



in touch with

epilepsy 
foundation

TOGETHER WE ARE MAKING A DIFFERENCE

As you are one of our very important and generous supporters, I want to take this opportunity to thank you and report back to you on the critical difference that your donations have made to the work of the Epilepsy Foundation. The year is passing quickly and I believe it is vitally important that you know how grateful we are, and to know that your support has a life-changing impact on the lives of people who live with epilepsy.

The Epilepsy Foundation is here to solve the major problems that people living with epilepsy face. We are here to stop avoidable deaths from epilepsy, ensure children get a good education, help people to get and keep jobs and ensure people feel safe and connected.

No one should go it alone with their epilepsy and your support has enabled us to make good progress.

The important principles that guide our work

We have two clearly defined principles that guide our work. These two guiding principles are to:

- Continue to develop best practice in all our programs and services; and
- Extend our reach to every person with epilepsy who needs our services.

Mediocrity in service provision is not an option for us. We are not content with supporting only some people with epilepsy and are innovatively and intelligently working to achieve the best possible practice in all areas

of epilepsy services. Our aim is to reach every person who needs information and support about epilepsy throughout Australia.

We have made significant progress with programs such as **Epilepsy Smart Schools**, **Epilepsy in Later Life** and **changing perceptions about deaths from epilepsy** and you can read more about those in this edition.

A key component of our programs is training the community about epilepsy and we provided training about epilepsy to over 6,000 people in the year ended June 2017. That means that professionals in special schools, disability organisations, kindergartens, primary schools, and families are trained in all aspects of epilepsy: what it is, how it might affect children and people in their care, how to deal with seizures, how to ensure inclusion for children with epilepsy, how to administer emergency medication. This is 6,000 more people who now understand about seizures and feel more confident in supporting the people for whom they provide care or with whom they work.

Research is also an important facet of the Foundation's work and the **Australian Epilepsy Research Register (AERR)** is a database of people with epilepsy and their carers who have agreed to participate for the purpose of social and psychological research. Through a social media campaign, an additional 187 people have joined this research project over the past year.

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GAME CHANGER

In March 2017 we launched a real “game changer” – the Epilepsy Smart Schools program and website resources Educate Me, Include Me.

Epilepsy Smart Schools employs a multi-level approach to building the capacity of school staff, families and students. This capacity building ensures students living with epilepsy can achieve their potential and is underpinned by the new Victorian Government, Department of Education and Training school *Policy for Epilepsy and Seizures*, which was developed in conjunction with the Foundation, Epilepsy Smart School online resources and training programs to educate school staff across Victoria.

- Policy: <http://www.education.vic.gov.au/school/principals/spag/health/Pages/epilepsy.aspx>
- Online Resources: <http://www.epilepsysmartschools.org.au/>

- Online training: <http://learning.epilepsyfoundation.org.au/>

Our goal is to extend the reach of this successful program across all 3,200 Victorian schools and then over the next five years, to reach all 9,000 Australian schools.

To achieve this goal we require your financial support – support that will enable us to partner with epilepsy organizations across Australia; support that will enable us to work closely with State and Territory Governments to review their epilepsy policies; support that will ensure all education policies nationally that relate to supporting students with epilepsy are consistent with researched best practice; support to help school

communities understand the impact of epilepsy on learning and what they can do to support every student achieve their potential.

The Epilepsy Smart Schools has been made possible through the support of the Victorian Department of Education and Training, the Lord Mayor’s Charitable Foundation, UCB and the generosity of our donors.



CHANGING PERCEPTIONS

We know that epilepsy deaths is a sensitive topic – no one likes to think that epilepsy can be the cause of the sudden death of a loved one.

As a community we accept other conditions like anaphylaxis or asthma or diabetes can be life-threatening, so we need to change the discussion about epilepsy and its potential for sudden death by educating people

about the risks associated with epilepsy and seizures.

Research shows that there are around 300 deaths from epilepsy across Australia each year with almost 50% of these deaths being avoidable. Minimising risks will save lives that are unnecessarily lost. During the year we have continued to raise awareness of the possibility of sudden death in

epilepsy. This includes encouraging the medical profession to talk to their patients who experience seizures.

That so much epilepsy death is preventable is a big opportunity. We will keep highlighting the problem and providing education.

Start the conversation and help raise awareness to manage the risks.

KEEP IN TOUCH WITH NEW TECHNOLOGY

We are bringing *In Touch* to life through an exciting new app “DreemAR” so we can share our epilepsy stories with you in greater depth.

It is as easy as 1-2-3 to download the app onto your phone or tablet and begin enjoying your “*In Touch* AR experience”.

Step 1: Download our Augmented Reality app “DreemAR” from the app store (works on both Android and Apple)

Step 2: Launch the app and simply hold your smart phone or tablet over any printed page denoted with a phone icon

Step 3: To watch in full screen, simply tap the video

Happy viewing.



How to use the DreemAR app

1. Download the DreemAR app from the app store
2. Scan any image marked with the phone icon
3. Watch the print come alive

TOGETHER WE ARE MAKING A DIFFERENCE

This research will assist us to provide better services and help when lobbying government for improved outcomes for Australians living with epilepsy. Wave 4 of our longitudinal study into the impact of epilepsy has been undertaken and the data report on the findings is due soon.

Tough economic times call for tough measures and the more efficiency gains we can make, the better we are able to provide services to people with epilepsy. During the year, we have built up a collaborative relationship with Parkinson's Victoria, now co-tenants with the Foundation. This collaboration works particularly well because we share reception and other resources such as volunteers and information technology services. Co-location facilitates sharing expertise across areas of mutual interest, for example support groups.

I really hope that this overview of the work, achievements and innovations of the Epilepsy Foundation over the past year shows how much your financial support has really made a difference in the lives of the people for whom we exist.

Kind regards,

Graeme Shears
Chief Executive Officer



EPILEPSY FOUNDATION RECOGNISED

Professor Mark Cook, President of the Epilepsy Foundation, was delighted to accept the Victoria Day Council's "Community and Public Service by a Victorian Organisation or Association" Award on behalf of the Foundation on 1 July this year.

With so many worthy nominations, all of whom have made significant and valuable contributions to the Victorian community, it was gratifying that the Trustees recognised the work the Foundation has done for many years to improve the lives of those living with epilepsy.

The Awards are presented as part of the celebrations for Victoria Day which, in 2017, marked the 166th anniversary of the official separation of Victoria from New South Wales and the formal proclamation as an independent State by Governor La Trobe.

HARNESSING THE SMART PHONE FOR AN EARLY WARNING

For people living with epilepsy that is not well controlled, a major anxiety is not knowing if or when the next seizure will strike.

Professor Mark Cook, President of the Epilepsy Foundation, Epileptologist and Director of the University of Melbourne Graeme Clark Institute, and his team, have developed an implantable device to monitor seizures and warn people of impending episodes.

More accurate recording of seizure activity will also help fine tune medical treatment. With sufficient funding, human trials could start next year.

Congratulations to Professor Mark Cook and his team!



The first of its kind, this device would record and decode brainwaves. It would then send a smart phone alert seizure forecast that will hopefully allow people to make treatment or lifestyle changes to manage the risk of seizures. The smart phone could also notify other people or call for assistance if people have a seizure. It is hoped this will increase people's independence.

MISUNDERSTOOD, UNDIAGNOSED AND UNDERREPORTED

Epilepsy in older people is largely misunderstood, undiagnosed and underreported through lack of understanding and awareness. An older person's 'funny little turn' may in fact be undiagnosed epilepsy.

Research shows that around five per cent of people aged 65 or over develop epilepsy in later life. The incidence of any type of seizure increases substantially for people over 60. There are many causes of this such as stroke, dementia or simply the ageing process.

This is of great concern to the Foundation because with the rapid growth in our ageing population, the challenge for the Foundation is to be able to respond to the demand that we are already beginning to see in our services.

Together with our partners the National Ageing Research Institute, Council on the Ageing, and Brotherhood of St Lawrence, we have focused our project to address this serious problem in our community. We are nearing

completion of developing a suite of resources and training both for the older person diagnosed with epilepsy and for aged care staff and carers who will be supporting the increasing numbers of people experiencing epilepsy in the later years.

Our **Epilepsy in the Later Years** resources will include a best practice guide, information sheets and booklets specifically designed for aged care workers, carers, older people with epilepsy and their family and friends.

The resources are being prepared for launch in early August 2017.



GIRLS' NIGHT OUT

Who doesn't love the chance to shop, have a glass of bubbles and help a worthy cause – all in one night?

Gather a few fellow fashionistas, arrange to host your own private fundraiser at your nearest Diana Ferrari store and shop up a storm!

Diana Ferrari will provide canapés and refreshments – and a Diana Ferrari stylist to help with those tricky “does this make my bum look big” moments – to showcase the latest clothing, shoes, jewellery and accessories for fabulous day and night fashion.

With 20% of sales going to the Epilepsy Foundation to help people living with epilepsy, all you have to do is register your interest by emailing events@epilepsyfoundation.org.au and send out the invites!

Who could resist an offer like that?



THE PURPLE TUTU STRIKES AGAIN...

When it comes to Purple Day, it can sometimes bring out the 'crazy' in us.

Joe Azoulay, an Epilepsy Foundation Board member made a rash promise to run the Sydney Harbour Bridge in a Purple Tutu if he reached his target. Joe is a man true to his word and while he didn't renege on his deal, neither did his wonderful supporters.

They raised an amazing \$42,000 – this brings the total of his past three challenges to \$115,000.

The generosity of his supporters will help in areas of research, providing

care to those in need and assisting in the roll out of wonderful initiatives such as the Epilepsy Smart Schools Programme.

A sincere thanks to everyone for supporting Purple Day this year to raise funding and awareness for the Epilepsy Foundation.

P.S. Bouquets go to Joe's wonderful wife Mandi – it may take a big man to run in a tutu but it takes a pretty special lady to love one!



TREKKING THE GREAT WALL OF CHINA

Some intrepid trekkers set out on the adventure of a lifetime, all with one goal in mind – to raise funds with every step they took along the Great Wall to help the Epilepsy Foundation provide the best quality of life for Australians living with epilepsy.

In April, six adventurers left the sunny shores of Oz to walk the Great Wall of China and explore rural Chinese villages set in the shadow of otherworldly mountains. As they navigated some of the most remote parts of the Great Wall, they saw stunning vistas and met interesting locals. Discovering the contrasts of ancient and modern

Beijing, including Tiananmen Square and the grand imperial architecture of the Forbidden City were major highlights of this quest.

Our CEO, Graeme Shears, joined other bold travellers not only to raise awareness of the impact epilepsy has on the community but, through their efforts, enable the Foundation to offer programs which make a difference to those living with epilepsy.

Graeme said, “My overall experience of The Great Wall of China Trek for Epilepsy was one of generosity. Generosity from the donors and from UCB in matching

Ian Common's fundraising; from the participants toward each other; from the Inspired Adventures leader and from our amazing Chinese Guide Jessie. An amazing and heartening experience”, and with this year's trip being such a resounding success, plans are underway for the next one to be even more exciting.



The trek in China was absolutely amazing. My friend Sam and I did it in honour of our friend Tristan, who we lost last year due to SUDEP. I loved that we got to fundraise for the Foundation and going to China was unreal. It was definitely the trip of a life time!

~ Esther Waininau

VOLUNTEER ALERT!

Do you have a few spare hours to share? Our Op Shops in Parkdale, Cranbourne, Port Melbourne and Bentleigh need some extra hands to help with our busy end of year!

We need volunteers to come along for a half day, or if possible, full day Monday to Saturday. If you would like to be part of a fun and professional retail team, please call Tracey on 0405220132.

CALLING ALL BOOK-WORMS

Our Epilepsy Op Shops need any books you no longer want cluttering up your bookshelves for their extravaganza Book Fest later this year.

Everything we raise will go towards the important work the Foundation does so be ruthless – that old Chocolate Goes with Everything cookbook? Gone! How to be a Millionaire in 30 days – toss it! Shakespeare's latest Blockbuster – we'll take it...

Just drop them off at any of our Op Shops or call the Epilepsy Foundation office for more information on 8809 0600 – then you'll have more room for more books!

Win-win!!



KICK ^A GOAL ⁴ EPILEPSY



Friday September 1st, 2017 is 'Kick a Goal for Epilepsy' day! It's a fun, new initiative where you & your colleagues dress up in your favourite footy team colours, devour a traditional footy lunch & raise funds for the Epilepsy Foundation! Support Aussies living with epilepsy.

#kg4e



For more info on how to Kick a goal for Epilepsy email events@epilepsyfoundation.org.au or phone 1300 437 453

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No one should go it alone

