



the flame

the newsletter of epilepsy queensland inc

Issue 1 - 2021

Make March Purple for Epilepsy

PURPLE MUCK CHALLENGE

BRETT'S ANGELS

VALE MADDIE GILL

30 minutes with
Melissa Simpson

COVID -19 VACCINATION AND EPILEPSY



MUCK ME PURPLE

CHRIS DOUGHERTY, CHIEF EXECUTIVE

During March, I pledged to be purple slimed if we could raise \$1000 for Queenslanders impacted by epilepsy. This bit of fun, became the #PurpleMuckChallenge. Your Epilepsy Queensland team took delight in filming this event and you can view my purple mucking on our social media channels.

If you can spare a few dollars, you can still donate at: <http://bit.ly/ChrisPurpleMuckChallenge>. You can also join me in this challenge! It's super easy and only takes a few minutes to set up.

1. Set up a fundraising page and target here: <http://bit.ly/PurpleMuckChallengeforEpilepsy>
2. When you reach your target- get slimed, painted or cream pied, silly-stringed, cake-smashed, or shaving-creamed- just MUCK IT PURPLE!
3. Film your purple muck moment and share it on your social media channels with the hashtag #PurpleMuckChallenge.

We give you permission to MUCK UP for a great cause- to help raise awareness and funds for epilepsy.

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EDITORIAL DISCRETION

Epilepsy Queensland welcomes you to share your stories for inclusion in Flame. However, the Editor is responsible for the content of Flame and for ensuring the integrity of all work that is published in it.

The Editor is responsible for ensuring an appropriate balance of stories published and for taking reasonable care to ensure that no work is published that contains material that is unlawful, or otherwise objectionable, or that infringes any other person's copyright, right of privacy, or other rights.

The Editor reserves the right to edit or exclude stories from inclusion in Flame at their discretion.

The Flame is published quarterly by Epilepsy Queensland – www.epilepsyqueensland.com.au

GET INVOLVED IN EPILEPSY RESEARCH

Why we need research

30% of people diagnosed with epilepsy will not achieve seizure control through medications. The other 70% know that epilepsy is more than seizures. The side effects of the anti-epileptic drugs (AEDs) that help to manage seizures can include fatigue, memory loss, poor concentration, issues with vision or speech, coordination, nausea, depression and more. People living with epilepsy can face stigma and discrimination and the risk of premature death in people with epilepsy is three times higher than in the general population.

Where there is research there is hope

There is so much more to know about epilepsy and our ultimate hope is to find a cure. But in the meantime we work closely with universities and other research institutions to ensure your voice is used in determine the path of research that brings you the most hope. Our research partnerships include clinical understanding, psychosocial impacts, health economics and participation and social impacts.

Why join our research register?

You can be part of the solution, you can help us bring hope to people all over Queensland.

Your active participation in all forms of research helps the entire epilepsy ecosystem better serve you. It helps us design better services, and to advocate for system change on your behalf.

By joining our register you will be invited to participate in research that relates to your interests. We also will keep you upto date on research form around the globe bringing hope for a future where everyone has access to effective treatments and deaths are prevented until a cure is found.

Register and view current opportunities on our website <http://bit.ly/EQlresearch> or call 1300 852 853.



MAKE MARCH PURPLE FOR EPILEPSY



What is Make March Purple for Epilepsy?

Each March the world turns purple in support of the 50 million people living with epilepsy. In 2021, Epilepsy Queensland invites you to join the movement happening in over 130 countries around the world and Make March Purple for Epilepsy!

Make March Purple is an Australia wide campaign supported by epilepsy organisations across the country and the national peak body – Epilepsy Australia.

Purple Day, held on 26 March is an international day of awareness for people impacted by epilepsy. <http://bit.ly/QLDPurpleDay>

How can you Make March Purple for epilepsy?

During the month of March, we invite you to get involved. There are many ways you can raise funds and awareness in support of the 280 Australians diagnosed with epilepsy every week.

You can choose to host your own event at home or work, set yourself a personal challenge OR join our ULTIMATE challenge and climb the Story Bridge on 26 March just as it lights up PURPLE.

During March you will see iconic landmarks around the world light up PURPLE. If your town or city has a tree, a building, or even a windmill you can light up purple, let us know.

Remember to share your purple moments and share your story with us to help raise community awareness this March.

It's always Doughnut Time - Right? Well, now you have the perfect excuse. Epilepsy Queensland is teaming up with Doughnut Time this March. They will turn their crowd favourite the OG doughnut PURPLE for the month of March and donate \$1 from every one sold to support people living with epilepsy. Host the most epic PURPLE morning tea ever with delicious doughnuts! Order a 6 pack or get your workplace involved and order a 60, 80 or 100 pack! Visit the Doughnut Time website to see the PURPLE doughnuts they have dreamed up... you can even order a gift box that includes our PURPLE plush toy! <http://bit.ly/PurpleDoughnutTime>



Will you be Brave and take on our ultimate Purple Day challenge?

Join us and climb the Story Bridge to Make March Purple for Epilepsy. <http://bit.ly/PurpleBridgeClimb>

This is the ultimate Purple Day event on 26 March, climbing the Story Bridge at twilight just as it lights up purple for World Purple Day.

Not only is this an exclusive experience, limited to 30 VIPP's (very important purple people), we will hold your place for an \$80 donation (usual cost of climb is \$160) and you will also receive a professional photo package to commemorate your climb to the top of the PURPLE Story Bridge!

You will then be required to meet the minimum fundraising target of a total \$400 to confirm your climb.

Please see the Pre-Climbers Checklist of Story Bridge Adventure Climb to check your eligibility before registering for this event. For your safety and the safety of other climbers, some pre-existing medical conditions will not be permitted to climb. Prior to climbing you will be required to sign the Story Bridge Adventure Climbers Declaration & Acknowledgment Form. <https://storybridgeadventureclimb.com.au/pre-climb/>

Onwards and UPWARDS for Epilepsy Warrior Ellie!

Ellie Curtis, 18, has had to surmount many obstacles since her epilepsy diagnosis at nine years of age:

"Epilepsy has impacted my life a lot, mainly my mental health, self-esteem, and how well I do in school."

But undeterred, Ellie is ready to scale new heights by joining the ultimate Purple Day Challenge.

"I have always wanted to climb the Story Bridge and being able to do it for something I'm very passionate about is perfect!"

Ellie's dad is Deputy Principal of a Special Education School and they fundraise each year for Purple Day and Epilepsy Queensland. Ellie also enjoys following our organisation on Facebook and Instagram.

She would like to send the following message to the epilepsy community:

"I would say to everyone impacted by epilepsy to know that even though they might not feel it, they are very strong and I have a lot of admiration for them."

Enjoy the view Ellie and thanks for your support in raising funds and epilepsy awareness!

If you'd like to support Ellie, head here: <https://myimpact.epilepsyqueensland.com.au/fundraisers/elliecurtis>

Keen to sign up yourself? There are limited spots left! <http://bit.ly/PurpleBridgeClimb>

Other ways to Make March Purple for Epilepsy

- Host your own Purple event - Become the host with the most this March. Host a morning tea, a BBQ, a girl's night in or a games night. Host at home, at work or the local park – the choice is yours. <https://bit.ly/QLDPurpleEvent>
- Create your own challenge – Get fit, play your favourite sport, join a race, give up coffee or shave your beard off! Whatever you do – Make it Purple. <http://bit.ly/QLDPurpleChallenge>
- Make a donation to the Purple appeal and help end epilepsy. <https://bit.ly/DonatePurple>
- Share your purple images on social media with #makemarchpurple #purpleday #epilepsyqueensland <http://bit.ly/SharePurpleStory>
- Purchase purple day merchandise from your participating pharmacy or from our online shop <http://bit.ly/PurpleMerch>

BRETT'S ANGELS



Brett, 25, has been living with epilepsy since he was born, after a difficult birth in which his Mum was whisked away for an emergency delivery. With support and understanding, Brett has built a busy and rewarding life, proving living well with epilepsy is possible.

Early Challenges

Brett says he experienced frequent tonic-clonic seizures in his early years, which his Mum and sister found scary to witness when he was so small. He takes two different anti-seizure medications and said it took some time and adjustment to get the dosage right.

He experienced his last tonic-clonic seizure at 12 years old at his Auntie's place when his Mum was away on a retreat. Whilst his Auntie was a bit panicked initially, Brett got through it and recovered without needing medical intervention.

Brett continues to experience focal seizures, which he describes as "staring into space, going blank."

He describes some of his frustrations with people's misconception of epilepsy: "People think they are protecting you, but this means you don't get the same opportunity for growth. You mention epilepsy and people run for the hills."

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"A Second Family"

Brett describes Epilepsy Queensland as "cool cats. They are like a second family, where they understand what you are going through."

Brett attends E-Connect, our program for teens and young adults, and really appreciates being able to meet new people and build skills for different life situations. "Leonie (Services Development Officer) and the other attendees make me feel included and I have fun role-playing and mucking about with them."

He also participates in our weekly Zoom social group. "If it wasn't for Epilepsy Queensland, I wouldn't have met new friends. Working and my other commitments mean I have less time to socialise."



A Community Champion

Brett has worked for Woolworths since 2013 and is a very community-minded and charitable person who is involved with several non-profit organisations. An accomplishment that he is really proud of is raising over \$1700 for the Salvation Army Bushfire and Drought Relief Appeal by setting up a Christmas lights display fundraiser.

Brett has also travelled to Fiji with Samaritan's Purse Australia as part of "Operation Christmas Child" and distributed shoeboxes filled with toys, hygiene items, school supplies, and fun gifts to disadvantaged children.

"Talking to the children and seeing their smiles was amazing," he says.

A Flourishing Future

In the future, Brett hopes to help establish a Redlands Lions group to "enable people to rally together and connect parents." Brett also would like to form a parent's dinner night where parents of children living with epilepsy can connect "so they don't feel so alone."

"When growing up as a child, Mum didn't really have support. Mum is really deadly. She is my hero and has always been there to make sure I am OK."

Brett wants others living with epilepsy to know:

"Times are gonna get rough. The waves are gonna hit, at the end of the day, you gotta ride the waves. Don't give up."

He wants to convey there is support available: "Having an army of angels behind you makes you feel like you can do anything. They want to see you flourish."

To share your epilepsy story email
pr@epilepsyqueensland.com.au or
contact us on 1300 852 853.



ASK AN EDUCATOR

Are COVID- 19 vaccines safe for people with epilepsy?

The data to date suggests the vaccines are very safe. The Epilepsy Foundation of America reports there is currently no evidence that people with epilepsy are at higher risk of side effects after vaccination. There is also no evidence that this vaccination results in worsening of epilepsy, or brain injury.

As with any vaccine, some people may develop a fever which could lower their seizure threshold for the short term. In very rare circumstances, this potentially could result in a breakthrough seizure. We suggest consulting your doctor for advice on what is best for you.

The COVID-19 vaccines have been developed so quickly - are they safe?

COVID-19 vaccines have been developed more quickly than previous vaccines, but this is no cause for concern. Here in Australia, the vaccines need to be approved by the Therapeutic Goods Administration (TGA) before they are distributed to Australians. The Australian government advises of extensive checks and balances that are required at every stage of the development of a vaccine, and this is no different for a COVID-19 vaccine. No stages in the development have been by-passed. All vaccines are tested through three phases of clinical trials to ensure they meet the gold standard.

Which COVID-19 vaccines have been distributed so far?

According to the Center for Disease Control, (CDC) in the US, two vaccines have been authorised and recommended to prevent covid-19:

- Pfizer-BioNtech COVID-19 vaccine and,
- Moderna's COVID-19 vaccine

The National Health Service U.K. lists the following vaccines

available across the United Kingdom:

- Pfizer/BioTech COVID-19 vaccine
- Oxford/AstraZeneca COVID-19 vaccine
- Moderna vaccine for COVID- 19 vaccine

Which vaccine will Australians be getting?

As of January 25, 2021, the Therapeutic Goods Administration has provisionally approved the Pfizer/BioNtech COVID-19 vaccine for use in Australia. This is for individuals 16 years and older. Two doses will be required for this vaccine, at least 21 days apart.

Australia has entered into four separate agreements for the supply of COVID-19 vaccines, if they are proved to be safe and effective.

These are currently:

- University of Oxford/AstraZeneca (provisionally approved by the TGA)
- Novavax
- Pfizer/BioNtech (provisionally approved by TGA)
- COVAX Facility

How is the vaccine being distributed?

According to the Australian Department of Health website, the rollout of safe and effective vaccines will be guided by Australia's COVID-19 Vaccination Policy.

In Australia, state and territory governments will each be responsible for developing their COVID-19 vaccination implementation plans, in line with this and Australian Government expectations.

More information on vaccine distribution in Australia is pending.



When will the First vaccine doses arrive and be administered in Australia?

On 15 February, more than 142,000 doses of the Pfizer/ BioNTech COVID-19 vaccine arrived at Sydney airport in a major milestone in Australia's response to the pandemic.

According to a Statement by the Prime Minister: "Approximately 80,000 doses will be released of the Pfizer vaccine in the first week. Approximately 50,000 vaccines will be made available for the states and territories for hotel quarantine and border workers and frontline healthcare workers. Approximately 30,000 vaccines will be made available for the Commonwealth vaccine in-reach workforce to aged care and disability care residents.

It is expected that of these, at least 60,000 will be administered by the end of February with others to be continually administered thereafter."

Who will be vaccinated first?

The Australian Technical Advisory Group on Immunisation (ATAGI) has provided advice to the Australian Government on which groups should be prioritised for the first doses for possible COVID-19 vaccination in Australia. *These groups may be reviewed and changed as more information becomes available.

How much is the COVID-19 vaccination going to cost?

The COVID-19 vaccine will be voluntary and safe and effective vaccines approved by the TGA will be available to all Australians for free.

Have there been any reported side effects to COVID-19 vaccines?

The Epilepsy Foundation of America states that some people may get very mild flu-like symptoms post administration of the U.S. vaccines, including low grade fever.

The NHS UK reports most side effects of the vaccines are mild

and should last no longer than a week such as a sore arm where the needle went in, feeling tired, a headache, feeling a bit sick or achy.

Is there any evidence that the vaccine will interfere with anti-seizure medication?

There is currently no scientific evidence to suggest COVID-19 vaccines interact with anti-seizure medications. However, according to the Epilepsy Foundation of America the U.S. vaccines may not be as effective for people on immunosuppressant therapies (for example: intravenous immunoglobulin (IVIg) or high dose steroids) for the treatment of their epilepsy (usually autoimmune epilepsies). This is because the immune system may not respond in the same way. Nevertheless, the vaccine is still recommended in these circumstances as it may reduce the severity of COVID-19 if it is contracted.

Who should get the COVID-19 vaccination when it becomes available?

As previously mentioned, it is advisable to speak to your healthcare provider about the vaccine. Individual risk will vary from person to person, so it's best to seek medical advice on what is appropriate for you or your loved one.

At this stage, the vaccines are not recommended for children under 16 years and all other precautions are in line with usual immunisation recommendations.

How long will the effect of the COVID vaccination last?

It is not yet known how long the vaccines will be protective. It's possible people may need periodic boosters, similar to a flu shot.

Sources:

Australian Government Department of Health. (2020). Covid-19 vaccines. Australian Government Department of Health. Retrieved January 20, 2021 from <https://www.health.gov.au/initiatives-and-programs/covid-19-vaccines>

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Epilepsy Foundation of America. (2021, January 12). Thank you for joining our Facebook Live about the COVID-19 vaccine. Please enter your questions in the chat! [Facebook Live video]. Facebook. <https://www.facebook.com/EpilepsyFoundationofAmerica/videos/115517787040277>

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30 minutes with...

Melissa

Simpson

About your role

What is the title of your role?

Fundraising and Partnerships Manager

Where do you currently work and how long have you been working there?

I made the career change from the commercial sector to build a career in the for purpose world more than 10 years ago and am absolutely here to stay. Prior to coming to Epilepsy Queensland, I have worked for various not-for profit health organisations including HeartKids, White Cloud Foundation, and Lymphoma Australia.

Where else have you worked in your life?

As I have a passion for improving health literacy and health outcomes, particularly in vulnerable populations, I also hold advisory and governance positions with Children's Health Queensland and Queensland Health. I have had the privilege to be involved in some rewarding projects such as launching a new online portal for families and children to access their medical information.

What is your personal connection to epilepsy?

My son, who is now 12 was diagnosed with epilepsy when he was 18 months old. His first seizure was Christmas morning and I was terrified. I did not recognize it as epilepsy at the time. Last year, surprisingly my dad, who is in his 70's was diagnosed with epilepsy after suffering a stroke. Watching him lose his independence when he was unable to drive was challenging for all our family.

What do you love about your job/working in the profit for purpose space?

Working for an organisation that exists solely to improve people's lives, often when they are at their most vulnerable is both motivating and humbling. Each day I know that what I do will have a flow on effect. My role in fundraising and partnerships allows me to be imaginative in the way that we work with supporters to not only raise funds but also awareness. There are occasions when I get to witness incredible generosity, sometimes following tragedy, which always renews my faith in human beings!

How do you think Epilepsy Queensland can have the biggest impact for people living with epilepsy?

With 280 Australians being diagnosed each week, our capacity to be there for those people, in the first overwhelming days and weeks is incredibly important. Ensuring they can access the help they need to live well with epilepsy is life changing. When you learn that 1 in 10 people will have a seizure in their lifetime, it becomes apparent that building a society, be that schools, employers or that wider community, that is aware of epilepsy and seizure first aid could be lifesaving!

What are your top priorities/aims in your new role?

Big picture is to generate income that not only meets our current needs but allows Epilepsy Queensland to expand our services. As a team we all want as help as many people in as many ways as possible. Building mutually beneficial partnerships with other organisations' who share our values and can help us reach financial and marketing goals is a priority.

What do you feel would greatly improve epilepsy care currently in Queensland?

From an Epilepsy Queensland perspective, I think helping people address the psychosocial impacts of epilepsy is incredibly important work. I do not think the general public realises that managing epilepsy is more than managing a seizure. The side effects that medication can have on personality and energy or the impact on a person's independence if restricted from driving can be life changing and not something a person should have to do alone.

Where would you most like to travel?

I have been very lucky to visit over 40 countries, which is fortunate, as for the short term, I think my travels will be limited to Australia! I would love to spend more time exploring Perth and a long weekend in Sydney or Melbourne is always fun.



What is your favourite food?

Mexican is a popular choice in our household if I am cooking, but I cannot go past a lamb dish on a menu if I am out at a restaurant.

Describe your most embarrassing moment?

I honestly cannot think of just one. My kids are always doing things to embarrass me, although now they are teens they seem to think that my mere existence is the most embarrassing thing ever!

What is your favourite book/author?

I go through phases; I do not think I could pick just one. Jodi Picoult and Harlan Coben are always a safe bet for a good read. The diary of Anne Frank I read when I was about 12 and I still find it incredible.

Who is the most famous or infamous person you have ever met? Or who would you like to meet?

In my job, I have met a few celebrities but the most famous would have to be Princess Diana. I had a cup of tea with her when I lived in London and it was incredible.

What genres of music do you like listening to/ favourite song?

I am a pop music tragic from way back!

Do you have any interesting hobbies you would like to tell us about?

Probably nothing unusual, I enjoy interior design and horse riding and I should probably classify shopping as a hobby too!



SUPPORTER SPOTLIGHT



St Flannan's Catholic Primary School - Powering up for Purple Day

Recently St Flannan's Catholic Primary School, Zillmere student Mia, and Mum, Shannon organised a purple dress day with yummy cupcakes. Their efforts raised \$488.10 generously donated to Epilepsy Queensland. Thank you very much!

Purple Day, which is our major awareness and fundraising day for epilepsy, was severely impacted by COVID-19 in 2020. It is so heart-warming that our community has overcome obstacles to continue to show their support.

Would your school or organisation like to be involved in Purple Day 2021? Save the date and register your school to participate today!

The first 20 schools to register their Purple Day event will receive a free Purple Day Power Pack with shoelaces, wristbands, stickers, balloons and posters to boost their fundraising efforts.

We would love every school to know and understand more about epilepsy so that every child that lives with epilepsy can feel safe and included.

On average, we have 30 early learning, primary and high schools across Queensland collectively raise more than \$7,500 to help ensure our Epilepsy Helpline is available to families when they need it the most. Our goal this year is to double that amount to \$15,000. With your support – we know we can do it!

For more info and FREE resources <http://bit.ly/PurpleSchools>



Auswide Bank show their support during Epilepsy Awareness Month

We are incredibly grateful to Auswide Bank for showing their support for people living with epilepsy by raising awareness and funds for Epilepsy Queensland.

Auswide dedicated their State of Origin Boardroom lunches to promote epilepsy awareness and raise funds. They also held a cupcake drive, circulated epilepsy awareness information to their staff via their intranet and on their website.

A special thank you to their Head Of Private Bank at Auswide Bank Ltd, Elsewerth Ephraums. Elsewerth is a former board member and a wonderful advocate for Epilepsy Queensland.



St Francis Xavier - HAIR for Hope

St Francis Xavier Primary School at Goodna recently held their annual Crazy Hair Day fundraiser for Purple Day. This is the school's FOURTH year of holding this epilepsy awareness event. Despite having to post-pone due to COVID-19, we think you'll agree the kids and parents went all out!

This event brought the school's total raised for Epilepsy Queensland in 2020 to \$541.30. Thank you!

An estimated 12,000 children in Queensland are currently living with epilepsy. Purple Day is a wonderful way for your school to show support for children and teachers living with the neurological condition. Save the date, March 2021 and register your school here <http://bit.ly/PurpleSchools>

Barrels for a Cause

On the 9th of March 2018, tragedy struck the western Queensland barrel racing community when they lost Jenny Schmidt to epilepsy. Jenny always had a kind and encouraging word to say to everyone and is still greatly missed almost three years on. In late January of 2021, the Jenny Schmidt Memorial, now in its third year, was held in Aramac to honour Jenny's memory and to raise awareness and funds for epilepsy. The Barrels for a Cause event raised \$5000 for Epilepsy Queensland. What an outstanding effort!

Bulimba Fashion Festival

Shannon Harvey, Place Estate Agent salesperson and Hawthorne resident, started the Bulimba Fashion Festival in 2009 as she wanted to give back to the community. Now in its 11th year, the 2020 Festival raised \$5000 for Epilepsy Queensland. A big thank you to Bret Neilson for nominating Epilepsy Queensland to benefit from this event.

Jeremy goes from zero to 50 kms for his sisters living with epilepsy

With zero running experience, Gold Coast man Jeremy Drabsch ran a 50km Ultra Marathon.

"The hurt of running this race is nothing compared to those fighting epilepsy on a day to day, moment to moment basis.

Around 50 million people worldwide have epilepsy, including both of my sisters. Each day they face this challenging condition. I ran this race for them, to raise money and awareness," Jeremy said.

Jeremy raised over \$4000 for Epilepsy Queensland to support people with epilepsy.





SERVICES SPOTLIGHT

One of our high priorities is delivering premium Epilepsy Understanding, Seizure First Aid & Management for schools, OSHC, Early Learning Centre's and Disability workplaces throughout the State. We are committed to providing exceptional training and support in these areas, as well as increasing awareness and therefore safety in the community for our members.

It's been a busy year thus far with many schools and organisations refreshing their epilepsy training or preparing for the arrival of new students, children and adults into other services. It's always a pleasure to have conversations with support workers and carers, educators and teachers about the best care and the best practice they want to provide in the community. The educators at Epilepsy Queensland have been to Townsville, Cairns and Rockhampton already this year, with other visits in the pipeline for later in the year.

Workplaces are a major priority for the Epilepsy Queensland team. We assist, not only with conversations with employers to help build an understanding of epilepsy, but will also provide you with the right words and support should you wish to disclose epilepsy to your employer. We also offer in-house or on-site training for 'Understanding Epilepsy' and 'Seizure First Aid' to help build understanding in the workplace and help employees feel comfortable in assisting someone who has a seizure.

Here what one training participant had to say:

"I would highly recommend this workshop to everyone. I found it highly informative and gave me a greater understanding of epilepsy." Weeroona – Gympie team member

There are different mediums to access your training opportunities.

The following links will assist you with face-to-face, internal and on-site training as well as through the Zoom platform.

<https://bit.ly/EQIworkshops>

<http://bit.ly/EpiOnlineTraining>

alternately call the office on 07 3435 5000, or 1300 852 853

Or email the team: services@epilepsyqueensland.com.au

If you would like to register an expression of interest for future events tailored to children, teenagers, seniors, parents, women or men living with epilepsy, contact our services team on services@epilepsyqueensland.com.au.





VALE MADDIE GILL

We are devastated to hear of the sudden and tragic passing of young Brisbane woman, Maddie Gill.

Courier Mail journalist, Sophie Chirgwin, writes:

"Maddie Gill was "vivacious" with a zest for life. The 22-year-old, with an unforgettable smile, was a born storyteller, enthusiastically informing her family of every detail of her day - which often started from breakfast.

However, on 5 December 2020, Maddie's young life was taken from her.

She went to lie down after work and then hours later her roommate would make the heartbreaking discovery that she had passed away. There was no warning, no alarm bells.

Maddie - who was diagnosed with absence seizures when she was in primary school - died from Sudden Unexpected Death in Epilepsy (SUDEP) - where no clear cause of death is determinable after a post-mortem examination.

She was healthy, she loved life, and was building a strong future for herself, in her final year of studying marketing and advertising at QUT.

Her death has left her mother Debra Tibbotts, stepfather Chris Tibbotts and friends and family shattered.

While still grieving their beloved girl, Debra and Chris have vowed to honour Maddie's legacy by raising awareness for Epilepsy Queensland, and in particular SUDEP.

Maddie herself was a passionate advocate for Epilepsy Queensland and felt determined to shine a light on the condition.

"She understood how important education for epilepsy was, she was such an advocate for Purple Day and talking to people about Epilepsy Queensland," Chris said.

Epilepsy Queensland Chief Executive Chris Dougherty says, "so much more is yet to be known about SUDEP".

"Raising funds for both research and support in this space is so very important."

"Our thoughts are with Deb, Chris, Lara, Matt, and all of Maddie's family and friends. The wonderful memories her family shared with us include how passionate she was about advocating for others living with epilepsy and her support for Purple Day. Purple Day is an awareness and fundraising event held 26 March around the world."

To show their support Maddie's home town of Mt Perry, west of Bundaberg, will be Making March Purple.

Chris Tibbetts shares: "almost every business – and even the local police are wearing purple and raising funds in Maddie's memory. Her sister, Lara, is a schoolteacher in Brisbane and the school is getting involved. She also hopes to join Epilepsy Queensland on the Purple Bridge Climb."

If you would like to contribute to the families fundraising efforts you can visit: <http://bit.ly/InMemoryMaddieGill>

For more information about SUDEP, please visit: <https://bit.ly/SUDEPinfo>

For support please call 1300 852 853.

A number of members have made contact to let us know that more support and connection is needed for families who have lost someone to epilepsy. If a bereavement program is something you would like to help shape or to belong to please express your interest via the website link. This could include anything from raising awareness, accessing peer support or participating in research.

<http://bit.ly/SUDEPsupport>

2021

DIARY DATES

26 March

Purple Day

Each March the world turns purple in support of the 50 million people living with epilepsy. In 2021, Epilepsy Queensland invites you to join the movement happening in over 130 countries around the world and make March purple for epilepsy!

18 March

22 April

27 May

17 June

15 July

19 August

16 September

14 October

18 November

Understanding Epilepsy Workshops (Woolloongabba)

For Disability Support Workers, Child Care Workers, Nurses, Allied Health Professionals, Volunteers, People with Epilepsy and their Families

26 May

13 October

Understanding Epilepsy Workshops (Gold Coast)

For Families, People with Epilepsy, Carers, Child Care Workers, Teachers, Nurses and Allied Health Professionals

Informally First Saturday of the Month

1 May, 5 June, 3 July, 7 August, 4 September, 2 October and 6 November.

Brisbane Adult Support Group Meeting

Please call 07 3435 5000 for further information on any of the above events

AGM update



Our Annual General Meeting and Awards night is usually held each year in early December.

With the uncertainty of COVID-19, our board made the decision to hold the formal components of the Annual General Meeting (AGM) separate to our awards and celebration. The AGM was held 25 November at our office at Woolloongabba.

Epilepsy Queensland's CEO, Chris Dougherty states:

"Strong, stable governance is the cornerstone of any organisation and I am really pleased to see all existing Board Members re-elected to their positions. I look forward to working with the Board on bringing our new vision and strategy to life over the coming years!"

Chair - Sam Bryce

Deputy Chair - Kim Davis

Treasurer - Calvin Booth

Secretary - Louise Prychidczuk

Board Members - Charmaine Driver, Murray Fairgrieve, Andrew Barnes, William Tuffley, Katrina Tune, Simon Watt