

New global research just
released



Hello Friend,

Edition 18, 2019

Welcome to Brainwaves!

There are three very important research papers being
released during the coming months.

The first is the just-released World Health Organisation's report **Epilepsy: a public health imperative**. Read more about this important report below in this Brainwaves. The second will be **Epilepsy Australia's Burden of Disease** report developed by Deloitte and about to be released. The third is the latest **Tasmanian Research** report specific to our state.

Each report shows some significant common issues at a global, national and state level, including:

- Epilepsy carries a significantly increased risk of premature mortality.
- Roughly half of the people with epilepsy have co-existing physical or psychiatric conditions.
- Epilepsy is a treatable condition.

- People living with epilepsy face devastating social consequences.

A broad public health approach is needed to improve the care and quality of life of people with epilepsy. The implementation of policies and plans for epilepsy requires strong leadership and intersectoral collaboration. The management of co-morbidities should be an essential component at all levels of care. Actions to improve access to medicines should be addressed at the international, national, district, community and individual levels. Stigma can delay appropriate health care seeking, access to care, health financing and availability of treatment.

There remains, however, a dramatic inequality in access to and utilisation of research resources and expertise

across the globe. Investment in research for epilepsy is insufficient. Developing epilepsy research priorities around the world may be a vehicle to improve research support and advocacy.

The time to act is now. **Urgent actions are needed**, and these include:

- Promoting epilepsy as a public health priority to reduce its burden.
- Improving public attitudes, reducing stigma and promoting the protection of the rights of people with epilepsy.
- Investing in health and social care systems to improve accessibility to epilepsy care.
- Enhancing access to cost-effective anti-seizure medications globally.

- Preventing acquired epilepsies through improved care for common causes, such as perinatal injury, central nervous system infections, stroke and traumatic brain injuries.
- Increased priority given to epilepsy in research agendas.

Epilepsy Tasmania will be campaigning these issues when all three reports are available and will share more information as it comes to hand.

I hope you enjoy this Brainwaves.



Wendy Groot, CEO Epilepsy Tasmania.

WHO's New Report: Epilepsy, A Public Health Imperative

Epilepsy Tasmania proudly represents Tasmanians living with epilepsy and their right to have access to health care, support and education.

The recently published **World Health Organisation** report **Epilepsy, A Public Health Imperative** reinforces our mission and stresses the importance of "engaging governments and civil society in taking concrete action to promote access to care and to protect the rights of people with epilepsy."

Key messages in this report are:

BURDEN – The burden of epilepsy is high and often neglected in public health agendas. Epilepsy is one of the most common neurological diseases, affecting nearly 50 million people of all ages around the world. The risk of premature death in people with epilepsy is up to three times that of the general population. Roughly half of adults with epilepsy have at least one other health condition. Psychiatric conditions, such as depression and anxiety, make seizures worse and reduce quality of life. Epilepsy has significant economic implications in terms of health care needs and lost productivity at work.

STIGMA AND DISCRIMINATION – In all parts of the world, people with epilepsy are the target of

discrimination and human rights violations. The stigma of epilepsy can discourage people from seeking treatment and has consequences for quality of life and social inclusion. Improving knowledge and raising awareness of epilepsy in schools, workplaces, and communities is needed to reduce stigma. Legislation based on internationally accepted human rights standards can prevent discrimination and rights violations, improve access to health care services, and raise the quality of life for people with epilepsy.

PREVENTION – An estimated 25% of epilepsy cases are preventable. The major modifiable risk factors for epilepsy are: perinatal insults, central nervous system infections, traumatic brain injury and stroke. Preventing epilepsy is an urgent unmet need. Effective interventions for prevention are available and delivered as part of

broader public health responses in maternal and newborn health care, communicable disease control, injury prevention and cardiovascular health.

Read the full report here: [World Health Organization \(WHO\)](#).

A Day in the Life of ... Epilepsy Tasmania's Nurse

You won't find Epilepsy Tasmania's nurse, Emma, working in a hospital – she travels the state helping Tasmanians affected by epilepsy to access epilepsy-related support when and where they need it.

For example, Epilepsy Tasmania was recently contacted by a man who had been successfully controlling his seizures for three years with anti-epileptic medication ... until he suddenly and unexpectedly had a tonic-clonic seizure at work.

In her role as our nurse, Emma supported this man by developing an Epilepsy Management Plan that he can give his employer. **Click the button below** to see how an EMP will help at work and what else Emma did for him.

Epilepsy Tasmania's nurse (Emma) was recently contacted by the mother of a teenage son who was experiencing more seizures than normal. **Click the button below** to see how Emma (after some detective

work) was able to dramatically reduce this teenager's seizures.

Nurse Emma then took a phone call from a single mum who had just had her first seizure – in front of her children. Understandably, she was concerned about having more seizures at home in front of her children and placing responsibility for her care with them. **Click the button below** to see how Emma helped this single parent out.

It's all in a day's work!

Teenage Seizures

Single Parents and Seizures

Unexpected Seizures



Meet Lily and Harper

They might still be in primary school, but these two girls are professional fundraisers!

Pictured above are Harper (front) and big sister Lily presenting Epilepsy Tasmania's Bec Wylie with a cheque at their school assembly.

Their hard work growing succulents and handmaking hundreds of beautiful soaps paid off with an amazing \$3,240 raised for Tasmanians affected by epilepsy.

Our heartfelt thanks goes to Lily and Harper and all their family for the significant donations made of their time and material costs to achieve this result.

NDIS

Epilepsy Tasmania is starting to develop some user-friendly guides in relation to the NDIS.

What we know so far is that if people are on the NDIS and self-manage their funds, they can use money to buy our services and equipment. BUT it is important their epilepsy is a co-morbidity condition and written into individualised plans.

If people then experience a current functional impairment or develop one, they can access their plans for future support. Call us for more information.





Congratulations and Thank You to St Virgil's College

Last week Epilepsy Tasmania was invited to attend the Junior School of St Virgil's College – Tasmania's latest Epilepsy Smart School.

Pictured above is CEO Wendy Groot with just some of the students who chose to 'go purple' to support Tasmanians affected by epilepsy. The day featured a

Parent Information Session focussing on what it is like to not only live with epilepsy but how to help someone who may have a seizure.

During assembly, Wendy presented the College with an Epilepsy Smart School Certificate that they earned after undertaking epilepsy training.

Students entered into the spirit of the day by dressing in purple and running stalls to sell purple items for Epilepsy Tasmania which raised \$572. Wow!

Prizes were awarded for the best dressed and some amazing outfits were showcased.

Thanks, St Virgil's for a great day and generous donation.



for 13 to 24-Year-Olds

Our new Facebook community for 13 to 24 year olds is growing!

We hope this free group will provide an easy way for young people to chat with others who are experiencing similar things around epilepsy. 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 but it must be shared respectfully. Members who are not courteous and respectful will be removed from the group.

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 Facebook Group

Free Resource for you

We have a great downloadable resource suitable for anyone with questions about epilepsy, including:

- how is epilepsy diagnosed?
- what exactly is a seizure?

- why do seizures occur?
- what types of seizures are there?

It also includes a section on seizure first aid. [Click here for your free copy.](#)

More information about epilepsy can also be accessed on our website page [Diagnosing Epilepsy.](#)

FREE Diagnosing Epilepsy Booklet

*"I can't change the direction of the wind,
but I can adjust my sails to always reach
my destination."*

Jimmy Dean



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

Mailbox: PO Box 1834, Launceston, TAS, 7250

Hobart Office: ABC Building, 1 Liverpool Street

Launceston Office: 462 Wellington Street

Telephone: 03 6344 6881

Website: www.epilepsytasmania.org.au

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

[Preferences](#) | [Unsubscribe](#)