

MEDIA RELEASE

28 September, 2020

People with epilepsy more prone to seizures due to COVID-19.

Virtual **Walk for Epilepsy** to support **1 in 25 Australians** who have epilepsy.

Epilepsy is a chronic disorder of the brain characterised by recurrent seizures. People experience epilepsy differently, depending on the part of brain the seizure starts and how far it spreads.

20,000 Tasmanians have epilepsy with a further 80,000 family members, colleagues and school friends directly affected. Epilepsy can develop at any age and can have a big impact on quality of life and learning or work opportunities.

Wendy Groot is the CEO of Epilepsy Tasmania, a charity that has been improving the quality of life and community participation of Tasmanians affected by epilepsy for over 45 years.

"People with epilepsy are more prone to seizures when they have heightened anxiety, depression and feelings of isolation," said Ms Groot.

"COVID-19 is exacerbating this and even here in the relative safety of Tasmania we have had more phone calls and support requests than in any other year.

"As part of our staff, we have a nurse and social worker who travel the state to provide personalised support and training," she said.

"If you know someone who has epilepsy and is in need of support, please encourage them to reach out to Epilepsy Tasmania or discuss their possible psychosocial or health issues with their physician to prevent further deterioration."

This year, Epilepsy Tasmania is asking people to take to their local streets from 1 to 25 October and **Walk for Epilepsy**, in support of the 1 in 25 Australians who have epilepsy.

COVID-19 has meant this year's planned outdoor event, which was to be a major fundraiser for the charity, has been replaced with a 25-day virtual event. All funds raised for Epilepsy Tasmania will remain in the state to support Tasmanians.

Ms Groot said this year's virtual **Walk for Epilepsy** means people can participate in their own time and in their own way while contributing to a collective effort and raising

much-needed funds for people with epilepsy and their families, many of whom are doing it particularly tough at the moment.

"We're asking people to walk, run, cycle or swim in their local suburb and tally up the distance covered to reach a national collective target of 25,000 kilometres - the distance around Australia," she said.

"Participants can decide how many kilometres to contribute to the tally then choose when, where and how they will complete them, between 1 and 25 October."

"We want them to set their own kilometre goal, set their fundraising target and hit the footpath! We have many Tasmanians jumping on board this fundraiser, including local celebrities that people can sponsor and even a canine team that people can join with their dog."

"We hope people will ask their friends, family and neighbours to sponsor their challenge. It's a virtual walk that can be done safely, at leisure, while helping Tasmanians epilepsy," Ms Groot said.

It is free to register for the **Walk for Epilepsy**. For further information and to register visit: www.walkforepilepsy.org.au

- ENDS -

MEDIA OPPORTUNITY

Tuesday 29th September at 11 am
at the Domain Walking/Cycle Track, (carpark near the Cenotaph) Queens Domain, Hobart.

Visuals:

Larrikin CROON lads Andrew Colrain, Colin Dean and John X mix black and white tuxedos with ever-receding hairlines and are Tasmania's very own taste of Vegas.

CROON have formed their own **Walk For Epilepsy** fundraising team and will be warming up on the exercise equipment at the Queens Domain with CEO of Epilepsy Tasmania, Wendy Groot and her dog who is part of a Tassie canine team!

Spokespeople:

- CROON members, Colin Dean, John X and Andrew Colrain.
- CEO of Epilepsy Tasmania, Wendy Groot (phone directly on 0427 044 074).
- Nilla the dog.

MORE INFORMATION:

Claire Burnet 0448 585 947 or www.epilepsytasmania.org.au

ABOUT EPILEPSY

Epilepsy is a chronic disorder of the brain that is characterised by abnormal electrical activity causing seizures or unusual behaviour, sensations and sometimes loss of awareness.

20,000 Tasmanians have epilepsy, but for every person with epilepsy there are approximately 4 others providing care and support. This means **one-fifth of Tasmania's population is directly affected by the condition**.

Epilepsy can develop at any age. **One in 10 Australians experience a seizure during their life**. One in 26 of these develop epilepsy, which is two or more unprovoked seizures.

The causes of epilepsy are complex and vary depending upon the age at which the first seizure is experienced. **Known risk factors include serious head injuries** sustained during motor vehicle accidents, trauma or serious falls; **strokes** or brain haemorrhages; prolonged **oxygen deprivation**; **brain infections** and abnormalities; tumours; **degenerative conditions** such as dementia; and genetic factors. In 40% of cases the cause cannot be determined.

Tasmania has the highest prevalence of epilepsy than any other state or territory in Australia, with the figure expected to rise due to an older than average population, general rising life expectancy and an increasing proportion of people surviving incidents that often lead to epilepsy.

Epilepsy is the second most burdensome neurological condition after dementia.

Epilepsy has significant economic implications in terms of health care needs and lost productivity at work.

1 in 7 people who present to hospitals are there due to epilepsy.

The economic burden of epilepsy in Tasmania is shared mainly between individuals and the State Government at a **cost of \$11.8 million per year**. It imposes a greater burden on Tasmania's health system than prostate cancer, and one similar to that of lung cancer and Parkinson's disease.

People with epilepsy die at 3 times the rate of the general population. The mean age of death from epilepsy in Australia is 52 years (compared to the general current life expectancy of 80 - 84 years of age). The Years of Potential Life Lost through epilepsy-related deaths are greater than asthma (a national health priority) and similar to prostate cancer.

People with epilepsy have a 15 to 19 times greater risk of drowning.

The World Health Organisation reports that **47 per cent of employed Australians with epilepsy report unfair treatment in the workplace** but the Tasmanian statistic is worse, at 52 per cent. The most common place for discrimination is at work and school.

In schools, epilepsy is now the third most common health condition (in the order of diabetes, asthma, epilepsy then anaphylaxis) and one of the top five avoidable causes of death among five to 29-year-olds.

People with epilepsy are often unable to safely drive a motor vehicle: **only one third of Tasmanians with epilepsy drive their own car.** The remainder must rely on others, public transport or taxis and imposes an additional financial burden of around \$231 per year.

People with epilepsy are up to eight times more likely to have other health conditions such as depression, dementia, heart disease and arthritis. Half of all adults with epilepsy have at least one other health condition. Depression and anxiety from epilepsy make seizures worse and reduce quality of life.

Advanced Alzheimer disease has been identified as a risk factor for new-onset generalized tonic-clonic seizures in older adults and is associated with a 10% prevalence of seizures, particularly late in the illness. Increased prevalence of seizures have also been documented with other types of dementia.

Epilepsy is a lot more than seizures - people with epilepsy typically face an array of challenges additional to those involved in trying to prevent seizures, including cognitive, social, medical, mental health and psychosocial. **The seizure is just the tip of the iceberg: underneath are many factors affecting concentration, memory, connections and the ability to function day-to-day.**

30% of people with epilepsy cannot control their seizures with medication.

ABOUT EPILEPSY TASMANIA

Epilepsy Tasmania is a not-for-profit community organisation that has been improving the quality of life of Tasmanians with epilepsy, and those around them, through education, coordination and support for over 45 years.

CEO, Wendy Groot, is Chair of the national Epilepsy Australia coalition.

Epilepsy Tasmania is committed to bringing epilepsy out of the shadows, and breaking down the stigma and discrimination associated with epilepsy in Tasmania.

Its vision is to ensure all Tasmanians who have epilepsy have the same opportunities as the broader community. Its statewide services and support includes:



Workplace training



School training



Peer support



Fundraising and awareness