MARCH IS EPILEPSY AWARENESS MONTH

Let’s all go PURPLE for people living with epilepsy.

Join thousands of people in Australia and around the world going purple to help raise awareness and vital funds during Epilepsy Awareness Month in March 2020.

Epilepsy is one of the most common serious brain disorders globally. Yet, there is a great deal of misunderstanding about what epilepsy is and what it is like to live with.

At the Epilepsy Foundation, we believe understanding is the key to promoting a better quality of life for people living with epilepsy – through reducing stigma and discrimination, providing better support for those with epilepsy and their families, and promoting research into reducing unnecessary deaths and finding a cure.

Purple Day is on Thursday March 26. It is the most significant day during Epilepsy Awareness Month. So, wear purple, host an event, buy Purple Day merchandise, donate. Your support will help reassure those living with this condition that they are not alone.

Last year over 100,000 individuals, businesses and schools around Australia got involved in Epilepsy Awareness Month. This year help spread the word by going purple and encouraging family, friends and colleagues to do the same.

Visit www.purpleday.com.au or call 1300 437 453 and GO Purple this March.

Get involved!

- Host a purple event
- Fundraise online and share
- Visit an Epilepsy Foundation Op shop
- Sell merchandise
- Donate online purpleday.com.au or call 1300 437 453

26 March #GOPURPLEForEpilepsy
PUTTING THE SPOTLIGHT ON EPILEPSY

Since 2008, Epilepsy Awareness and Purple Day on 26 March have represented a time for us to focus on epilepsy – particularly those people who have the condition, their families and carers who support them. A time when, together, we can help raise funds and awareness, and reduce the stigma about epilepsy that still exists today.

The recently-released report by Deloitte Access Economics, “The economic burden of epilepsy in Australia, 2019-2020”, highlights the need for more funds, more research and more support services for people with epilepsy to help overcome the barriers they face in education, employment and daily living. Your support is vital in enabling us to continue providing much-needed services.

In this issue you will read about the difference people like you and our wonderful community of donors have made to people living with epilepsy. You’ll read how people with personal experiences with epilepsy have worked hard to help raise funds and awareness. Sarah O’Brien, who shaved her head in support of her niece who has epilepsy, and Mitch and Mark from the 2019 season of Channel 9’s The Block, whose granddaughter has epilepsy, are among them. We thank them wholeheartedly for their most generous support.

You’ll also read about my involvement in the work of various international organisations that helps us identify best-practice services around the world and apply them to our experiences here in Australia, as well as stories about some of our services and the people who make them happen.

I urge you to take up the challenge this March and Go Purple for Epilepsy. Your support is greatly appreciated.

Graeme Shears
Chief Executive Officer

EPILEPSY MEMORIAL SERVICE 2020

In remembrance of those who have died as a result of epilepsy.

Every two years, the Epilepsy Foundation holds a memorial service to remember those who have died as a result of epilepsy, and to offer comfort and support to their families and friends.

The service takes the form of music, reflections, readings, meditation and prayer, and includes a candle-lighting ceremony, reading of names and display of photos and mementos. At a reception afterwards, families are encouraged to reach out to others to share their memories.

This year’s event will be held at St Mark’s Anglican Church, 1 Canterbury Road (corner Burke Road), Camberwell on Sunday 24 May 2020 at 2.00pm.

Refreshments will be served afterwards in St Mark’s Hall.

Please RSVP your attendance to events@epilepsyfoundation.org.au or call 1300 437 453.
NEW REPORT HIGHLIGHTS ECONOMIC BURDEN OF EPILEPSY

Epilepsy Australia recently released “The economic burden of epilepsy in Australia, 2019-2020” by Deloitte Access Economics, which estimates the cost of epilepsy in Australia for the 142,740 people currently living with active epilepsy is $12.3 billion.

This cost includes the burden on the health system, lost productivity in the workforce, costs associated with the provision of informal care, equipment costs, transportation costs and losses associated with reduced income and increased reliance on government welfare payments. It is also estimated that the lifetime costs for the 14,603 new cases of epilepsy per year is $22.2 billion.

Graeme Shears, CEO of the Epilepsy Foundation says, “Epilepsy is a serious neurological condition that carries with it stigma, psychiatric comorbidities and high economic costs. Epilepsy does not discriminate, being prevalent across age, gender and location.”

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. However, in half of all cases, the cause cannot be determined and the individual may never understand why they suffer from the condition.

Mr Shears says, “Epilepsy’s effects can range from mild and manageable with appropriate medication, through to unmanageable and severely impactful on an individual’s quality of life. This report has defined the extent of the burden of epilepsy on the economy and the need for interventions at each life stage to mitigate the impact of this condition, both on the individual with epilepsy, at whatever age they may be diagnosed, and their families and carers.”

Whilst the economic impact is substantial, the social and psychological impacts are equally, if not more, important.

To read the full article visit www.epilepsyfoundation.org.au/report where you can also download a copy of the complete report from Deloitte Access Economics.

In 2019-20, there will be an estimated 142,740 people living with active epilepsy in Australia, costing a total of $12.3 billion for the year. Lifetime costs for the estimated 14,603 new cases per year is $22.2 billion.
In support of her niece, Eleanor, who was diagnosed with epilepsy in 2019, Sarah O’Brien decided to shave her locks and raise funds for the Epilepsy Foundation.

With help from the Fundraising team, Sarah set up an online donation page, hosted a morning tea and let the highest donor shave her head. Setting a goal of $2,500, Sarah raised a phenomenal total of $10,290, becoming a true community fundraising hero for people with epilepsy.

“I still am amazed at the generosity of our family, friends and people we don’t even know!” she says. “It has been a beautiful experience to be a part of.”

Eleanor was diagnosed with epilepsy just before her first birthday, having four seizures in three weeks, each of them resulting in hospitalisation. Sarah’s brother John, his wife Amanda, along with their 5-year-old daughter, Caitlyn, were left not knowing what was causing the seizures, when the next one might occur and what could be done to prevent them.

“I can’t imagine anything worse than seeing your baby in hospital and feeling so helpless,” Sarah says. “I started thinking about what we could do to improve the lives of people living with epilepsy – especially our young ones. I decided shaving my head would give people a laugh, but also let them know how much we wanted to change things.”

Congratulations to Sarah and her family on a wonderful fundraising result. Funds raised will help the Foundation continue to provide services to people with epilepsy and their families.

You can support the Epilepsy Foundation by fundraising, volunteering or hosting an event. For more information, get in touch with one of our friendly Fundraising team members by phoning 1300 437 453 or emailing events@epilepsyfoundation.org.au.
HOLD A PURPLE DAY EVENT AT YOUR SCHOOL AND BECOME EPILEPSY SMART

1 in 200 students in Australia has epilepsy and with over 16 epilepsy syndromes and 13 types of seizures, epilepsy can have a big impact on a child’s experience at school. Because of the seizures and medication students may be taking, this makes it harder for them to concentrate or remember information. Students with epilepsy have lower education outcomes and need additional support at school if they are to reach their potential.

With around 40 schools across Victoria now Epilepsy Smart Schools, more principals and teachers are recognising the benefits of better understanding and managing students with epilepsy.

Holding a Purple Day event during Epilepsy Awareness Month or at any time during the year will count towards your school becoming an Epilepsy Smart School. This means your school has helped raise awareness of what it means to have epilepsy.

Becoming an Epilepsy Smart School is as simple as 1-2-3!

1. Hold current Epilepsy Management Plans for each student with epilepsy and, if necessary, Emergency Medication Management Plans (these must be updated annually)

2. Undertake epilepsy-specific training (first aid training is not enough)

3. Raise awareness of epilepsy to reduce stigma. This could involve holding a Purple Day awareness-raising event or fundraiser, or a curriculum-based activity in the classroom.

For more information on how your School can get involved this Purple Day visit www.purpleday.com.au

GO Purple this Month for Purple Day
There are several fun and fantastic ways you can get involved and GO PURPLE this Purple Day!

- Donate online www.purpleday.com.au or call 1300 437 453
- Host a purple event, such as a morning tea, trivia night or bake sale
- Fundraise online and share with your online networks
- Encourage your local school, workplace, community involvement by wearing purple
- Visit an Epilepsy Foundation Op Shop and make a purchase
- Purchase or sell Purple Day merchandise
- Join the growing Epilepsy Foundation community:
  - /epilepsyfoundation
  - /epilepsy_fdn
  - /epilepsyfoundationaus

A HUGE thank you to the Melbourne Star Observation Wheel, the Sydney Opera House, and WestConnex’s M4 Tunnels in New South Wales that will light up on Thursday March 26!

You can visit these famous landmarks and any other landmarks lit up in purple to show your support for people with epilepsy. Upload your Purple Day photos to your Facebook, Instagram or Twitter page. Don’t forget to tag the Epilepsy Foundation and use the hashtags:

#GoPurpleForEpilepsy #PurpleMonth2020 #PurpleDay2020
#EpilepsyAwareness #EpilepsyAwarenessDay #EpilepsyAustralia
#EpilepsyFoundationAustralia

For more information on how to get involved visit www.purpleday.com.au or get in touch with our friendly events team by calling 1300 437 453 or email purple@epilepsyfoundation.org.au

DON’T MISS THESE FAMOUS LANDMARKS GOING PURPLE!

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AUSTRALIAN EPILEPSY RESEARCH FUND MAKES ITS FIRST GRANTS

The Epilepsy Foundation congratulates the recipients of funding through the inaugural round of the Australian Epilepsy Research Fund. We are excited to be able to fund such cutting-edge research, examining the genetic basis of epilepsy and mood disorders in epilepsy, with the hope of improving the lives of those living with epilepsy.

One successful grant recipient is Dr Genevieve Rayner, a clinical neuropsychologist and outstanding early career researcher in the field of epilepsy and mood disorders. Dr Rayner’s research project is focusing on “Phenotyping depression and anxiety in people with epilepsy”.

Depression and anxiety commonly co-occur with epilepsy and can often go undiagnosed, significantly impacting the quality of life of people with epilepsy. Dr Rayner and her team from the University of Melbourne are taking an exciting and novel approach by examining whether genes that cause specific epilepsies are associated with depression and anxiety. This will help to expand our understanding of the different ways in which depression and anxiety may manifest and may open up exciting new opportunities for the treatment of mood disorders in epilepsy.

To read a synopsis of all research projects funded by the Australian Epilepsy Research Fund, visit www.epilepsyfoundation.org.au/funded-research, call 1300 761 487 or email research@epilepsyfoundation.org.au for a copy to be sent to you.

INTERNATIONAL AFFILIATIONS FURTHERING OUR CAUSE

Each year, Epilepsy Foundation CEO, Graeme Shears, networks with international epilepsy organisations across the globe. These organisations work in diverse fields including scientific research, education and training, service development and the dissemination of knowledge about epilepsy.

Graeme’s work at an international level ensures that the projects the Foundation undertakes and the services we provide to people with epilepsy are evidence-based and drawn from the latest thinking and best practice currently available in the world. This is evident in the development of the Epilepsy Foundation’s Epilepsy Smart Australia - a national program of services to support people living with epilepsy and their families, which will be based on international best practice.

Already in 2020, this has been a big year for developments on the international scene.

In January, the Epilepsy Foundation signed a Strategic Alliance Resolution with the Epilepsy Foundation of America (EFA). The purpose is to support both organisations in their shared vision and mission of creating a positive impact on the lives of people living with epilepsy.

Just like the Foundation, since 1968 the EFA has worked to prevent, control and cure epilepsy through community services, public education, federal and local advocacy, and supporting research into new treatments and therapies. We look forward to a fruitful working relationship and the sharing of information and resources with our counterparts in the USA.

To read more about CEO Graeme Shears’ international positions and partnerships forged between the Foundation and other epilepsy organisations visit www.epilepsyfoundation.org.au/epilepsypartnerships
As an Epilepsy Support Worker and team leader, Rheana’s voice is often the first one that someone new to the Epilepsy Foundation hears on the end of the telephone.

That person may be newly diagnosed with epilepsy and experiencing the anxiety or fear that comes with their diagnosis, a parent calling on behalf of a child or family member who has epilepsy, or an adult looking for advice on employment issues. Whatever the personal circumstances of the caller, Rheana and the team are there to answer queries, allay fears and provide information and support tailored to the person’s individual needs.

It’s a job Rheana relishes and one that calls on both her past work in the Australian Army and as a social worker, as well as a most personal experience...

In 2013 Rheana’s son was diagnosed with Juvenile Myoclonic epilepsy. “Sam’s seizures were so bad at the time that it was not possible for me to work.” While her son’s epilepsy is now well-controlled with medication, Rheana says, “It’s that ongoing fear and anxiety that’s there every day. My personal experience of having a child with epilepsy gives me a special empathy for our clients.”

“Everyone's journey is different.”

“My experiences as a mother of a child with epilepsy helps me understand people’s struggles, particularly that of other mums. We all handle it differently, from mums with babies, through to the those with children transitioning from late primary to adolescence and then into the adult neurology system. I feel privileged being able to support those families. I really do love my job.”

Rheana says she also loves the team she works with. “The team that I work with is amazing in their skills, support and knowledge.”

To speak to one of our Epilepsy Support workers, contact our Infoline on 1300 761 487.

Epilepsy is the most common brain disorder in Australia. One million Australians currently alive will be diagnosed with epilepsy at some point in their lives. With epilepsy impacting the lives of so many, it is important that, as a community, we understand the challenge and know how to help.

- Is a chronic medical condition that affects the brain and results in recurring seizures.
- Is diagnosed if someone has at least two unprovoked seizures or one unprovoked seizure and a probability of further seizures happening.
- Can develop at any age, regardless of gender or cultural background.
Yes, I want to help people with epilepsy and their families!

Title: Dr / Mr / Mrs / Miss / Ms (please circle)

Name ____________________________________________

Address ____________________________________________

Suburb ____________________________________________

State ___________________________ Postcode ____________

Mobile ____________________________

Email ____________________________

Enclosed is my tax-deductible donation

☐ $35  ☐ $50  ☐ $75  ☐ $150  My choice _________

☐ One Time OR  ☐ Monthly

Payment details

☐ My cheque and/or cash gift is enclosed payable to Epilepsy Foundation

☐ Visa  ☐ MasterCard  ☐ Amex  ☐ Diners

Card Number _______ / _______ / _______ / _______

Name on card ______________________________________

Expiry date _______/______

Please return in the prepaid envelope provided.

Donations $2 and over are tax deductible.

I would like to find out more about:

☐ Becoming a monthly supporter OR

☐ Leaving a gift in my will to Epilepsy Foundation

THANK YOU!
YOUR SUPPORT IS WONDERFUL!

People from around Australia continue to show their support in so many wonderful ways for those living with epilepsy. Here are just a few we want to say a huge thank you to:

THE BLOCK PARTY FOR EPILEPSY

You may know Mitch and Mark from last year’s Channel 9 show ‘The Block’. During filming they learnt their little granddaughter was having severe seizures. A desire to help led to a wonderful night at Mitch and Mark’s Block house in St Kilda that raised almost $14,000 last November. Around 60 people attended, enjoying a tour of the stunning home that won them much praise from The Block Judges. Delicious food and an auction rounded out the night. We thank Mitch and Mark for their support of the Foundation, our Ambassador, Rebecca Maddern, for MCing with grace and humour, and our wonderful sponsors including Channel 9, TarraWarra Estate and James Richardson Furniture.

BEST FRIENDS TOAST EPILEPSY GUY TEA SUCCESS IN NAMBUCCA

There may not have been a lot of tea drunk, however, a memorable day was had raising awareness and close to $2,000 in ticket sales and auction items for the Epilepsy Foundation. The sold-out event held at the Macksville Ex-Services Club in Nambucca, NSW, late last year, was hosted by best mates, Paul Hennessey and Luke Shields. Luke was diagnosed in his teens and although he’d been living seizure free for many years, his seizures returned early 2019. Thank you to Judy Ward, CEO of the Macksville Ex-Services Club, for supporting the cause.

WAGGA AGRICULTURAL CLUB SUPPORTS WILL MITCHELL IN RAISING FUNDS

Wagga Wagga once again supported Will Mitchell, whose brother Andy passed away in July 2018, caused by an epileptic seizure. Will has raised significant funds for the Epilepsy Foundation over the past few years. The Wagga Agricultural Club raised $6,700 from ticket sales and auctions at two outstanding events, the Ag & Vet Ball and WAC Ball. President of the Wagga Agricultural Club, Will O’Leary, says the club will continue their support of the Foundation well into the future.