Welcome to the first edition of our 2018 'Epilepsy Matters' newsletter. We’ve called our newsletter Epilepsy Matters because its meaning is two-fold; we want to acknowledge that epilepsy does matter while also highlighting that matters relating to epilepsy should be shared. We hope that you also like the purpose and intent sitting behind the title.

The Epilepsy Foundation supports people living with epilepsy, as well as everyone who cares for those who do. We believe no one should go it alone with epilepsy. Our purpose is to reduce epilepsy-related deaths, ensure that children receive a good education, ensure people obtain and retain jobs, and assist people to feel safe and connected.

This edition updates you on our Australian Epilepsy Research Foundation fund and the Australian Epilepsy Research Register; both of which are working towards finding a cure for epilepsy and improving the lives of people living with it. Information about ways you can access our training programs, Epilepsy Management Plan development, NDIS updates and upcoming events is also included. I’m sure you’ll also enjoying ‘meeting’ the passionate and interesting members of the Epilepsy Support Work Team who are profiled in this edition.

With Purple Day just around the corner, March 26, you’ll find some ideas and tips for how you can support this important epilepsy awareness day inside. We hope you can join us in going purple too!

I’d like to take this opportunity to thank the volunteers and staff who work tirelessly to have a positive impact on the lives of people with epilepsy. I would also like to express my gratitude to the generous community members who donate to us; support we rely on to provide crucial assistance to our epilepsy clients.

I hope you enjoy our first edition of Epilepsy Matters!

Graeme Shears, CEO
Australian Epilepsy Research Fund

The Epilepsy Foundation is growing a fund that will support research into finding a cure for epilepsy and reducing the impact of epilepsy on people’s lives.

We are committed to supporting innovation and excellence in the medical and psychosocial research of epilepsy. This will involve supporting researchers from universities, research institutes and hospitals to advance our understanding and improve treatment of epilepsy, from the research lab to the community.

To guide us we surveyed key experts, professionals and people living with epilepsy in order to understand where research can help the most.

We have also assembled some of Australia’s leading epilepsy research experts as our Research Fund Committee. This will ensure we are able to support an ongoing high standard of research that meets the needs of people living and working with epilepsy.

For more information contact 1300 761 487 or email research@epilepsyfoundation.org.au

“We are working towards finding a cure for epilepsy.”

Australian Epilepsy Research Register

The Australian Epilepsy Research Register (AERR) is a national initiative of the Epilepsy Foundation.

The AERR is a voluntary register for people living with epilepsy, as well as their family members/carers. Those listed on the register are invited to complete a survey or participate in research for the Epilepsy Foundation or an affiliate.

Our aim is to involve as many people living with epilepsy as possible from across Australia - men and women, young and old, at school, at work or at home, those living in the country and those living in the city. Because no two people with epilepsy are the same.

We hope this will be one of the largest epilepsy research communities in the world and will allow us to understand and improve the lives of people living with epilepsy.

We encourage you to read more about our publications or be involved with the AERR by visiting - http://epilepsyfoundation.org.au/research/
Social media

Social media is increasingly being used as a source of information. A recent study of the use of social media for epilepsy information found a 100% increase in the number of Facebook and Twitter accounts relating to epilepsy between 2012 and 2016. The most commonly discussed themes on these pages related to providing information about medications and misconceptions about epilepsy, as well as providing support, and product advertisement. Much less was posted about specific treatments, such as surgery.

The authors noted that care should be taken when looking for epilepsy-related information on social media to identify credible sources from commercial marketing sites.


Apps

Researchers are investigating the use of smartphone apps (e.g., Sydney Children’s Hospitals’ EpApp) for improving epilepsy knowledge, storing medical info and seizure diaries, and providing medication alerts/reminders. A recent study of the EpApp for teens with epilepsy found that it significantly improved epilepsy knowledge and medication management. Smartphone apps have the benefit of being easy-to-use and easy-to-access.

Again, care should be taken to identify credible apps – it may be worthwhile discussing options with your doctor or specialist.


Personalised seizure predication

Recent research from the University of Melbourne and IBM Research-Australia is looking at creating a wearable, real-time seizure warning system. Using artificial intelligence (AI) technology, researchers have analysed brain signals from retrospective patient data and were able to use this information to successfully predict an average of 69% of seizures.

While it may be a while before we develop a reliable means of predicting seizures, these initial results are very promising.


For more information about these, other research studies and Epilepsy Foundation research work:
Call - 1300 761 487
Email - research@epilepsyfoundation.org.au

Why not visit our Facebook page too, where we regularly share research articles - www.facebook.com/epilepsyfoundation
Support News

We kicked off the year with members of our YES (Young Epilepsy Support) group attending a screening of ‘The Curious Incident of the Dog in the Night-Time’ at The Arts Centre in Melbourne. The play was not only fun but a great chance for people to connect with their friends and meet new members.

Ari and James having fun at ‘The Curious Incident of the Dog in the Night-Time’.

Our team has also been very busy in the lead up to the new school year. We have been supporting families to develop Epilepsy Management Plans and working with our Education and Training Team who have been training school staff to support students with epilepsy.

Epilepsy Management Plans aren’t just for students though - they are a great tool for anyone to communicate their seizure type/s and how they like to be supported. To download one visit - http://epilepsyfoundation.org.au/epilepsy-management-plans/

Our Family Activities Day is happening in March. The day is a chance for children with epilepsy, siblings and parents to enjoy a fun day participating in activities such as face painting, arts and crafts, seeing zoo animals and meeting other families.

We are also excited about rolling out a new group, ‘Parent 2 Parent’, for parents of children under 18 later in the year - watch this space for more information!

If you need some support or information speak to one of our Epilepsy Support Workers on 1300 761 487

Education & Training News

Did you know that the Epilepsy Foundation offers a range of training programs, both online and face-to-face, for people living with epilepsy and all those who support them?

Through our education and training programs we develop the capacity of individuals and families, organisations and the community to better understand and support the needs of a person living with epilepsy. In this way we are working towards building an Australia that is more ‘epilepsy aware’.

Our training programs include:
- Understanding and Managing Epilepsy
- Administration of Emergency Medication
- Understanding the Epilepsy Management Plan.

In recent weeks our Education and Training Team have been very busy training people living with epilepsy, families, schools and carers so that even more people in the community are epilepsy aware and prepared. Our team members, comprised of registered nurses and community workers, welcome the opportunity to share their experience and knowledge while delivering our evidence-based and externally reviewed training programs. In some cases the training is via our online training platform, at other times it’s in a group setting and we also offer training via webinar. So, there’s a delivery style to suit everyone.

Check out our dedicated learning and training website!

For training program queries
Email - edutra@epilepsyfoundation.org.au
KNOW US, KNOW YOU

The Epilepsy Support Worker Team

These are the friendly faces of your Epilepsy Support Team who are only ever a phone call away.

Every month we receive hundreds of enquiries on our Information Line or via email. Amongst the many supports we provide are those around key life events, NDIS information, equipment advice, and access to community supports. We also work closely with our Peer Support Group Leaders to coordinate support groups activities and events over the year.

One of our main supports is assisting people to develop Epilepsy Management Plans and we are excited that we will offering counselling services later this year.

Now to meet the team (from left to right) ...

Maree started volunteering with the Epilepsy Foundation in 1999 after having a left temporal lobectomy for her epilepsy, as she was keen to support others. After completing a welfare course Maree joined the Epilepsy Foundation as a staff member. Maree recently completed a remedial massage therapy and is kept very busy looking after her young daughter.

Monique has been with the Epilepsy Foundation for three years. She has a background in occupational therapy (OT) and has previously worked in hospital, rehabilitation and community sectors. In her spare time she spends too much time posting photos of her dog on social media.

Rheana has only recently joined the team. She is a social worker with 10 years of experience and has worked in the areas of military and PTSD. Rheana’s son has Juvenile Myoclonic Epilepsy and has a seizure alert dog. In her spare time Rheana is a passionate dog trainer!

Lisa has worked for the Epilepsy Foundation for 29 years and is an encyclopaedia of epilepsy knowledge and experience. Lisa is a strong advocate for people with epilepsy. In her spare time Lisa likes to keep fit and loves live music.

David initially worked with our Peer Support Groups and organised our weekend getaways, and then joined the Epilepsy Support Worker team in 2017. Originally from London he loves soccer and is really looking forward to this year’s World Cup finals where he will spend late nights and early mornings following both England and the Socceroos.

As you can see our team is comprised of very passionate and experienced people keen to support anyone who lives with epilepsy, or cares for someone that does.

Our Videos

Did you know that the Epilepsy Foundation YouTube channel contains 25 videos!

The videos share the stories of people of all ages living with a range of epilepsy types. Our videos feature people who work in different employment sectors, are students or have specific interests. Our videos also feature some of our well-known ambassadors and profile key Epilepsy Foundation events.

So, why not jump online and check out some of our videos - www.youtube.com/user/EpilepsyVictoria
2018 Purple Day

Get ready, get set, go PURPLE!

Epilepsy affects each and every one of us. It does not recognise age, gender, culture or socio-economic status. Close to 250,000 Australians currently live with epilepsy. While more people are being diagnosed with epilepsy today, the reality is that few people talk about living with epilepsy.

March 26 is Purple Day – a day to raise community awareness of epilepsy and let people who live with epilepsy know they are not alone.

There are many ways you can get involved and show your support including:

- signing the 'Purple Pledge'
- considering '26 ways in 26 days'
- going purple on Purple Day from top to toe
- wearing a Purple Day pin or t-shirt
- purchasing Purple Day merchandise
- making a donation in the month of March
- selling Purple Day merchandise to family and friends
- hosting your own Purple Day event
- setting up your own fundraising page - sharing with your network to help spread awareness and raise funds
- sharing information about Purple Day on social media, or sharing the Epilepsy Foundation posts with your network.

So, if you would like to get involved this Purple Day just call our Events Team on 1300 437 453, log on to www.purpleday.com.au, or visit one of our Op Shops.

Epilepsy Memorial Service

A time to be together and remember ...

This year marks the 9th biennial Epilepsy Memorial Service. Families and friends will once more join members of the Epilepsy Foundation to remember and celebrate those who have died through epilepsy.

The memorial service will be held at 2pm on Sunday 27 May at St Michael’s Uniting Church, 120 Collins Street, Melbourne. It is a wonderful and heart-warming opportunity to come together and be comforted by others who have also experienced unexpected loss and deep sorrow.

Our Service will include presentations of poems, reflections from a family and musical contributions.

At the end of the ceremony, afternoon tea will be held where mementos sent by families, in the form of photos, stories and other items will be displayed. Many people who are unable to attend the service also send cherished memories to share.

Invitations will be sent to those on our Memorial list but all those who would like to attend the service are most welcome.

If you would like to attend please RSVP Gail Breen on 03 8809 0650 or at events@epilepsyfoundation.org.au
National Disability Insurance Scheme (NDIS)

The NDIS and you ...

The NDIS continues to roll out across Australia. If you live in a region where the NDIS is currently being implemented and are or have received services from the Epilepsy Foundation you may be eligible to receive funding from the NDIS. Some of you may have already been contacted by NDIS and in the process of developing your plan, others may have completed an NDIS plan, and others yet to contact the NDIS.

Not everyone will be eligible to receive services under the NDIS. You can find out more about your eligibility by going to the NDIS website www.ndis.gov.au and checking their eligibility requirements.

The introduction of the NDIS means some changes to how you receive services from us. Previously we were funded by the government which meant you didn’t have to pay us to receive services. Now, if you have been assessed as being eligible for the NDIS and you want to access our services, you will need to reflect that in your plan to ensure you will continue to receive services from us.

Our Epilepsy Support Workers are here to assist you with understanding the NDIS and how it works.

Some of the ways in which we can help you include:

- understanding what the NDIS is and how it works
- the pathway into the NDIS
- advising you how to check eligibility with the NDIS
- supporting you to identify Epilepsy Foundation services you may wanted included in your plan
- preparing for your NDIS meeting.

We are aware that the National Disability Insurance Agency (NDIA) in collaboration with the Victorian Department of Health & Human Services (DH&HS) is systematically contacting potential applicants by various means including phone. The Epilepsy Foundation has been requested by DH&HS to validate contact details as part of this process.

If you have any questions about the NDIS or how this may affect you receiving Epilepsy Foundation services feel free to contact us on 1300 761 487 or visit - http://epilepsyfoundation.org.au/ndis-you/

Play for Purpose Raffle

A new support initiative for the Epilepsy Foundation is the online ‘Play for Purpose’ raffle. Charities are chosen to participate in this, with an array of different organisations taking part.

Tickets are $25, and the Epilepsy Foundation receives $15 per each ticket. Prizes include $500K in gold bullion, a $150 luxury car package, a $25K travel experience, a $10K travel escape, $5K travel recharge and many, many more.

To learn more or purchase a ticket visit - https://playforpurpose.com.au/epilepsy-foundation

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