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GET READY FOR PURPLE DAY FOR EPILEPSY!

Purple Day (26 March) each year is an opportunity for anyone living with epilepsy and the people who support them, to help bring epilepsy out of the shadows. People from around the globe wear purple, help build understanding of epilepsy and break down the myths and misconceptions. This year our National theme for Purple Day is 'I can'. Throughout March we will be focussing on the amazing things people living with epilepsy CAN do. We will also be highlighting what you CAN do to get involved with Purple Day and show your support for Queenslanders living with epilepsy. Your support will assist the 100,000 Queensland children and adults with epilepsy to live without fear and prejudice, while you spread awareness of one of the world's most common serious brain disorders.

How Can I get involved?

Whether it is at home or work, with your local school, pharmacy, club or in your community, there are so many ways you can raise funds and awareness for Purple Day. We've included a small sample to get you started below.

1. Wear purple on 26 March and share your pictures on Facebook or Twitter with #PurpleDay.
2. Host a Purple event or activity and go in the draw for great prizes! This can be as simple as a morning tea at work, BBQ with friends.
3. Become a Purple Day Hero with your very own online Purple Day fundraising page. Simply share your epilepsy story or take on a challenge.
4. Buy or sell Purple Day Merchandise – including our cute new purple dinosaur and purple charm bracelet! Order using the enclosed flyer or purchase online.
5. Share your story or our posts on social media – change your cover photo to let others know why you Go Purple, add one of our frames to your profile picture, snap a selfie with a Purple Illumination or share our Purple Day Facebook, Instagram and Twitter posts.



Contact Us Now!

Contact our team on 07 3435 5000, 1300 852 853 or email purple@epilepsyqueensland.com.au. visit www.epilepsyqueensland.com.au/purple-day or www.facebook.com/EpilepsyQueensland, www.instagram.com/epilepsyqld for more information, to register today and GO PURPLE!

Join our Purple Climb or Purple Day Celebration

This year we have options for everyone, whether you are a thrill seeker looking to climb the Story Bridge as it goes purple, attend our Purple Day Celebration in Brisbane or take the free City Hopper to see Brisbane light up purple. We have great incentives for Purple Heroes willing to join the Adventure Climb on Purple Day and fundraise for our essential services and programs. To find out more about the Purple Climb or Celebration visit www.epilepsyqueensland.com.au/purple-climb-celebration or phone 07 3435 5000.

Purple Illuminations

On Purple Day 2019 we will have more purple illuminations and fountains across the State than ever before. Confirmed sites include Story Bridge, Brisbane City Hall, QPAC, Parliament House, Suncorp Stadium, Gasworks ULA group gasometer, Treasury Casino, Sir Leo Hielscher Bridges, Victoria Bridge and Kurilpa Bridge (Brisbane), Logan Water Towers (Underwood, Shailer Park and Hillcrest - Logan), Victoria Street Bridge (Toowoomba), Civic Centre (Ipswich), Town Hall (Maryborough), trees (Hervey Bay), Gladstone Yacht Club fountain (Gladstone), and Oxley Street fountain (Townsville).

We will continue to keep you updated via our Facebook page www.facebook.com/EpilepsyQueensland with more sites.

EPILEPSY AND GENETICS

Epilepsy is a complex neurological disorder, which is highly variable in its presentation from person to person. The main reason for this is that there are many things that can cause a person to have epilepsy, for example, it may be caused by structural changes within the brain (e.g. growths/tumours, malformation of brain); metabolic conditions (e.g. GLUT1 Deficiency); Immune System Disorders (with Central Nervous System Inflammation eg, Rasmussen Syndrome, Coeliac disease); Infections involving the Central nervous System (eg. Meningitis, Cerebral Malaria); & Genetics. However, for many people living with epilepsy, the cause of their condition remains unknown. As a result, there is large volume of research occurring in the epilepsy space, with much focusing on underlying causes & in particular genetics.

The International League Against Epilepsy (ILAE) describes genetic epilepsy as being the direct result of a known or presumed genetic defect/s, which causes a person to have seizures. This does not necessarily mean that the genetic defect is inherited. Genetic epilepsy can either be inherited or acquired. Inherited gene abnormalities occur when the defect is passed down from the parent/s at conception. Parents who pass on the gene defect may or may not have epilepsy themselves or have relatives who also have epilepsy. Acquired gene abnormalities occur randomly & are not inherited from the individual's parents. So what does this mean for people living with Epilepsy?



Advances in testing methods has assisted in reducing costs & allows clinicians to look more broadly & in a much quicker time frame. Coupled with this, research has led to the discovery of more & more genes believed to cause epilepsy (both focal & generalised) & in turn an increasing trend towards genetic testing. For some, this means undergoing genetic testing for the first time, sometimes many years after their initial diagnosis & subsequent treatment for epilepsy & for others, re-testing may be required. So what are the benefits of genetic testing?

Genetic testing can be beneficial as it aids in the diagnosis of specific epilepsy syndromes, for example Dravet Syndrome. It can also aid in determining treatment options, helping to understand prognosis & plan appropriate support therapies. It also opens up the opportunity for genetic counselling, which assists individuals & their families to understand the potential risk of passing the genetic defect/s on & therefore allowing them to make informed decisions on family planning.

However, it is important to note that not all people who have epilepsy will require genetic testing. Your neurologist or paediatrician will consider many factors when determining the need for genetic testing, including the person's epilepsy presentation, whether seizures are controlled, family history & past investigations. With ongoing research into the genetics of epilepsy comes an ever-changing understanding of the impacts for individuals. For this reason, you should discuss your individual circumstances with your neurologist or paediatrician.

Up until recent times, genetic testing was something that was rarely performed & only in very specific circumstances. It was expensive & difficult to access & the benefits were poorly understood.

If you have any further questions or concerns, please feel free to contact the Services team at Epilepsy Queensland on 3435 5000 or 1300 852 852.

Did you know?

Queensland Collective for Inclusive Education (QCIE) has announced times for Term One 2019 for their Queensland Peer Support Network 'coffee and a chat' sessions for families interested in finding out more about school inclusion or joining with other families pursuing an inclusive education. If you are interested in hosting or attending a session in those areas (or in other communities), please contact gldcollectiveie@gmail.com. You can find QCIE on Facebook.

REGIONAL MEET UPS - 16 TO 25 YEAR OLDS LIVING WITH EPILEPSY

Regional MeetUp's – focused on 16-25yo living with epilepsy in regional and remote Queensland.

Our services team member, Leonie attended the Regional MeetUp's in Yeppoon and Townsville in January 2019. The purpose of this trip was to connect with people aged 16-25yo who have epilepsy and are living in regional or remote communities.

We had 8 participants attend the MeetUp's. There was also interest from other participants, who were unable to attend on that particular day, so a really great start.

Initial conversations with the parents of the young adults identified that continued learning, social opportunities and employment supports were the main challenges that their child faces.

The MeetUp was facilitated in an informal and engaging way, to promote inclusion and future engagement. This included:

- opportunities for parents to attend (if that was right for the young adult and parent);
- open conversations about pressure points that these young adults experience (see below);
- M&M game to promote social connections and to have fun
- Chatting about social media and the best way to connect with them moving forward.

The pressure points that the young people identified were:

- Being bullied at school
- Troubles with not finishing school/ missing a lot of school – needing extra help with completing employment forms etc.
- Most were at the stage that they have recently finished school, and are now seeking employment. They all spoke of the challenges they have had in this space. Two parents who were present at this session, spoke about an interest in learning more about Social Enterprises/Micro-businesses

The group also spoke of ways they would like to raise awareness of epilepsy within their communities. I look forward to seeing the ideas that come from this.

Following on from the initial MeetUp, the participants have developed a facebook group to stay connected and get to know each other better.

Did you know?

Concessional parking available for eligible families

Families who wish to access concessional parking at the Queensland Children's Hospital can go to the Patient and Family Travel Hub on Level 6 of the hospital for assessment (between lifts A and B). Children's Health Queensland has a policy for concessional car parking at a rate of \$12 per day for parents, carers and families where there is evident financial or social need. Families who require additional support are welcome to visit the Social Work and Welfare team in 6f.

Patient and family travel assistance

Children's Health Queensland, Translink and AirTrain have partnered to provide goEvent cards and AirTrain tickets for eligible inpatients (admitted for three days or longer) and one parent or carer at the Queensland Children's Hospital. The initiative provides eligible families with free goEvent cards for unlimited travel on Translink services (bus, train, ferry) for either five or seven days at a time. AirTrain tickets to the Brisbane Airport will also be provided to eligible families. To find out more, visit the Patient and Family Travel Hub on Level 6.

Watch this space

ORDER MERCHANDISE
NOW FOR PURPLE DAY

26 MARCH 2019



Purple Day
for epilepsy QLD



Purple Day for epilepsy QLD

Purple Day Celebrations 26 March 2019



Epilepsy Queensland 50th Anniversary
Celebrations 2019

A REMINDER for your SCHOOL - 2019! BOOK IN NOW!

Does your school need to update its Epilepsy Awareness training?
Does your school need to update the Administration of Midazolam for your
child?

It's easy! Simply download a 'training request' form from our website
(epilepsyqueensland.com.au) or call us on 07 34355000 or 1300 852 853 (toll free)
to discuss a training package and a suitable date and time.

'UNDERSTANDING EPILEPSY' and the 'ADMINISTRATION OF MIDAZOLAM' WORKSHOPS Brisbane and Gold Coast

Contact us for details

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