

MEDIA RELEASE

26 February, 2020

Going Purple for Epilepsy

Schools, workplaces, buildings and even buses are preparing to raise awareness and funds throughout March for a condition that affects over 20,000 Tasmanians.

Epilepsy Awareness Month is a national campaign to get more people talking about epilepsy - a neurological disorder of the brain that involves recurring seizures that can affect a person's ability to study, work, drive a vehicle and enjoy an active social life.

"Going purple creates opportunities to have conversations about epilepsy, learn about it, know what to do if we witness a seizure and let those with epilepsy know they have the support of everyday Tasmanians," said Wendy Groot, CEO of Epilepsy Tasmania.

One in 200 school students are estimated to be living with epilepsy and it can have a significant impact on their academic performance and social relationships.

Trevallyn Primary School is proud to be a nationally accredited Epilepsy Smart School and is looking to go purple this March for the **Purple Finger Knitters' School Challenge**.

Schools are being challenged to drape a school building or piece of equipment in purple finger knitting and share their results on social media using the **hashtag #PurpleFingerKnitters** to raise awareness of epilepsy within Tasmanian schools.

Glenda Lee is the owner and manager of Lee's Coaches and East Tamar Bus Lines and has a granddaughter with epilepsy.

"Lila is 7 years old and was ironically born on Purple Day - the 26th March," said Glenda.

"I was there for her birth and remember looking into her eyes wondering what her life would be like, but I didn't imagine it would include Dravet Syndrome (a severe form of epilepsy) as well as ADHD and autism."

March is an important month for Glenda's family, who for many years have helped raise awareness of epilepsy and funds for Epilepsy Tasmania, but this Epilepsy Awareness Month they have gone one better and decorated a whole bus in purple!

"We've called our newest bus 'Miss Lila' and have decorated it in purple to draw attention to epilepsy and show our support for Lila and others like her."

More information on Purple Month and the Purple Finger Knitters' School Challenge is available on Epilepsy Tasmania's website www.epilepsytasmania.org.au, Facebook and YouTube channel.

- ENDS -

Watch 7-year-old Paige demonstrate how easy it is to finger knit in this short YouTube clip:

<https://youtu.be/GNomm6Brwjc> or scan the QR code to take you there.



MEDIA OPPORTUNITY

Thursday 27th February at 12.15 pm
at Trevallyn Primary School, 55 Gorge Road, Trevallyn.

Visuals:

Purple bus 'Miss Lila' will be outside the Trevallyn Primary School for a photo opportunity with primary school students 'going purple'.

Spokespeople:

Glenda Lee, Owner/Manager of Lee's Coaches and East Tamar Bus Lines.
Annette Holingsworth, Principal of Trevallyn Primary School
Wendy Groot, CEO of Epilepsy Tasmania, phone 0427 044 074

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 is 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 40 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