Autumn Edition
February 2025

InTouch with Epilepsy

EPILEPSY FOUNDATION
60 years of service
No one with epilepsy should go it alone.
MAKE MARCH PURPLE FOR EPILEPSY

Wally Lewis Lachlan Gillespie Matt Preston Emma Foster Brett Ratten

Will you be a Purple Hero for epilepsy?

It's Make March Purple time again! March is a big month in the epilepsy calendar, and this year it will be bigger than ever.

It's when we highlight epilepsy in the community as a serious neurological condition that affects more than 270,000 Australians, with many more lives indirectly impacted. And, importantly, it's also when we fundraise for much-needed services for people with epilepsy.

In 2025, Make March Purple will shine a bright spotlight on the enduring courage of people living with and caring for those with epilepsy.

With this year's theme, 'Purple Heroes', we acknowledge the courageous spirit of people with epilepsy who deal with this challenging condition on a day-to-day basis. We salute the thousands of parents and carers, doctors, nurses, researchers and other medical and allied health professionals who support people with epilepsy. And we applaud you for your most caring and generous support for those impacted by this unpredictable condition.

Our job is to raise awareness – to bring epilepsy out of the shadows, get people talking about it and wipe out the stigma and shame that still surrounds this condition. And, importantly, to raise vital funds for our information, comprehensive support, education and training services that will enable us to continue to help people with epilepsy manage their condition better.

Become a Purple Hero and Make March Purple.

Join Dr Emma Foster, neurologist, and co-head of the First Seizure Clinic at Alfred Health, and take on a Purple Hero Challenge by incorporating something purple every day in March to show your support for people living with epilepsy.

Or channel your inner barbeque grillmaster alongside renowned food critic Matt Preston, whose brother sadly died from SUDEP, by taking on the **Purple Grill Challenge** and organising a barbecue for family and friends while raising much needed funds and awareness.

Perhaps go that one step further and accept our **Purple Muck Challenge** by dousing yourself in purple muck, with Rugby League legend Wally Lewis and champion AFL player and coach Brett Ratten, while you encourage family and friends to support you.

If you have a child, you might like to ask their school or early learning centre to follow Purple Wiggle, Lachy Gillespie's lead and host a Purple Hero Day, including hero dress ups, a costume parade, classroom lessons and activities to educate students about epilepsy.

You can also create your own fundraiser or make a donation for those living with epilepsy. For all the information you need to become a Purple Hero this March visit www.makemarchpurple.org.au or call the Fundraising Team on 1800 437 453.

A huge thank you once again to UCB for its support of our national Make March Purple campaign.

Looking back and moving forward

2024 was a milestone year for the Epilepsy Foundation – a year where we celebrated 60 years of providing information, training and support to thousands of individuals and families living with epilepsy.

A year where we recognised and acknowledged the advances in programs and service delivery, groundbreaking research, innovation and the continuing quest to find a cure, and the positioning of the Foundation as a world leader in epilepsy management and care.

A year where our wonderful community of supporters went above and beyond showing their generosity in so many different ways – participating in our annual Make March Purple and Walk for Epilepsy events, providing one-off or regular donations, making significant and philanthropic gifts, and leaving the ultimate gift in their Will, creating a lasting legacy of generosity.

It is because of the support we receive from you and every supporter that we're able to expand our programs to help even more people impacted by epilepsy.

However, 2024 was also a year where the Foundation has found itself in a position of potentially losing government funding come 30 June 2025 – funding that enables us to maintain our current programs, services and staff. On page 3 you'll read of our efforts to Save our Services and the ways you can help, including sending a message to your local member of parliament.

Outside of hospitals and other medical-based organisations, there are next to no other organisations focused on providing support, information and training for people affected by epilepsy. That means individuals, families, schools, businesses and organisations are at risk of not receiving the education, training and support they would need to help someone with epilepsy.

That's why it is so important we Save our Services to ensure we are able to continue to provide the very best care for every person living with epilepsy.

Lastly, I encourage you to get involved in Make March Purple 2025 and become a Purple Hero. March is the most significant month of the year focused on epilepsy awareness. Together, let's go purple and demonstrate our commitment to help the more than 270,000 people diagnosed with epilepsy and the unmeasured number of carers, families and friends also impacted by this unpredictable condition.

Graeme Shears
Chief Executive Officer

Will you say "I'm Here" for people living with epilepsy?

It can happen to anyone, at any age, at any time. With more than 60 different types, epilepsy is an unpredictable, life-changing condition. As it has been for Daisy and her family.

"My son was just 12 when he was diagnosed with tonic clonic epilepsy. He was a boy becoming a young man, having to deal not only with this condition but with the stigma of it.

Epilepsy not only affected him. It also had a huge impact on me. I became anxious, stressed, worried. But I was fortunate. I connected with the Epilepsy Foundation. ***They helped me so much. I had someone knowledgeable and informed to talk with.***

They understand, they care, they help, they follow up! They're the reason I chose to say 'I'm Here' and became a Monthly Giver. I want my contributions to help others struggling with epilepsy. I want them to get the support I got from the Foundation. Because together, we can make a difference and change a person's life."

Will you join Daisy and say "I'm here" for a person living with epilepsy? It takes just $1 a day to give a person the support, information and tools they need to live well with epilepsy.
Visit www.epilepsyfoundation.org.au/monthlygiving to learn more.

Our services are at risk and we need your help!

Since 1964 the Epilepsy Foundation has been providing vital services to people living with epilepsy, whether diagnosed with this condition or supporting someone with epilepsy. Over the years we have been able to grow the level of support we provide because of allocated state government funding and the generous contributions we receive from our wonderful community of supporters.

While community support has enabled us to innovate and expand our services, the Foundation relies on the Victorian State Government's recurrent funding to deliver essential services.

Unfortunately, our ability to continue to provide vital services is at risk of being diminished as there is no ongoing funding commitment from the State Government beyond 30 June 2025.

So, what's at stake for people living with epilepsy?

- Understanding diagnosis, impacts, risks and management strategies
- Understanding treatment options and impacts (medication and surgery side-effects)
- Help with developing Epilepsy Management Plans and Emergency Medication Management Plans
- Education and training in understanding and managing epilepsy and how to administer emergency medication
- Health information on a range of topics related to epilepsy and living well with the condition
- Peer support activities
- Assistance with accessing disability supports through the NDIS.

We urgently need your help to Save our Services.

We are asking you to help us lobby the State Government by sending a message to your local member of parliament. Your message, along with the messages from many concerned members in the epilepsy community, has the power to shift the Government's current position.

Please consider sending a message to your local member. To assist you, we've crafted a letter ready for you to download from our website and send. You can adjust the message in any way you wish. You may like to tell your story – about how our services have helped make a difference in your life or the life of someone you care for, and how a loss of these services would be detrimental to you and/or your family.

Your efforts will go a long way to ensuring certainty of service delivery for Victorians living with epilepsy. To download our letter please visit www.epilepsyfoundation.org.au/saveourservices, call Nicole Coulthard (03) 8809 0600 or email ncoulthard@epilepsyfoundation.org.au.

Save our Services – donate now.

As we continue to engage with the Victorian Government, you can help us right now, and make a donation to Save our Services. The wonderful and generous support we have received from the community has enabled us to grow and expand our breadth of services. Today, your donation can help ensure we continue to provide our most fundamental services so every Victorian living with epilepsy receives the tailored support they need.

Your donation will demonstrate to the Government that Victorians will never give up on supporting people living with epilepsy. It will also give us breathing space as we continue and ramp up our advocacy efforts.

Please show your support – donate now – www.epilepsyfoundation.org.au/InTouch

Farewell to four Epilepsy Foundation legends

Four long-standing employees of the Foundation have all decided that retirement beckons. We are sad to say farewell to Lisa, Helen, Marg and Larni and acknowledge the amazing contributions they have each made to our organisation and to people with epilepsy.

Lisa Rath, Epilepsy Advisor, Client Services

Our longest-standing employee, Lisa has been with our Client Services team for more than 30 years. Lisa's positive impact on the wellbeing of literally thousands of people with epilepsy and their families cannot be measured and her loss to the organisation is immense. Lisa's knowledge of epilepsy, her empathy and her ability to connect with people on a personal level had clients coming back to her again and again, sometimes years after their first contact, and she never forgot a client. Many clients have told us they could not have coped as well as they did without her support. Lisa will be missed by many.

Helen Smith, Fundraising & Bequests

Helen has had an incredible career in fundraising over many decades, including more than 10 years at the Foundation. She has steered our Fundraising Department through many changes and challenging times including maintaining fundraising revenue while navigating the effects of COVID-19 on physical events and maintaining incredible stewardship of donors. While she has tried to retire on at least two occasions in the past, we were fortunate to be able to lure her back. However, this time she assures us it's final. We fondly farewell Helen and thank her for her amazing work.

Margaret Jarvis, Epilepsy Nurse Educator/Trainer, Education and Training

After an incredible eight years of dedicated service, Margaret decided that 2024 would be her final year with us. Throughout her tenure, Margaret has been a cornerstone of the Education and Training team, leaving a profound and lasting impact on both the Foundation and the epilepsy community. Her extensive knowledge, compassion, generosity, and sense of humour have been invaluable, and the countless lives she has touched through her work cannot be overstated.

Larni Severn, Epilepsy Nurse Educator/Trainer, Education and Training

Larni has dedicated over five years to the Foundation, offering holistic and compassionate care to everyone she encountered. Her tenure, which concluded earlier in 2024, was marked by her invaluable expertise and experience, benefiting all staff members. Larni's unwavering commitment to exceeding the needs of her clients and their families is truly remarkable. Her departure leaves a significant void in the Education and Training team and the entire organisation.

We wish Lisa, Helen, Marg and Larni a happy and well-earned retirement.

New video empowers doctors to discuss SUDEP with patients

We are pleased to launch our new video, “SUDEP: A Conversation Worth Having”, which aims to encourage general practitioners, neurologists and epileptologists to inform patients who have epilepsy about the possibility of Sudden Unexpected Death in Epilepsy (SUDEP) and discuss risk factors and strategies to minimise the risks.

Graeme Shears, CEO of the Epilepsy Foundation, says, “Clients who’ve lost a loved one to SUDEP have told us they wish they had known death from epilepsy was a possibility. Had they known, they would have taken different steps or been better prepared. This video is about encouraging clinicians to have the conversation with their patients, to ensure they are informed as to their individual risk factors and are equipped to manage those risks.”

SUDEP often occurs during sleep, with no clear cause. Approximately 1 in 1,000 people living with epilepsy in Australia die each year from epilepsy, around 300 of those being from SUDEP. Those who are among the 30 percent of patients who have drug-resistant epilepsy are at an increased risk.

Managing personal risk factors, substance disorders and alcohol withdrawal, and taking medication as prescribed, can reduce risk along with the use of monitoring devices.

This topic is close to our hearts since one of our own Epilepsy Advisers, Rheana Nation, sadly lost her son, Sam, 23, to SUDEP in January 2024. Rheana said, “From a mother’s perspective, I think doctors and specialists have a responsibility to talk about SUDEP in those cases where they think it’s a possibility.

“You can’t act on something if you don’t know about. There’s the devastation of the person passing away due to SUDEP – you can’t take away that grief – but if you knew all the things you’d done to lower the risk, if you have the information, and the person with epilepsy had the information, then it reduces a lot of the ‘what-ifs’ you tend to go through.”

We’re grateful for the support of clinicians and researchers at Alfred Health and Monash University who helped make this video a reality and give special thanks to the Massey Charitable Foundation for their donation, which made it possible.

You can view the video on our YouTube channel - https://www.youtube.com/watch?v=4LPOvOLaMZ0

Above: Sam Nation, 23, tragically died from SUDEP in January 2024.

RALLOU
MASSEY CHARITABLE TRUST

Coordinating change for the better

The Australian Epilepsy Consortium is a collaborative group of members across community agencies, patient advocacy and the Epilepsy Society of Australia, which was established to address the World Health Organization’s Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders (2022–2031) (IGAP). The group is working together to identify ways to best coordinate and implement the IGAP recommendations within the Australian health and medical sector.

Members met in Hobart on 5 November to discuss the priorities identified in the IGAP that will improve access to treatment, elevate the quality of life for those with neurological disorders, and promote brain health across all ages. By identifying shared priorities and taking a coordinated approach, the consortium will make meaningful strides towards a future where all people affected by epilepsy and other neurological disorders have the support they deserve.

A marathon, not a sprint. Thank you for Walking for Epilepsy.

The amazing results and feedback from our Walk for Epilepsy last October showed that you're all in it for the long haul. Together, you collectively donned your comfy shoes, headphones and sunscreen and showed incredible staying power by walking a whopping 116,288 kilometres, raising more than $500,000 nationally in support of people living with epilepsy.

We're so grateful to you all – our ambassadors, event champions and the everyday heroes who got behind our Walk for Epilepsy. **We know our ongoing drive to support people with epilepsy so they can live their best possible lives, is a marathon, not a sprint.**

You took on the challenge and walked the equivalent of 2,768 marathons. It was an enormous physical and emotional effort on everyone's part. We were so heartened to see many families and individuals participating, raising awareness and funds for their loved ones with epilepsy.

We give special thanks to Heath Hocking, whose son Roman has epilepsy, and who showed incredible commitment, passion and resilience when he took it upon himself to walk 250 kms on a treadmill to fundraise. Thanks to the generosity of Fitness First Richmond, Heath started his treadmill quest early on the morning of 1 October, along with others who were there on the day to participate in our Treadmill Challenge. Then, as participants departed, Heath soldiered on for the rest of the day, through the night and well into the next day.

By the time he finished around 3pm, Heath completed an incredible 200 kms, with nothing left in the tank, but happy with his efforts and humbly accepting the warm congratulations from family, friends and Epilepsy Foundation staff. His achievement was nothing short of staggering and we can't thank him enough for participating and giving it his all – physically, mentally and emotionally.

Heath said, "Epilepsy will always be a part of our lives and there are many people out there who are not as fortunate as Roman. Your support means everything to me and people living with epilepsy."

Overwhelming community spirit in our annual Treadmill Challenge

Part of the Walk's events included our second annual Treadmill Challenge, hosted by Fitness First Richmond. This year's event grew in participation, with 13 teams and more than 65 people taking on the personal challenge of running or walking 5 kms each, to get each team to 25 kms. The community spirit was overwhelming, and it was a fun, uplifting and enjoyable event that raised more than $26,000 towards epilepsy services. The Challenge was won by UBS.

A big thank you to all the teams that participated, including:

Fitness First
UBS
Bared Footwear
SEN
Walk for Ratts
UCB
Shop for Shops
Pitcher Partners
Meetra's Marchers
Walk for Balmey
Melbourne Body Corporate Management
Epilepsy Foundation clients & staff

The event was also held for the first time at Fitness First Bond St, Sydney. We thank everyone at the club for getting the inaugural event off the ground, as well as the teams that participated, including:

Fitness First
Australia Post
Bupa
Nexon Asia Pacific
SEN
Intuitive Insurance

Thanks to Nexon Asia Pacific and UCB for their national support of Walk for Epilepsy 2024. A big thanks also to Neil Balme and Brett Ratten, our Ambassadors for the Walk, for their participation and support.

nexon

ucb

Walk for Epilepsy 2024

Educating children and teachers to be epilepsy aware

Knowledge and understanding of epilepsy and the many ways it affects people with this unpredictable and sometimes debilitating condition, can help make a huge difference in someone's life. Our mission is to ensure individuals, families, school communities, businesses and organisations are educated and trained to recognise the signs of seizures, and to confidently assist a person during a seizure, and to provide safe, inclusive environments in which people with epilepsy can thrive.

Epilepsy affects 1 in 200 students, creating a greater likelihood that every teacher will have a child who has epilepsy in their classroom at some stage in their career. With this in mind, it's vital that schools are educated and trained to know what to do when one of their students has epilepsy.

For Jenni and her partner Adam, it's an absolute must; their sons – Cooper and Ryder – attend schools that are Epilepsy Smart.

"Cooper's seizures started when he was at Kinder. They were fantastic. They contacted the Epilepsy Foundation and got midazolam training. That's Ryder's Kinder now and they did the training again well before he started attending, to be ready for him.

I did a tour of Cooper's school where I spoke to them about his epilepsy. They were totally fine and already had staff with epilepsy awareness training. But credit to them, they contacted the Foundation to get midazolam training as well.

Having education and training is vital to keeping my sons safe should they have a seizure at school. The one hiccup we had was when Ryder's seizures first started – he was in occasional care and they asked that we not send him again until they could get midazolam training. I think they were just a little bit nervous about having him there. I asked them to call the Foundation and once they understood their responsibilities of a child with epilepsy, they said Ryder could go back.

The Epilepsy Foundation went through every single detail of both Cooper's and Ryder's epilepsy with the schools. Their Epilepsy Management Plans were so personalised that I was more than happy and confident to give the plans to the boys' schools.

And to be able to give the Foundation's phone number to the schools - to say to them if you need information call them, don't just take it from me, speak to the professionals and get the advice you need so you can confidently decide what you need to do to best support my boys and their learning."

Every school in Australia has a duty of care to provide a safe learning environment for all its students and to ensure they accommodate their individual needs. Our Epilepsy Smart Schools program has been designed to help schools provide a safe, inclusive education experience for all students with epilepsy.

If you would like to learn more about our Epilepsy Smart Schools program or how you can access our Education and Training programs, please visit www.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 is enclosed payable to Epilepsy Foundation

☐ Visa ☐ MasterCard ☐ Amex

Card Number ______ / ______ / ______ / ______

Name on card ______________________________

Expiry date ______ / ______ CVV ________

Signature ______________________________

Please return in the prepaid envelope provided.
Donations $2 and over are tax deductible.

Visit epilepsyfoundation.org.au/intouch or use our unique QR code to DONATE online.

I would like to find out more about:

☐ Becoming a monthly supporter
☐ Leaving a Gift in my Will to Epilepsy Foundation

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Post to: Epilepsy Foundation
Reply Paid 69422, SURREY HILLS VIC 3127
You can also donate online at epilepsyfoundation.org.au
OR by calling 1800 437 453

☐ *Please do not send me any further fundraising appeals*

Carers get together

Recently, the Epilepsy Foundation hosted a carer education session aimed at providing carers with a greater understanding of epilepsy and the services and supports available to assist them in their role as a carer. A group of parents and carers, gathered to hear our Epilepsy Nurse Educator talk about seizures, seizure first aid and epilepsy treatment.

One of our Epilepsy Advisors acknowledged the difficulties that can arise for full time carers such as loneliness, isolation and fatigue. Tips and strategies to maintain one's own mental health and physical wellbeing were shared and discussed by the group.

The event was sponsored by Carer Gateway, an organisation dedicated to supporting carers across Australia, with a presentation by Amanda Southwell, Partnership Lead, who spoke about the supports and services available through Carer Gateway, including emergency and planned respite care, counselling, tailored support packages and information and advice.

The event was very well received by those who attended, and we will be holding more of these events in the near future to meet demand. Follow us on our socials where we will post upcoming dates.

Carer Gateway
An Australian Government Initiative