

MEDIA RELEASE

Friday 9th November, 2018

Lily's Fabulous Fundraiser

At just 10 years of age, Lily Smith, is passionate about increasing awareness of epilepsy and raising funds to better support Tasmanians affected by the condition.

Two years ago, Lily lost her mum unexpectedly to SUDEP (Sudden Unexplained Death in Epilepsy), something that can happen to people with epilepsy but to which the cause is not yet known.

"When Daddy said Epilepsy Tasmania was getting new KeepCups for Father's Day, I wanted to get involved," said Lily. "I thought that if I could sell a box of each colour, it would raise a lot of money to help people with the condition that mummy had."

Lily promoted the KeepCups through her school's assembly and newsletter, and sent order forms home with every student. The response was amazing and between her and dad Shaun, sold over 150 cups and raised almost \$3000!

"It makes me feel happy knowing I'm helping Tasmanians with epilepsy and helps me to honour my Mummy. I think she would be proud of me for doing this," said Lily.

Sacred Heart Catholic Primary School actively supports students who want to make a difference in the world and Principal, Brent Wilson, said: "Lily has, following a personal experience, used her initiative to raise funds for Epilepsy Tasmania and we're immensely proud of her."

Dad Shaun, said "At school, Lily is part of a sustainable Green Team and constantly reminds me of things we can do at home to reduce unnecessary landfill so fundraising by selling reusable KeepCups was an extra bonus for her."

"I'm really proud of Lily," he said. "She has done a tremendous job with this fundraising initiative and shown great courage despite the adversity she has faced."

Epilepsy Tasmania CEO, Wendy Groot, said "We are very grateful to receive this cheque from Lily today. It will help us provide services and support to the 100,000 Tasmanians who are living with or affected by epilepsy."

"One of the most powerful things Lily is doing through her fundraising is sharing her personal story and getting so many more people talking about epilepsy."

Lily is already planning her fundraising activities for Purple Month during March 2019 and looks forward to raising more awareness about epilepsy, and funds to support Tasmanians affected by the condition.

- ENDS -

Lily will present her \$3,000 cheque during school assembly to Epilepsy Tasmania at the Sacred Hearth Catholic Primary School at 227 York Street, Launceston at 2 pm on Friday 9th November.

MORE INFORMATION:

Claire Burnet, 147 EAST Public Relations - 0448 585 947
Epilepsy Tasmania Website - www.epilepsytasmania.org.au

PHOTO OPPORTUNITY AND SPOKESPEOPLE:

- Shaun Smith, Ambassador with a family experience of SUDEP.
- Lily Smith, 10-year-old fundraising extraordinaire.
- Bec Wylie, Epilepsy Tasmania (on behalf of CEO, Wendy Groot).
- Anita Mercer, Sacred Heath Primary School (on behalf of Principal, Brent Wilson).

ABOUT EPILEPSY

What is SUDEP?

Sudden Unexpected Death in Epilepsy (SUDEP) occurs when a person with epilepsy dies suddenly and prematurely - and no other cause of death is found.

In general, the risk of SUDEP for an adult with epilepsy is low, at one in 3,000 persons over a one-year period. For people with poorly controlled seizures the risk is one in 1,000 persons over one year. In children, SUDEP is an even rarer occurrence with the risk as low as one to two in 10, 000 over one year.

We do not yet know what causes SUDEP. Current research leads to respiratory or cardiac dysfunction, but the cause of this dysfunction still eludes us and we cannot know who will be affected. More funded research is needed.

Epilepsy Tasmania CEO, Wendy Groot, said "While there is much we don't know about SUDEP, there are things that can be done to reduce the risks for people with epilepsy."

"The most important known way to lessen the risk of SUDEP is for people with epilepsy to try to ensure they have as few seizures as possible (particularly Generalised Tonic Clonic Seizures).

"This can include taking prescribed seizure medications consistently, identifying and avoiding seizure triggers, keeping regular appointments with your doctors and considering other epilepsy treatments, such as surgery, when medications are not working to control seizures," said Ms Groot.

"To reduce the risk of non-SUDEP epilepsy-related deaths, we encourage people to be as healthy as they can (diet, exercise, stress-reduction etc.), create a supportive network and be aware of potentially risky situations."

More quotes from Dad, Shaun Smith:

"It is obvious from the response Lily received that there are so many people willing to support her in her efforts to support others affected by epilepsy, and it's reassuring to know that support is out there."

"Sacred Heart Catholic Primary School has been a wonderful support and when I approached the Principal there was no hesitation at all in having the school play a role, I'm grateful for all the care and opportunity they give both of my daughters."

More quotes from Principal of Sacred Heath Catholic Primary School, Brent Wilson:

"Lily is to be commended for her exceptional attitude and willingness to devote her own time and energy to improve the cause of her fellow Tasmanians."

Epilepsy is a chronic disorder of the brain that affects people worldwide. It is characterised by recurrent seizures, which are brief episodes of involuntary movement that may involve a part of the body (partial) or the entire body (generalised), and are sometimes accompanied by loss of consciousness and even incontinence. Characteristics of seizures vary and depend on where in the brain the disturbance first starts, and how far it spreads.

Epilepsy can develop at any age regardless of ethnicity or gender. One in 10 people experience a seizure during their life, and one in 25 Australians (20,000 Tasmanians) will go on to develop epilepsy (2 or more unprovoked seizures).

Epilepsy is not contagious. The most common type of epilepsy (affecting 6 out of 10 people with the disorder) is called idiopathic epilepsy and has no identifiable cause. The known causes of secondary epilepsy include a severe head injury, a stroke, an infection of the brain, or a brain tumour.

Up to 70% of people with epilepsy can be successfully treated (i.e. their seizures completely controlled) with anti-epileptic drugs.

Epilepsy is one of the world's oldest recognised conditions, with written records dating back to 4000 BC. Fear, misunderstanding, discrimination and social stigma have surrounded epilepsy for centuries. This stigma continues in many countries today and can impact on the quality of life for people with the disorder and their families.

In Tasmania, epilepsy remains widely misunderstood with **51% of Tasmanians experiencing discrimination as a result of their condition within the last 12 months**. The most common place for discrimination is the workplace, followed closely by educational environments.

Only one third of Tasmanians with epilepsy drive their own car. The remainder are forced to rely on public transport or taxis, the cost of which is often prohibitive given that **55% are on low incomes (half of these below the poverty line)**, due in part to heightened medical expenses, and an inability of many to work full-time.

People with seizures tend to have more physical problems such as fractures and bruising from injuries related to seizures and epilepsy is **up to eight times more common in people with other health conditions** such as depression, dementia, heart disease and arthritis - further affecting seizure outcome and quality of life.

The risk of premature death in people with epilepsy is up to 3 times higher than the general population, with the highest rates found in low and middle-income countries and rural versus urban areas.

ABOUT EPILEPSY TASMANIA

Epilepsy Tasmania is a not-for-profit community-based organisation that has been improving the quality of life and community participation of Tasmanians affected by epilepsy for over 40 years.

Epilepsy Tasmania is committed to bringing epilepsy out of the shadows, and break down the stigma and discrimination associated with epilepsy in Tasmania. Its overarching aim is to increase opportunities for those living with or affected by epilepsy and it will not be satisfied until Tasmanian children with epilepsy are receiving a good education, and Tasmanian adults are able to gain and maintain regular employment.

Its statewide services and support includes:



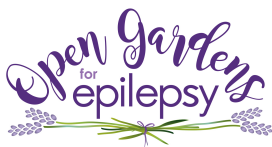
Workplace training.



Telephone-based peer support service.



Assurance that your donation will help Tasmanians affected by epilepsy.



In partnership with Blooming Tasmania to raise awareness of epilepsy within a relaxed environment.

**EDUCATE ME,
INCLUDE ME**

Smart Schools resources and training.

**KNOW ME,
SUPPORT ME**

Disability resources and training.

**UNDERSTAND ME,
SUPPORT ME**

Epilepsy in later years resources and training.