

Hello Friend,

Edition 9, 2018

October is a really busy month, full of so many themed weeks that I don't have the space to write here about how Epilepsy Tasmania's key messages relate to each of them. You can read more on our Facebook page here though.

The theme for this year's **Senior's Week** is based around food and as this week is also **National Nutrition Week** it seems like a good time to ask if you have heard about the Ketogenic Diet yet? It is the only known diet having a significant positive impact for many people with epilepsy.

The **Ketogenic Diet** is a very high fat, very low carbohydrate and moderate protein diet that ensures the body will burn fat instead of carbohydrate for energy. Burning fat for energy produces "ketones", and for some people, having a very high level of ketones in their blood helps to reduce seizure activity. The mechanisms which it does this by are not fully understood yet, but it is certainly worth considering. Read more here.

This week is also **National Carers Week**, a time to recognise and celebrate the outstanding contribution unpaid carers make to our nation. In Tasmania, there are around 80,000 carers, family members, friends and colleagues who care for and support people with epilepsy.

And although this is officially Work Safe Month, employers should always prioritise making their workplaces safe for staff and visitors. When it comes to epilepsy-safety, our workplace training will ensure you create an **Epilepsy Friendly Workplace**.

I hope you enjoy this edition of Brainwaves and as always, encourage your feedback.



Wendy Groot, CEO Epilepsy Tasmania.



A Life Electric

Epilepsy Tasmania is supporting an ongoing multimedia documentary project called A Life Electric. It will document the lives of people (including some Tasmanians) around the world living with epilepsy to shine a light on this mysterious affliction.

Creator/producer, Fraser Morton's brother sadly passed away from Sudden Unexplained Death in Epilepsy (SUDEP) when he was just 19 years old. Fraser's hope is that this project will get people talking about epilepsy and help reduce the stigma that still exists all around the world. We are very excited to share Tasmania's voices for epilepsy on an international scale, so watch this space!

Fraser is looking for people willing to share their story surrounding epilepsy, so if you would like to be part of A Life Electric please register your interest online here.



SUDEP Day

International SUDEP Day (Sudden Unexpected Death in Epilepsy) occurs when a person with epilepsy dies suddenly and prematurely and no other cause of death

is found.

SUDEP raises a lot of questions and there is much that can be done to keep people with epilepsy safer and prevent more epilepsy deaths from happening each year.

Epilepsy Tasmania is an official participating organisation for this year's SUDEP Action Day, and we encourage you to #ACT:

A sk questions

- 1. Why don't more people know about SUDEP?
- 2. What are the risk factors and how can I reduce my risks?
- 3. What should I ask my clinicians?

C ommunicate

1. Share your SUDEP stories.

T ake action

1. Talk to us about fundraising for more research into SUDEP.

Read more information about the day here.



New Keep Cups

Epilepsy Tasmania ambassador, Shaun Smith, and his daughter Lily can be seen here loading boxes of our new black Keep Cups.

Shaun and Lily sold an amazing 152 cups and we can't thank them enough for all their work helping Tasmanians who are affected by epilepsy.

You can buy our KeepCups (small, medium and large)

from Flick the Bean cafes; JJs Bakery in Launceston, Longford and Campbelltown; the ABC cafe in the ABC Building, Hobart; and Epilepsy Tasmania offices in Launceston and Hobart.



Photo / Video Competition

To celebrate International Epilepsy Day 2019, there is a competition underway with some great prizes to win.

People with epilepsy, their families, friends and carers, are encouraged to create non-professional individual short videos, using a smartphone or personal camera, to inspire others or to highlight problems faced.

Entries close 14 December 2018. Read more details here.



Open Your Garden ... for a good cause!

Since 2017 Epilepsy Tasmania has been encouraging Tasmanians to open their gardens to increase awareness of epilepsy within relaxed environments and reduce the discrimination endured by more than half of Tasmanians with epilepsy.

Open Gardens for Epilepsy events (in partnership with Blooming Tasmania) are an excellent opportunity to make new friends while raising funds for Epilepsy Tasmania, a charity that has been helping Tasmanians for over 40 years.

Around 100,000 Tasmanians are affected by epilepsy and opening your garden will help provide them with the services and support they need.

NAT Q&A Event

The Neurological Alliance of Tasmania (NAT), of which Epilepsy Tasmania is a part, was given a grant from the Mental Health Council of Tasmania to raise awareness of mental health issues in people with neurological conditions.

Research indicates that people who live with a neurological or progressive neuromuscular condition are more likely to develop a mental health condition than the general population.

A successful inaugural panel event was organised during Mental Health Week and audience members were encouraged to ask questions of the panellists: Dr Cynthia Honan (neuropsychologist), Dr. Helen Castley (neurologist) and Assoc. Professor Des Graham (MSL board member and person living with MS). It was facilitated by Wendy Groot from Epilepsy Tasmania.

Mental Health Week is held every October to engage communities in activities that promote mental health and wellbeing and raise awareness and understanding about mental illness and its affect on the lives of people in our community.

If you know someone who is struggling, suggest they contact: Lifeline 13 11 14; Suicide Call-back Service 1300 659 467; or Beyond Blue 1300 22 4636.

"At any given moment, you have the power to say:

this is not how the story is going to end."

Christine Mason-Miller



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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