WELCOME TO OUR BUMPER SPRING ISSUE OF IN TOUCH WITH EPILEPSY.

In this issue, we look at life in lockdown for people with epilepsy and their families during these unprecedented times, reveal exciting news in research and making Australia epilepsy smart, along with some heart-warming stories from those living with epilepsy. And although our public events have been cancelled due to COVID-19, we invite you and your loved ones to be part of a most special event this year. Our 2020 Walk for Epilepsy 25-Day Challenge.

2020 WALK FOR EPILEPSY - TAKE OUR 25-DAY CHALLENGE!

Like many things that have had to be done differently this year, our Annual Walk for Epilepsy in October is getting a makeover.

While we can’t hold our physical annual event, in 2020 our Walk for Epilepsy will give everyone the opportunity to walk safely and get some welcome exercise out of the house, while raising much-needed funds for people with epilepsy who are doing it especially tough at the moment.

Recognising that 1 in 25 people in Australia has epilepsy, we’re asking you to take up our Walk for Epilepsy 25-Day Challenge and take a walk every day, from 1 to 25 October. You can walk around your neighbourhood, the local park, down by the beach – wherever it’s safe for you to do so and, please, only in small numbers! Please also bear in mind social distancing and any new lockdown rules that may be in place in your area.

Most importantly, we hope you’ll ask your friends, family and neighbours to sponsor your challenge. It’s a virtual walk you can do safely, at your leisure, all while still helping people with epilepsy.

Get Ready to Walk for Epilepsy in a whole new way! 1st to 25th October 2020.

Visit www.walkforepilepsy.com.au to register or for more information.

Walk, run, cycle or swim and together let’s travel 25,000 kilometres around Australia over 25 days. Every kilometre helps raise money and awareness for people living with epilepsy.
A MOST CHALLENGING YEAR BRINGS GREATER SUPPORT AND OPPORTUNITIES.
A SPECIAL MESSAGE FROM THE CEO.

This year has been unprecedented. But it has also been a year where our caring donors, volunteers, staff and board members have shown their compassionate support for people with epilepsy. I thank each and every one of you. It is because of you we can continue to provide a range of programs and services to people with epilepsy and their families.

The terrible impact of COVID-19 on people with epilepsy

We know this pandemic is causing heightened anxiety amongst people with epilepsy, leading to potential increase in seizures. Callers to our Information Line - people with epilepsy, their family or carers - have shown concern about a number of factors during lockdown, such as difficulties with accessing medical appointments or medications, anxiety over loss or reduction in employment, and concerns about the effect COVID-19 may have on their seizures, should they contract it. You can read more about the impact this virus is having on people with epilepsy on page 9.

Findings from the international COVID-19 survey

Nearly 400 people across the globe responded to a survey (conducted by Antwerp University Hospital in Belgium) to better understand the impact COVID-19 was having on them. Here are some of the interim findings:

- 39.8% reported signs of depression and 50.4% showed signs of anxiety
- 19.6% experienced difficulties in obtaining their anti-epileptic drugs
- Follow-up consultations with the treating physician were cancelled in 47.4% of the cases
- Many reported flu-like symptoms but only 17.7% were tested for COVID; this test was positive for 25% of the tested subjects.

The very high frequency of depression, anxiety and difficulties with accessing anti-epileptic drugs was remarkable. Therefore, we recommend people with epilepsy discuss possible psychological problems and problems with accessing anti-epileptics with their physician in a timely manner, so that action can be taken.

Our staff at the frontline of support, information and care

Throughout the pandemic, our Epilepsy Support Workers have continued to provide much-needed telephone support to our clients via our Information Line. I’d like to thank them and all our wonderful staff for stepping up to the challenge that the COVID-19 has created. Everyone has willingly adapted to working from home with great commitment and diligence and are continuing to maintain services while meeting the increased demand from our clients.

Making Australia epilepsy smart

I am also delighted to announce that the Epilepsy Foundation now has a signed contract in place with the Australian Government’s Department of Health, with new funding that will enable us to take our best practice Epilepsy Smart programs to new markets around Australia over the next four years. We are looking to make sure that every person with epilepsy, no matter where they live, has access to the best possible support services in a nationally-consistent way. We will keep you updated as we progress the project, which promises to be very exciting.

Lastly, my heartfelt thanks go to every one of our donors. Thank you for digging deep and helping us continue to provide much-needed services for people living with epilepsy and their families. I thank you and wish you all the best during these difficult times.

Graeme Shears
Chief Executive Officer
YOU ARE HELPING TO KEEP PEOPLE WITH EPILEPSY CONNECTED.

The COVID-19 pandemic continues to present serious challenges to people living with epilepsy. But the support of our caring donors means people with epilepsy will be connected to the information, guidance and care they need from the Epilepsy Foundation during this challenging time. Read below to see the difference your support has made.

Throughout May and June, compassionate donors responded generously to our request to ensure people with epilepsy were able to access our epilepsy support services. Because of you, the Foundation team has been able to expand our Telehealth, phone and digital services so every person receives the support and care they need, now and over the coming months.

For first-time mums like Emma, the generosity of our donors has been life-changing.

Emma was diagnosed with epilepsy when she was just 19 years old. At the time there were few avenues for a young person to connect with others who were also living with epilepsy. “When I moved to Melbourne in 2014, social media and other online forums such as blogs, were hugely popular. So many people were openly talking about their epilepsy online. That’s when I became more comfortable in openly talking about mine,” says Emma.

As the Foundation’s Communications and Social Media Coordinator, Emma created and grew platforms where more people could openly share their personal experiences of living with epilepsy and get the support, information and care they needed.

Being connected to support, information and advice is essential, especially right now.

Emma gave birth to her beautiful baby girl in late March, as Australia was going into its first lockdown. With her family in Queensland and Emma in Melbourne, COVID-19 scuttled any plans of her family meeting their granddaughter and providing Emma with the support she needs as a first-time mum. Being connected to the Foundation’s epilepsy support services through technology has been life-changing for Emma and many others living with epilepsy.

Along with Emma, we remain committed to our mission that no person with epilepsy will ever feel alone, especially at this challenging time. Thank you for your support and for ensuring people living with epilepsy are connected.
SUDDEN DEATH A DEVASTATING SHOCK.
THIS IS SARAH GRAHAME’S STORY.

October 25, 2018, was the day that changed Sarah Grahame’s life forever and, as she says, “Broke me like I never thought could happen.”

Sarah’s brother, Joe, 40, died that day, from Sudden Unexpected Death in Epilepsy (SUDEP).

Sarah received an early morning phone call from her mother who said Joe had had a seizure and that the paramedics were working on him. Sarah says her mum’s words were, “I think he’s gone.”

A second phone call, this time from the paramedic, confirmed the family’s worst fears. Despite all their efforts they had declared that Sarah’s big brother and only sibling had died. “I still remember standing in his kitchen with Mum and Dad sitting down. We’d had police and coroners around us, then they took Joe and what was always a family of four were now a broken family of three, wondering what had just happened to our loved one,” says Sarah.

The aftermath of Joe’s death has been devastating for the family. “It took seven months for us to get notification of cause of death. Seven months of wondering what happened and how everything went so wrong.”

SUDEP is a little-known phenomenon that is still being researched; there are no known reasons why people with epilepsy die this way.

Sarah explained the shock of the unexpected. “Joe was diagnosed with epilepsy at age 13. He passed away age 40 at home while packing his lunch for work. No one deserves to die this way. Everyone is worth something and not knowing why is tough to handle.”

“Until October 25 last year I had no idea SUDEP even existed. I have lived with Joe through all the years he had epilepsy and yet I had no idea that you could die this way. How could I not know?”

Every year around 300 Australians die from epilepsy-related incidents, while fifty percent of these die from SUDEP. To support services to people with epilepsy and raise awareness of the condition, Sarah and her family participated in our Walk for Epilepsy last year.

“This is why I walked with my family. I will do everything in my power to spread the word that absolutely no one should go it alone when it comes to epilepsy.”
RESEARCHING FOR BETTER SERVICES, BREAKTHROUGHS AND CURES.

The Epilepsy Foundation has been engaging in research over the last 10 years, recognising the crucial role research plays in improving the lives of people with epilepsy. High quality research plays an important part in ensuring good clinical practice, policy development and the delivery of education and training programs.

New research into impact on patients of first seizure clinics

Patients attending Emergency Departments after a first seizure receive variable, and not always evidence-based, management. The extent to which this impacts on their health and economic outcomes has not been systematically studied.

A new research project, jointly funded by the Australian Epilepsy Research Fund and Monash University, will identify outcomes for 10,863 first seizure patients who attended four Melbourne hospitals over a 10-year period. It will specifically assess the impact of First Seizures Clinics (FSCs), a health intervention aiming to optimise first seizure care.

Headed by Professor Terence O’Brien and Young Epilepsy Section member (early career neurologist) Dr Emma Foster, this project is an exciting opportunity to improve treatment for people with epilepsy in the earliest stages of treatment.

Clinical trial seeking Lennox-Gastaut Syndrome participants

Lennox-Gastaut Syndrome (LGS) is one of the most rare and severe forms of childhood epilepsy. The syndrome usually affects children between the ages of 1 and 8 years (typically between 3 and 5 years), but occasionally has its onset in children who are older than 8 years. LGS begins in childhood but continues to manifest into adulthood and has a significant morbidity and mortality.

The Australian arm of a global study recently started recruiting participants for a clinical trial that is evaluating the efficacy of an investigational epilepsy drug in patients with LGS when taken with other standard treatments. Qualified participants must be at least 18 years of age with a confirmed diagnosis of LGS. If you are interested and would like further information regarding this trial, please contact the following participating hospitals:

Royal Melbourne Hospital (Vic)
RMHLGSinfo@gmail.com

St Vincent’s Hospital Melbourne (Vic)
LGSinfo@svha.org.au

Royal Brisbane & Women’s Hospital (Qld)
epilepsyclinicaltrials@health.qld.gov.au

The Alfred Hospital (Vic)
neurologyresearch@alfred.org.au

Article on Longitudinal Study Wave 4 findings published

We were pleased to have an article published earlier this year with findings from the Wave 4 research survey. The article “Needs for aids and equipment for the management of epilepsy in an Australian cohort” by Chris Peterson, Honor Coleman and Christine Walker investigated the bases of needs for a range of epilepsy aids and equipment and expressed concerns about the use of such devices.

You can read the full article on our website:
While Easter is normally a time for family get-togethers, holidays and too much chocolate, Good Friday 2019 was a terrifying time for the Mudge family, as 14-year-old Bridget experienced a series of seizures, including a tonic-clonic seizure, culminating in a trip to the emergency room at Melbourne’s Monash Medical Centre.
INSPIRING THROUGH ACTION.
THIS IS ADRIAN SALVATORE’S STORY.

Adrian Salvatore is a wonderful example of what can be achieved, no matter your circumstances or disabilities. Adrian, 28, was diagnosed with epilepsy at the age of 10. He also has an intellectual disability and autism. Despite all this, he has shown that he can still achieve great things while making an impact in the community.

Keen to show young people what can be achieved with determination and enthusiasm, Adrian says, “I just want to help people and show that epilepsy doesn’t have to hold you back.”

Adrian leads a very full life. He is an athlete with Special Olympics Australia (Melbourne West). He has participated in State and National Games over a number of years, competing in numerous sports including athletics, running, power walking, turbo javelin, swimming and basketball. Adrian also volunteers as an assistant dance and sports coach in after-school programs for primary school children. In February this year, he decided to take on indoor sky diving, saying, “This was one of the most thrilling things I’ve ever done and I’d do it again.”

In addition to all of his sporting achievements and activities, Adrian is also an artist, having exhibited in group shows. He has artworks in public institutions in Melbourne and private collections Australia-wide.

Last year, Adrian participated in our Walk for Epilepsy, walking 6.2 kilometres to help fundraise for our epilepsy support programs. His mum Josie says she was proud her son wanted to do the Walk. “He wants to do whatever he can to support people with epilepsy, especially younger people.”

You can show your support for people living with epilepsy by registering to participate in our Walk for Epilepsy. Visit www.walkforepilepsy.com.au for more information.
This year’s Purple Day Campaign started well, with supporters purchasing merchandise and organising fundraising events on our behalf. Unfortunately, COVID-19 had other plans and our Purple Day campaign was thrown into turmoil. But we were lucky that a few community fundraisers were able to raise some funds and help to get the word out there about epilepsy before life changed dramatically.

Fortunately, our efforts to light up prominent landmarks in purple were not hampered by the pandemic, and we were able to organise for some very prominent sites to shine purple on March 26. We had more sites coming on-board this year and hope to keep this growing in years to come.

We would like to thank the following businesses and prominent landmarks that shone a purple light for epilepsy this year. In order, pictured are:

- National Gallery of Victoria
- M4 Tunnel NSW
- Melbourne Star Observation Wheel
- Crown Melbourne
- Flinders Street Station
- Federation Square
- Bolte Bridge

We look forward to Purple Day 2021, when we hope we can again fundraise through events and other activities that will benefit everyone living with epilepsy.
THE IMPACT OF COVID-19 ON OUR COMMUNITY
AND HOW WE ARE HELPING.

People with epilepsy live with the daily possibility of a seizure occurring. Moment to moment, any small change can be a trigger to a seizure. COVID-19 has created an unprecedented challenge for people living with epilepsy. But we are here to help you and every person who has epilepsy.

People with epilepsy never know when a seizure may occur. This in turn creates a great deal of stress and anxiety, not only to the person diagnosed with epilepsy, but also to their family and friends.

While epilepsy can disrupt daily routines, COVID-19 has meant that many in our epilepsy community are alone, afraid and isolated from those they love and the support they need.

This has the potential to cause a range of complications and problems, especially with their physical, mental and emotional health and wellbeing. Issues with activities such as attending medical and healthcare appointments, going out to the shops, or even venturing out to get some exercise, can impact on people with epilepsy.

As a result of the generosity of our donors and the innovation of our staff, the Epilepsy Foundation is able to help even more individuals, families, schools, businesses and the broader community become epilepsy smart and stay safe.

We’re growing and adapting our:

1) Epilepsy Support Services so people with epilepsy receive the information and advice they need to better understand and manage their condition.

2) InfoLine (1300 761 487) staffed by our Epilepsy Support Workers for anyone who calls requiring immediate advice and support.

3) Education programs delivered to families, businesses and organisations through video conferencing tools.

4) Social media and online forums that provide a sense of community with information, advice and a listening ear especially for those struggling with their epilepsy.

We’re here for every person who needs us.

If you or someone you know is needing support right now please contact the Epilepsy Foundation Support Team on 1300 761 487. You are not alone.
OPPORTUNITIES AWAIT YOU AT OUR OP SHOPS!

We were thrilled to launch our brand-new store on Chapel Street, Windsor, in Victoria, in March this year. Unfortunately, due to the Victorian Government guidelines and restrictions associated with COVID-19, all of our stores, including Chapel Street, have had to close for the time being.

Early feedback from customers about our new Chapel Street store has been excellent. The store is a funky, fun and vibrant shop brimming with gorgeous items including fashion, accessories, books and homewares.

It is well worth a visit. Our clothing range is extensive and particularly special with many current, high quality fashion items available.

Our stores managed to remain open whenever possible throughout the past few months, while following the government’s guidelines on social distancing and restrictions. We practiced all of the necessary safety precautions to keep our staff, volunteers and customers safe including limiting the number of people in our stores at any one time and making hand sanitiser and masks available for customers.

This has been a very challenging time for our Op Shops’ staff and volunteers.

In this era of lockdowns and restrictions on anything other than the four key reasons for venturing out, we’re very fortunate to have a dedicated team of staff and volunteers who have, whenever possible, kept our stores ticking over and raising much-needed funds for people with epilepsy. We thank them whole-heartedly for their efforts under very difficult circumstances. They have all shown amazing resilience, flexibility and a cheerful willingness to do what needed to be done.

When we do reopen our stores, we know there will be new opportunities for volunteers, who are so critical to the day-to-day operations and success of our stores. If you have a few hours or one or more days per week to spare, we would love to hear from you, in anticipation of a return to trading. Please visit our website for more information on volunteering at our Op Shops.

For the latest information on when we will be able to reopen our stores, trading hours, locations, making a donation of articles for sale and volunteering in our stores, please visit: www.epilepsyfoundation.org.au/op-shops

Below: The Chapel Street store, located at 84 Chapel Street, Windsor. Telephone: (03) 9240 5299. We’re looking forward to welcoming people back to our stores soon.
BECOME A CHAMPION FOR PEOPLE WITH EPILEPSY

Every day an Australian learns that they or someone they love has epilepsy. It is crucial that they receive the right information, guidance and support so they better understand and manage their epilepsy. **In fact, every person living with epilepsy needs a Champion right by their side. And that Epilepsy Champion could be you.**

When you become an Epilepsy Champion, you’re showing your commitment to help those living with epilepsy. For as little as $1 a day, your regular gifts can provide education and training, support services, information and resources, peer support and so much more to people living with epilepsy.

You can choose the amount you wish to give monthly, quarterly or half-yearly. Your regular gift will then be debited on the 10th, 15th or 20th of the month (just let us know which date suits you best). And you can nominate to make your regular gifts by credit card, direct debit from your preferred bank account, or set up your own electronic funds transfer (EFT) on the date of your choosing.

**Become an Epilepsy Champion and receive a range of exclusive benefits including briefings on research findings and advances in epilepsy support, invitations to special events, and much more.**

For further information, please call the Donor Relations Team on 1300 437 453 or 03 8809 0655 or email donations@epilepsyfoundation.org.au

REMEMBERING THOSE WE’VE LOST

While our biennial memorial service was due to be held this year, we were unfortunately unable to hold a physical event due to COVID-19 restrictions, but were thankful for the opportunity the digital world provided in enabling us to host a virtual memorial.

This year’s memorial, held on 24 May, was welcomed in by our CEO, Graeme Shears, who was followed by Lisa Rath, one of our Support Workers, who gave a reading. We then featured the names and images of many who have died as a result of their epilepsy, along with messages of love and loss from family and friends, to the beautiful operatic voice of David Hobson.

**The memorial was livestreamed on YouTube and Facebook. We were thrilled to see over 1,500 views across the two platforms.**

We welcome your feedback on the event and are keen to hear if you would like to see this type of event again in the future, or if you would prefer to participate in a physical event again, when it is safe to do so. **Please feel free to email your comments and thoughts to memorial@epilepsyfoundation.org.au**
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

☐ Leaving a gift in my will to Epilepsy Foundation

YOUR SUPPORT CAN MAKE A DIFFERENCE!

Now, more than ever, we need your support to help people with epilepsy, their families and carers through this unprecedented difficult time and beyond.

There are several ways you can support people with epilepsy and our work:

• Visit www.epilepsyfoundation.org.au/you-can-help/ to discover the different ways you can make a difference

• Donate securely online via epilepsy.foundation or call 1300 437 453

• Consider Celebration Giving where instead of receiving presents for your birthday, anniversary or wedding, you could ask family and friends to make a donation to the Epilepsy Foundation

• Participate in our 2020 Walk – visit www.walkforepilepsy.com.au

• Fundraise online and share with your online networks

• Join our growing Epilepsy Foundation community:

  epilepsyfoundation

  epilepsy_fdn

  epilepsyfoundationaus

For further information, please visit www.epilepsyfoundation.org.au or get in touch with our friendly team by phoning 1300 437 453 or email donations@epilepsyfoundation.org.au

Epilepsy Foundation is committed to protecting your privacy. We collect your personal information so that we can contact you regarding your donations to the Foundation. Epilepsy Foundation and our fundraising staff are members of the Fundraising Institute Australia (FIA) and subscribe to FIA's Code of Professional Fundraising Practice. If you wish to change the way we contact you for future communications please tick the box below or contact Phil Nicholls on 1300 437 453 or email donations@epilepsyfoundation.org.au

☐ Please do not send me any further fundraising appeals

Post to: Epilepsy Foundation
Reply Paid 69422, SURREY HILLS VIC 3127

You can also donate online at www.epilepsyfoundation.org.au

OR by calling 1300 437 453

epilepsy foundation