The latest brainwaves from Epilepsy Tasmania.

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### Hello Friend,

Edition 17, 2019

Welcome to our Brainwaves e-newsletter.

This last month has been an exciting and busy month with some new initiatives in the pipeline.

We have 4 amazing young people (and their parents) who continue to fundraise and bring epilepsy out of the shadows. Featured below are Sophie Bryan's girls who hosted a very successful and fun event. Sean Smith's girls, Lily and Harper, just keep on going and have almost sold all of the soaps they made (we only have 20 left in the office) and they will be presenting Epilepsy Tasmania with a cheque at their school assembly later this month. These two will be featured in our next edition of Brainwayes.

In other good news, we recently had a family buy one of our <u>Epilepsy Safe Bed Under-Mattress Seizure</u>

<u>Sensors</u> only to decide before using it that it was not what they needed after all – so very kindly donated it back to us. We have decided to "pay forward" their act of kindness by donating it to a family who could really

benefit from some better sleep. This family have a 5-year-old who is not responding well to anti-seizure medication and often needs to sleep in his parent's bed for monitoring. We have given them the seizure sensor in the hope they can all achieve better, safer sleep and his mum couldn't be happier or more grateful.

Through Facebook, we have been promoting the results of our first surveys and encouraging people to complete the current surveys. We are receiving good uptake on these and if you don't access Facebook please see the information and link below.

Last week was National Volunteering Week and we were pleased to have the opportunity to give thanks and show appreciation to regular volunteers who help us throughout the year, beyond Purple Month.

I hope you enjoy this Brainwaves.



Wendy Groot, CEO Epilepsy Tasmania.

# Office Space Available to Share With Us in Launceston

We are now settled into our Launceston office and we have spare office space available.

There is space available for 3 to 5 people with a shared meeting room with conferencing facilities, WIFI access,

photocopier and free parking.

If you are interested in joining our hub, call Bec on 63446881.



## Meet our New Epilepsy Smart Coordinator

Liz Kemp has an Honours Degree in Psychology and 12 years experience in the promotion of mental health and the prevention of mental ill-health and suicide. And she's joined our Epilepsy Tasmania team as our Epilepsy Smart Coordinator!

This new role will support our trainers to coordinate the increasing number of education and training requests received from disability service providers, schools, aged-care service providers and workplaces.

Liz's project work skills of administration and coordination will be useful in this role, as will the fact that she genuinely enjoys improving quality of life outcomes for people.

Welcome to the team, Liz!



## Epilepsy Connect for 13 to 24-Year-Olds

We've been asking Tasmanians affected by epilepsy how they would prefer to connect with others for peer– support and we received a particularly clear suggestion from our younger Tasmanians: a Facebook group!

So we are pleased to launch our new Facebook group – an online community for Tasmanians aged 13 to 24 years who have or know someone with epilepsy.

We hope this free group will provide an easy way for young people to chat with others who are experiencing similar things. Talking with people who have had similar experiences can help people feel more understood and less alone.

This closed group will be moderated by Epilepsy Tasmania and is founded on the belief that everyone has a right to their opinion as long as it is shared respectfully.

To join, people must answer 3 questions that will help Epilepsy Tasmania determine if they live in our state and are the right age category.

Because it is a closed group, people who are not members will not be able to see posts from those within the group. If someone within the group wishes to ask something anonymously they can PM our moderators to have it posted on their behalf for discussion.

So... if you know someone aged 13 to 24 years of age who may benefit from an online peer-support group, please direct them to our new Facebook group:

**Epilepsy Connect Tasmania 13 to 24 year olds** 



#### Meet a Friend!

Esther and Heidi Bryan are two very special Friends of Epilepsy Tasmania.

Along with their mum Sophie, they fundraised during Purple Month by holding a morning tea with face painting and nail painting. Can you believe they raised an amazing \$625!!!

Thank you, girls – your money will help provide services and support to Tasmanians affected by epilepsy.



We are very pleased to announce that we are now Tasmanian affiliate partners with Mediband.

Mediband has been a maker/supplier of life-saving products since 2004, providing alert bracelets for most medical conditions, other medical, first aid supplies and equipment.

If you want a custom bracelet or necklace ID, kid-friendly thermometer stickers, first aid kits, an emergency medical ID card for wallets/purses, seatbelt ID and more – visit the Mediband website shop (here) and click on the Epilepsy Tasmania logo before purchasing because 20% of your order value will then be donated to us. It won't cost you any extra because Mediband will donate to us directly. Great hey!



We are currently running our second annual survey to find out what issues are most concerning to Tasmanians affected by epilepsy. We have been getting really positive engagement and some great input that will directly affect our actions.

For instance, last year we were asked to prioritise education and employment opportunities for Tasmanians with epilepsy and this year we are delivering!

Our Smart Schools programme is helping schools embed inclusive, safe and educationally sound practices so that all primary, secondary and special school students living with epilepsy can achieve their academic potential and develop positive social relationships.

Our Epilepsy Friendly Workplaces programme is helping ensure friendly workplaces for staff and customers who have epilepsy.

Let us know where to next focus our attention by filling in our current survey:

For carers...

https://www.surveymonkey.com/r/ZK6HKXY

For people with epilepsy... <a href="https://www.surveymonkey.com/r/6ZL6XH9">https://www.surveymonkey.com/r/6ZL6XH9</a>

"You make a living by what you get."

You make a life by what you give."

Winston Churchill



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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