WELCOME
Graeme Shears (Chief Executive Officer)

The Epilepsy Foundation is pleased to share our first edition of Epilepsy Matters for 2019.

March 26th is Purple Day, a worldwide event aimed at increasing awareness of epilepsy. The Epilepsy Foundation is going purple in March, and we hope you can join us too!

Purple Day is just around the corner, and is a big focus of this edition. You’ll also find advice for staying safe if swimming, information about upcoming social activities, details about ways of donating to or volunteering at our Op Shops, and new aged care and disability training programs about to be released. You’ll also meet Archie and his family, who talk about their epilepsy journey.

In this edition we are privileged to honour Jai Reed, a young man who recently passed away and is leaving behind an incredible legacy with the support of his family and Monsta Surf.

I’m pleased to let you know that 2019 is shaping up to be a very exciting year. We will soon be launching a new website containing a lot of information to assist people in understanding and managing their epilepsy, as well as details about support we can provide in the community. We will also be launching digital Epilepsy Management Plans and Emergency Epilepsy Management Plans, allowing people to complete and update their information easily.

I hope you enjoy this edition, and contact us any time if you are looking for support or training.

Graeme Shears, CEO
In Honour of Jai

When two like-minded souls met at Lilydale Heights College, a unique friendship blossomed. Cam Greenwood, founder of clothing brand Monsta Surf and motivational speaker, was a guest speaker at Lilydale Heights College when he met Jai Reed, a young man living with epilepsy.

Jai’s passion for life, bright personality and joyful spirit had an immediate impact on Cam, just as it had always on everyone around him.

When Jai passed away in October 2018, following a seizure, Cam and the team at Monsta Surf wanted to create a range of clothing in memory of Jai. This became the Live Like Jai campaign - #livelikejai.

Live Like Jai is a range of clothing and prints, with $5 from every item purchased donated to the Epilepsy Foundation. But more importantly this initiative honours Jai’s extraordinary life while also helping to raise awareness of epilepsy in the community.

The Epilepsy Foundation would like to express a heartfelt thank you to the Reed family and Monsta Surf for honouring Jai, a young man who won the hearts of so many.

If you would like to support this campaign, please visit:
www.monstasurf.com.au
Purple Day 2019

Purple Day is a worldwide grassroots campaign dedicated to increasing awareness about epilepsy, held on the 26th of March each year.

Purple Day was founded in 2008 by nine-year-old Cassidy Megan from Canada, in an effort to get more people talking about epilepsy and assure those living with this condition that they are not alone.

Over the past 11 years the Epilepsy Foundation has been a proud official Purple Day partner, using this campaign as a platform to educate the community about epilepsy and challenge myths which still exist today.

Throughout March, the Epilepsy Foundation asks people to spread the word about epilepsy, get involved in Purple Day activities, share stories and consider donating to this important cause. Please join us to help ensure that no one with epilepsy goes it alone.

There are many ways to support those living with epilepsy on this important day, including hosting an event, selling merchandise, or setting up a fundraising page.

More information is available on the Epilepsy Foundation’s www.purpleday.com.au website and on the next page!

I can...

Ask my school to become Epilepsy Smart.

#purpleday
Approximately 250,000 Australians live with epilepsy. And around 65 million people around the world also live with epilepsy. Epilepsy doesn't just affect the person living with it, but it also impacts on the many people in that person's life. At the Epilepsy Foundation we are working to not only support people affected by epilepsy but also assist the wider community understand it and know how to help.

The 26th of March is **Purple Day** – an opportunity 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 this Purple Day. Whether you live with epilepsy, support someone who does or are an interested community member you can say “I'm purple and I can …”

- **I can ... spread the word about epilepsy.** Log on to our website for more information about epilepsy so that you can have a conversation about this neurological condition with people you know. You might also want to place a Purple Day post on social media or share Epilepsy Foundation posts with your family, friends and network.
- **I can ... donate.** With your help you can assist the Epilepsy Foundation to support others. Your donation will go a long way to help people with epilepsy have equitable access to education and employment, feel safe and connected in their community and no longer die from their epilepsy.
- **I can ... purchase Purple Day merchandise.** Think about purchasing Purple Day merchandise!
- **I can ... join our online fundraising community.** It’s easy to raise money and support the Epilepsy Foundation by having your own online fundraising page. You can personalise your page with a photo or video and share the reason why you are trying to raise money for Purple Day.
- **I can ... get my school involved.** Purple Day is a great way to get your school or early learning centre involved in raising awareness of epilepsy and building positivity amongst young learners. We have lots of activities and fundraising tips that you might be interested in using in your education setting.
- **I can ... get my workplace involved.** Think about getting your employer on board. Perhaps your employer or your business can get involved by fundraising, volunteering, providing pro-bono support, or even offering gifts in-kind. Fundraising and volunteering can be a brilliant team building activity, and opportunity to let the community know that your company is making a real difference for those living with epilepsy.
- **I can ... visit an Epilepsy Foundation Op Shop.** Visit one of our seven Op Shops across Melbourne to find something special, you might even find something purple! Or you can donate goods, volunteer your time, or just drop in and say hi to the team. Our Op Shops are located in Beaumaris, Blackburn, Cranbourne, Kensington, Parkdale, Port Melbourne and Seddon.

If you would like to get involved just:
- Call our team on 1300 437 453
- Log on to www.purpleday.com.au
- Email purple@epilepsyfoundation.org.au
Many people enjoy swimming and water activities during the summer months. Spending time in the water is often a social activity, providing a chance to exercise and a way of staying cool on hot days.

People living with epilepsy can be very competent and confident swimmers. However, seizures that occur in the water can lead to serious injuries and even death. Because of this, if you live with epilepsy, or care for someone who does, it is a good idea to take some precautions so that time spent in the water is as safe as possible.

This article offers some tips and strategies to assist people living with epilepsy, and those who support them, to stay safe in the water. It also provides first aid tips should you need to assist someone who has experienced a seizure in water.

**Staying safe in water**

- Seek advice from your doctor about any factors that could affect your safety in the water. Be prepared for the possibility of your doctor suggesting that, for your own safety, spending time in the water is not a good idea for you.
- Only swim with someone you know, who is familiar with your type of seizures, understands exactly what to do should you experience a seizure in water, and feels confident that they could provide first aid. Ensure that this person can provide you with one-on-one supervision.
- If at the pool or beach, and particularly if you have uncontrolled epilepsy, it’s a good idea to let the lifeguard know that you have a history of seizures.
- Consider wearing bathers or a swimming cap which is bright and visible so that lifeguards can easily identify you, particularly if your seizures are uncontrolled.
- People with uncontrolled seizures should wear a life-jacket or buoyancy vest in the water.
- Swim early in the day if your seizures are triggered by heat or fatigue.
- Do not swim or enter water if you are feeling unwell, tired, have missed your medication, and/or are experiencing any signs of a possible seizure.

**Staying safe with water sports**

It is important for people living with epilepsy to experience as much of life as possible, as well as pursue their interests and passions. However, some water sports have a higher risk of injury for people living with epilepsy and may also put bystanders at risk. The level of risk is very individual, and depends on a number of factors including the level of seizure control.

Some water activities can be particularly risky for a person living with epilepsy, and if you intend participating in these it is a good idea to speak to your doctor before taking part.
Swimming, Water Sports and Epilepsy

It is a good idea to speak to your doctor before taking part in certain water activities. These include:

- Canoeing, kayaking and white water rafting
- Sailing
- Wind surfing
- Water skiing
- Fishing
- Scuba diving.

Follow the instructions of the ambulance operator, who will instruct you on what to do while an ambulance is dispatched. This may include beginning resuscitation.

Even if the person appears to be fully recovered, they still require a medical assessment as inhaling water can cause lung or heart damage.

First aid for seizures in the water

A seizure in water (pool, bath/shower, river, ocean) is a life threatening emergency and an ambulance (000) should always be called. Even if a person is breathing after the seizure, they may have inhaled water and be at a significant risk of drowning.

If a seizure in water occurs:

- Support the person’s head so that their face and head stay above the surface.
- Tilt the person’s head back to ensure a clear airway.
- Remove the person from the water as soon as the jerking has stopped.
- Ask for assistance from others or use a floatation device when removing a person from water.
- Gently roll the person onto their side as soon as possible and tilt the chin upwards to assist with breathing and to protect their airway.

G. Is it safe for people with epilepsy to go to the water?

A. Yes, people with epilepsy can be very competent and confident swimmers, however extra precautions need to be taken. Children need to be actively supervised. If someone has a seizure, assist the person out of the water or if they are already there, help them to move from the water to a safe area immediately. If they are breathing after the seizure, they may have inhaled water and be at a significant risk of drowning.

G. What is the risk of drowning among people with epilepsy?

A. Studies report an increased risk of drowning among those with epilepsy, citing that they are between 5 and 16 times more likely to drown than people without epilepsy. In Australia, between 2006 and 2016, approximately 61 people with a history of epilepsy drowned. This strong risk is likely to be even greater in younger patient populations.

G. How and where do people drown?

A. The home environment is the most common place for epilepsy related drowning, specifically in the bathroom. It is important to not tend to the bathroom door to ensure assistance can be given immediately. After bathing, ensuring the room is not left unattended and child safety products are used can help prevent this. Some other common places are the pool, river, ocean or lagoon. It is important to speak to your doctor before taking part in certain water activities.

G. What precautions need to be taken for people with epilepsy when in the water?

A. The most important message to remember,无论 you are in a pool, bath or any other water environment, is to make sure someone else is aware of your activity and that they can assist should it be needed. Please refer to the Royal Life Saving Society of Australia website for more detailed information on drowning and epilepsy.

Follow the instructions of the ambulance operator, who will instruct you on what to do while an ambulance is dispatched. This may include beginning resuscitation.

Even if the person appears to be fully recovered, they still require a medical assessment as inhaling water can cause lung or heart damage.

If a person is found unconscious in or near the water and not breathing, treat as you would with any other drowning victim.

- Keep them safe – shout “is there anyone else here?”
- Call triple zero (000) and give details of what you have observed or heard
- Stay calm and continue with CPR
- Provide first aid to the person if they are conscious
- Get medical help for the person

If a person has inhaled water or has been in the water, speak to your doctor before partaking in any vigorous activity for the next 24 hours.

Real Life Story – Fishing tragedy highlights drowning risk

Two friends were fishing at the local jetty. They were drinking alcohol and not wearing lifejackets; one fell in and wasn’t aware of the fact. The friend found him floating facedown in the water. The man in the water had a history of epilepsy and had not taken his medication. This event highlights the need for family and friends to ask about medical conditions, avoid drinking around water, always wear a lifejacket when fishing and keep an eye on your mate when around water.

The Royal Life Saving Society of Australia have detailed information about drowning and epilepsy if you would like to learn more about this issue - www.royallifesaving.com.au
Our friendly and experienced Epilepsy Support Worker Team gain a lot of satisfaction supporting people living with epilepsy and all those who care for them. Just as epilepsy is a very individualised condition, so too are the requests for support from people living with epilepsy, parents, siblings, partners, friends, teachers, carers and co-workers.

The team also know just how important it is for people with epilepsy and those who care for them to understand the condition, to learn how to best manage it, and to feel supported. Peer support is a wonderful way of connecting with others who may be in a similar situation, and we run a range groups and events throughout the year to enable people to connect with others. Some events being hosted by our team are outlined below.

**Family Activities Day**
We are looking forward to our Family Activities Day in June which is an event sure to be full of fun and laughter! It is a chance for children with epilepsy, their siblings and parents to enjoy a fun day participating in activities such as face painting, giant parachutes, circus acts, zoo animals, and a photo booth. Importantly it’s also a chance for children and families from across Victoria to get together and meet.

**Who can attend:** Families of children living with epilepsy and parents who live with epilepsy.
**How to register:** A show of interest brochure will be forwarded in May.
**Location:** Mount Alexander College, Flemington
**Date:** Saturday the 22nd of June (time TBA)

**Victorian Youth Week: Drumming and Pizza!**
Victorian Youth Week is an annual, week-long celebration of young people throughout Australia held from the 5th – 14th of April.

The Epilepsy Foundation will be celebrating young people living with epilepsy, their achievements and resilience by hosting some fun and engaging activities, as well as providing some great food to share in a social setting.

This year we’ve partnered with our friends at Drum Beats and put together an awesome program, with an afternoon of African Drumming and pizza for young people aged 13-18 years old! See below for the details on the event and how to get involved:

**Date:** Monday the 8th of April
**Time:** 12:30-3:30pm
**Location:** Multicultural Hub 506 Elizabeth St Melbourne
**RSVP:** Contact us by Tuesday 2 April on groupsandevents@epilepsyfoundation.org.au

Get in quick as numbers are limited!
Support our Op Shops

The Epilepsy Foundation runs seven Op Shops across Melbourne! Our Op Shops are positive and friendly community hubs where volunteers, customers and staff have a chance to support people living with epilepsy. Our Op Shops rely on the generosity of local communities to offer an important service in the area and at the moment we are looking for more volunteers and donations in each of our shops.

Volunteering
We always welcome more Op Shop volunteers. Our volunteers are generous and dedicated people, who we consider to be the backbone of our retail stores. If you would like to donate your time, meet others, develop new skills and build community connections then volunteering with an Epilepsy Foundation Op Shop might be just what you’re looking for.

All volunteers receive training, are supported by experienced staff and, because our Op Shops are open from Monday to Saturday, flexible hours are available too.

If you would like to learn more just get in touch with your local Op Shop. Our friendly staff can answer any questions you might have and set you on the path to becoming an important and valued member of our volunteer team.

Donations
The Epilepsy Foundation welcomes donations of good quality furniture, clothes, homewares, kitchenware, books, electrical items and bric-a-brac. The sale of donated quality goods to the public allows the Epilepsy Foundation to continue supporting people living with epilepsy.

If you would like to drop off items, just visit your local Epilepsy Foundation Op Shop during opening hours, where the team will welcome and thank you for your generosity. Please don’t leave donations in front of our Op Shops outside of opening hours as your pre-loved goods may get damaged by the weather or even stolen. It also means we can’t greet you and thank you for thinking of us.

If your items are too large (such as furniture) or you have a lot to donate we can arrange for them to be picked up for free from your home. If you want item/s to be picked up just speak to staff at your local Op Shop who can let you know if the item is suitable, and whether a pick-up is available in your area. Unfortunately, we can't accept goods which are broken, damaged or stained.

So, if you are thinking about throwing away quality household items, consider donating them to your local Epilepsy Foundation Op Shop. Your generosity is always welcomed!

Our Op Shops
Whether you are interested in volunteering, donating or shopping for yourself, pop in to one of our great Op Shops in convenient locations across Melbourne:

**Beaumaris:** 341 Balcombe Rd, Beaumaris 3193 (9589 2307)
**Blackburn:** 82 South Parade, Blackburn 3130 (9894 8266)
**Cranbourne:** 10 Lurline St, Cranbourne 3977 (5995 2369)
**Kensington:** 513 Macaulay Rd, Kensington 3031 (9372 3972)
**Parkdale:** 258 Como Parade, Parkdale 3195 (9588 0455)
**Port Melbourne:** 2/322 Bay St, Port Melbourne 3207 (9676 9426)
**Seddon:** 1/101 Victoria St, Seddon
Australian Epilepsy Research Register and Research Project

Australian Epilepsy Research Register (AERR)
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 are keen to grow the AERR community, with the next major AERR survey scheduled to be sent out later this year.

We encourage you to read more about our publications or be involved with the AERR by visiting epilepsyfoundation.org.au/research/ or get in touch via research@epilepsyfoundation.org.au

Research Project - ‘Body Image and Epilepsy'
A research project is currently being undertaken by The University of Melbourne in collaboration with the Florey Institute of Neuroscience and Mental Health and the Epilepsy Foundation, looking at the impact of epilepsy on body image. In particular, this study is looking at body dissatisfaction and whether it might contribute to depressive symptoms in people with and without epilepsy.

Ultimately, the aim of this research is to help improve the quality of care provided to people with epilepsy, through better awareness and the development of effective treatment strategies for body dissatisfaction.

Volunteers wanted
The researchers are searching for volunteers, between the ages of 18 and 65, who have a diagnosis of epilepsy or know someone with epilepsy, as well as those without epilepsy. Involvement includes completing an online questionnaire asking about body image, mood and medical history, which takes approximately 30 minutes to complete.

Contact information
If you would like any further information concerning this project please feel free to contact either:
Dr Genevieve Rayner
Email: raynerg@unimelb.edu.au

Ms Honor Coleman
Telephone: (03) 8809 0654 (Tues & Wed)
Email: hcoleman@epilepsyfoundation.org.au
research@epilepsyfoundation.org.au
New Training Programs
We are delighted to announce that two new training programs to support people in the aged care and disability sectors will be launched shortly – so keep an eye on our Epilepsy Foundation Learning Website for when these are launched.

Epilepsy Explained for Aged Care Workers
With an ageing population, the fastest growing segment of people living with epilepsy in Australia is those aged over 60 years. Certain types of seizures can often be hard to recognise in people of any age, and it is often even harder to recognise them in older people.

Seizure symptoms may go unnoticed and be mistakenly attributed to the ‘ageing process’, when in fact the person may live with epilepsy. The new 'Epilepsy Explained for Aged Care Workers' program is aimed at training people who care for, work or live with older people. The training provides an overview of epilepsy and its impacts, the Epilepsy Management Plan, seizure first aid, and ways of providing appropriate support to an older person also living with epilepsy.

Epilepsy Explained for Disability Workers
Around 1 in 4 people with a disability (especially cognitive impairments) also live with epilepsy. This training program has been developed to support workers in the disability sector. Sometimes people who live with both a disability and epilepsy have more complex needs which need to be understood and appropriately responded to by those working with them.

This training provides advanced knowledge to support people working in the disability sector,

This training provides an overview of epilepsy and its impacts, the Epilepsy Management Plan, seizure first aid, and ways of providing appropriate support to a person who lives with a disability and epilepsy.

Current Training Programs
Did you know that the Epilepsy Foundation offers a range of training programs, both online and face-to-face, to 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 'epilepsy smart'. Our training programs include:

- An Introduction to Understanding and Managing Epilepsy
- Administration of Emergency Medication
- Understanding the Epilepsy Management Plan
- Understanding Emergency Medication
- Understanding Epilepsy for Registered Nurses

If you have any queries about our training visit https://learning.epilepsyfoundation.org.au/ or contact us:

Email: edutra@epilepsyfoundation.org.au
Phone: 1300 761 487
Seer Medical - Medicare Bulk-billed Epilepsy Diagnostics at Home

About Seer
Seer makes the diagnosis and management of epilepsy easy. Founded just two years ago in 2017, Seer has quickly become the largest epilepsy diagnostic service in Australia. Seer’s rapid growth is largely driven by their ability to make services more convenient, comfortable, accurate, and accessible.

At-home Monitoring
Seer offers a comprehensive service for at-home epilepsy diagnostic monitoring that moves services from the hospital to the home. This service is Medicare Bulk-Billed.

At best, hospital monitoring can be costly, inconvenient, and provides limited data analysis capabilities. At worst, hospital monitoring is not a possibility or feasible for many people who live in remote areas or have special needs.

To address these issues, Seer combines state-of-the-art technology and deep clinical expertise to provide a fully integrated service for 21st-century.

Features:
- Fully Medicare Bulk-Billed
- For all ages from 12 months
- Monitoring at home for up to 10 days
- Less than two-week waitlist
- Quick reporting
- Monitoring in the comfort of your home

How it works
1. Patients need to first get a referral from their doctor (GP, neurologist, cardiologist or psychologist).
2. Seer then organises the appointment to fit the monitoring system at a Seer Clinic.
3. Monitoring occurs in the comfort of the home.
4. After monitoring, Seer sends a detailed report to the referring doctor.

Locations
Seer has 16 clinics in metro and regional areas: VIC, NSW, QLD, TAS, SA, and ACT. Please check the website for locations.

About Beagle
You may have seen Beagle on TV last week. Seer has created a free health tracking app, Beagle. This allows you to report epilepsy-related events using your mobile and a small Bluetooth button. Beagle is safe, easy to use and makes it simple to share and review events with your doctor.
Download Beagle on Android or iPhone and use it today.

If you are looking to get diagnosed or a second opinion, contact Seer on 1300 869 888 and request an information pack. The information pack includes information for patients and clinicians and a printable referral form.

For more information, visit seermedical.com

Facebook, Instagram, Twitter: @SeerMedical
Feisty and fun-loving Archie was just four-years old when he had his first, severe seizure around 5.00am one morning. His Mum Alissia says, luckily, she was in his bed with him at the time so she was awakened when it happened. “It was a shock as he had been completely well, so I felt certain it wasn’t a febrile convulsion. Also, there was no history in our family of seizures.”

Alissia carried Archie outside thinking fresh air would help stop the convulsion but ultimately called an ambulance. “I thought he was dying,” she says. “As Archie's seizure went on for around seven minutes, I thought he was going to stop breathing at any moment. It was terrifying.”

Archie was taken to Geelong Hospital but Alissia was frustrated with the diagnosis. “They said he must have been at the back end of a cold, so it was a virus. They didn't believe me when I said he wasn’t fine. It was a mother's intuition; I had a gut feeling it was epilepsy. It was frustrating because they wouldn't explore the cause any further as it was a one-off seizure.”

Back at home, Archie then had another seizure approximately six months later. Again, Alissia called an ambulance and she recalls saying to her husband, Stuart, that she felt this is epilepsy. “He was sceptical but I knew, so I pushed the GP to order an EEG (electroencephalogram). A sleep-deprived EEG was done at the Royal Children’s Hospital when Archie did have a seizure.”

As a result of the EEG, a diagnosis of Benign Focal Epilepsy was made, when Archie was still just four-years-old. His seizures are always nocturnal, usually occurring in the early hours of the morning, and are similar to a tonic clonic seizure, with full-body shaking.

“While it was devastating to receive a diagnosis of epilepsy, I was also relieved as it could have been so much worse, in the scheme of things,” says Alissia.

Alissia explains that when Archie was diagnosed, the reality hit and she realised that this would be their life now. So she reached out to the Epilepsy Foundation for help. “I spoke with a Client Services Support Team Worker who recommended a special mat for Archie's bed that can detect his seizures and sound an alarm. I hardly sleep now, as I am constantly alert to whether he is having a seizure. It’s a mother’s life,” she says, “but the Foundation was really helpful.”

Archie continues to have nocturnal seizures, with his paediatrician closely monitoring and adjusting his medication in line with his growth.

Alissia says Archie can be a bit aggressive at times. “He can be very argumentative and he gets tired and frustrated easily. He may have a mood disorder, so he is seeing a behavioural psychologist at the moment.”
Archie's Story

His learning has been mildly affected too as, Alissia says, Archie has trouble with reading and handwriting, but is an average student. “However, he loves sport because it’s easy for him, particularly soccer, tennis, cricket and football. It’s an outlet for his energy and frustration.”

There is another factor that is impacting on Archie’s future prognosis. “A month after the diagnosis, Archie fell off his bike and hit his head, suffering a trauma to his skull,” Alissia says. “We know that he could potentially outgrow the Benign Focal Epilepsy, however, following the trauma to his head he may now never outgrow it or there may be another form of epilepsy waiting to show itself. So it’s a waiting game.”

However, she is happy to say that, four years on from Archie’s diagnosis, it hasn’t stopped her, Stuart, Archie and his brother Harry, 10, from doing anything. “We travel a lot overseas including the United States and Thailand and Archie is going on a school camp soon. We try to live as normal a life as possible.”

If you would like to share your story in future editions of Epilepsy Matters please contact the Epilepsy Foundation on 1300 761 487 or email epilepsy@epilepsyfoundation.org.au