seek to reduce the economic and social impact of epilepsy in Tasmania.

Read the complete document on our website by clicking the button below and selecting the top right link called – **Read Tasmania's Latest Research.** 

Read it Here

#### WorkSafer Expo 2019 - Launceston

October 30th from 10:00 am - 4:00 pm

This is a must-attend FREE event for all health, safety and wellbeing professionals.

Discover innovative and collaborative solutions to make your work safer, healthier and more productive.

An opportunity to:

- network with peers
- explore the latest trends and developments
- source the latest innovations in products, services and solutions in the field.

Presented by WorkSafe Tasmania the expo is an enriching addition to WorkSafe Tasmania Month. The WorkSafer Expo is an all-encompassing health, safety and wellbeing event with **exhibitors (including Epilepsy Tasmania)** and keynote speakers all working towards making Tasmanian workplaces safer, healthier and more productive.

**More Information** 

## **Position Vacant - Board Members**

The governing body for Epilepsy Tasmania is seeking some new people to help guide the future of the organisation.

Email Bec for more information.



## **Epilepsy Smart Workplaces**

15% off all Epilepsy Smart workplace training booked during October

1 in 26 Australians will develop epilepsy during their life, directly impacting four times as many family members, colleagues, carers and friends – that's **onefifth of Tasmania's population!**  52% of Tasmanians have experienced discrimination at work or school as a result of epilepsy.

Epilepsy Smart Workplace Training will demystify the condition of epilepsy, explain associated risks and seizure first-aid, and provide suggestions on creating a more epilepsy-friendly workplace for staff, visitors and customers.

Watch Our New Advert

**Reserve Your Discounted Workplace Training NOW** 

# Research - Infantile Epileptic Encephalopathies in Tasmania

A generous bequest allowed Epilepsy Tasmania to fund a three-year epidemiological study into the genetics of infantile Epileptic Encephalopathies (IEE) in Tasmania, the findings of which were recently published in the research paper in Epilepsia Open.

The purpose of the research was to discover the underlying genetic causes of the IEE condition which contributes significantly to the burden and cost of care for families and health systems through frequent hospitalisation for uncontrolled seizures.

Researchers at the Epilepsy Research Centre within the University of Melbourne performed detailed bioinformatics analysis of the sequencing data from the study and revealed that early diagnosis has positive consequences for identifying the most appropriate therapies and quality of life prognosis. The study reproduced the finding that severe epilepsies of infancy (SEI) are often caused by genetic diseases but although genetic, they are invariably new mutations in the child, rather than inherited.

The rate of SEI determined in the cohort is important due to the full capture of cases and has made an important contribution to the epidemiology.

Some of the cases have led to an expanded understanding of particular genetic conditions and for all patients, there is improved understanding of their disease, prognosis and treatment options.

NOTE - leaving a bequest in your will is a simple process that can make a huge difference and even result in new discoveries about epilepsy. <u>Email Bec</u> for details on how to write bequest instructions in your will.



## **A Blooming Success**

Epilepsy Tasmania's volunteer coordinator, Sheralyn, recently represented the organisation at the Blooming Tasmania Flower and Garden Festival in Launceston and to promote our Open Gardens for Epilepsy awareness and fundraising events.

Thank you very much to our volunteers: Amy & Cathy on Saturday and Cathy who even came back again on Sunday morning to help.

### Thank You, Mat

Mat Eadie recently held two fundraisers for Epilepsy Tasmania and we would like to thank him for his support.

The money Mat raised will stay in Tasmania and help Tasmanians affected by epilepsy.

### 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

#### "Peace begins with a smile."

Mother Teresa



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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