Spring Edition
September 2025

InTouch with Epilepsy

Let's Walk and Talk for Epilepsy. 1 to 25 October 2025!

Join thousands of passionate Australians to walk and talk for epilepsy.

Visit walkforepilepsy.org.au to register or donate. Together, every step makes a difference.

Thank You and Farewell

In September this year, we will say farewell to our long-standing CEO, Graeme Shears, who will retire after more than 17 years at the helm of the Epilepsy Foundation.

Throughout his time at the Foundation, Graeme has worked tirelessly for people with epilepsy and their families and has shown an enduring passion for improving healthcare outcomes for them.

> *"I have always had a passion for ensuring services have the capacity to enhance the quality of life of people living with epilepsy, whether it be through information, education, advocacy, support services or research. It's about their needs, and ensuring our support is person-centered and tailored to individual circumstances.*
>
> *"From a personal perspective, I have taken great satisfaction from forging and strengthening relationships, partnerships, alliances and collaborations that will support the purpose of the Foundation and enhance its outcomes into the future."*

While in the CEO role, Graeme held numerous external positions including President, Vice President and Treasurer of Epilepsy Australia, Treasurer of the International Bureau of Epilepsy (IBE), and member of the Joint Executive Committee of the IBE and International League Against Epilepsy (ILAE).

He was the driving force behind the successful achievement of the Australian Government grant to develop Epilepsy Smart Australia, a four-year program of service delivery and information enhancement managed in collaboration with other state epilepsy service providers.

Additionally, Graeme has co-authored numerous studies on epilepsy, including:

- Reported services needs at diagnosis of epilepsy and implications for Quality of Life
- Antiepileptic Drugs, Polypharmacy, and Quality of Life in People Living with Epilepsy Managed in General Practice
- Telemedicine in epilepsy, how can we improve care, teaching and awareness
- The social context of anxiety and depression: Exploring the role of anxiety and depression in the lives of Australian adults with epilepsy

Thank You and Farewell continued

- Management of Post-traumatic Epilepsy (PTE): An evidence review over the last 5 years and future directions
- A Fair Go for People Living with Epilepsy in Australia.

Graeme will continue to hold his international positions with the ILAE and IBE for another four years. He is also looking forward to having the time to indulge in his passion for sailing, bushwalking, and exploring Australia.

> *"I've been privileged to have been at the forefront of epilepsy services for almost two decades and to work with such a dedicated team of employees, volunteers, donors, corporate supporters and board members. I welcome Nicole Coulthard as the new CEO of the Epilepsy Foundation. Working closely with Nicole over the last six years, I have been impressed by her quiet determination, fierce advocacy, leadership skills, vision and enthusiasm to achieve the very best for people living with epilepsy.*
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> *I thank the Board for their trust in me. The staff for being with me on this journey. For the clients who reach out to the Foundation. And our supporters for their belief in our work. I leave the Foundation knowing it is in good hands focused on people living with epilepsy."*

Thank you, Graeme, for your service, compassion and care for people living with epilepsy. We all wish you the very best as you embark on a new chapter.

Introducing our new CEO – Nicole Coulthard

As we bid farewell to Graeme, we look forward to a new chapter for the Epilepsy Foundation, welcoming Nicole Coulthard to the role of CEO. Continuing the legacy set by Graeme and CEOs before, Nicole is the second female CEO in the history of the Foundation, following in the noble footsteps of founder, Mary Davis.

> *"I started my career as a physiotherapist working with young children with disabilities, including Cerebral Palsy, Down's Syndrome and other developmental delays. With a 1 in 4 chance someone with a disability also has a diagnosis of epilepsy, I came across epilepsy frequently.*
>
> *At the time I didn't understand epilepsy or its impacts enough, as my role focused on the achievement of physical milestones for the child such as sitting, crawling and walking. If I knew then what I do now, I would have better understood the impact of seizures on all aspects of a child's development.*
>
> *Training as a physiotherapist gave me a structured way of thinking - looking carefully at what was in front of me, while also considering all the background factors that might be influencing the situation.*
>
> *Over time, I built on those foundations and developed new skills in project management, innovative service design and leadership. So, when I joined the Epilepsy Foundation in 2019, this mix of experiences had set me up well to step into managing the **Epilepsy Smart Australia** program and now into the role of CEO.*
>
> *I am honoured to be leading a team who never waver from our core mission; **to improve the lives of people living with epilepsy.** I've always been impressed with how this commitment shines through in every decision made by each person and across the entire organisation.*
>
> *As CEO, I want to provide a service that is here when people need us, but also one which builds their capacity to feel more confident and better-equipped to manage their day-to-day lives. That means focusing on practical ways to strengthen people's understanding of epilepsy, supporting them to manage it effectively, and giving them the tools to advocate for themselves in schools, workplaces, and the community.*
>
> *I want to see a community that speaks openly about the challenges of epilepsy so that stigma is reduced. I want our teachers and employers to understand the impacts and be committed to ensuring people with epilepsy of all ages have fair access to education and employment.*
>
> ***Most importantly, I want every person with epilepsy and their families to know they are not alone;** there are supports and services available to help them. I want to build their confidence that you can live well with epilepsy, and that this diagnosis doesn't need to define them."*

A brain tumour. A diagnosis of epilepsy. They haven’t stopped Bianca from chasing her dreams.

Bianca was just 8 years old when in late January 2007, during school holidays, she had what she calls "a big seizure". Bianca was diagnosed with a tumour on her brain. As her parents worried over the upcoming surgery to remove the tumour, little did they realise their lives would forever change. This is Bianca’s story of living with epilepsy.

“Mum had come to wake me up. I have no memory of how this happened, but I woke up downstairs on the floor surrounded by paramedics. I remember feeling like I’d been hit over the head – a pounding headache, nausea, confusion. That moment is so vivid in my mind.

Looking back, there were signs. I would go to sick bay almost every day at lunchtime with headaches in my left frontal lobe area. One day I felt really unwell, with a bad headache and nausea, so I went home early. My mum, who’s a nurse, noticed I was slumping to one side, and when I laid on the couch, my eyes rolled back. **She wasn’t even sure I was breathing.**

We went to the GP, but they didn’t have answers. After my seizure, a CT scan revealed I had a brain tumour. I was officially diagnosed with epilepsy in October 2008, about 20 months after my tumour was removed, likely originating from residual tumour tissue or scar tissue.

My seizures included focal aware, focal impaired awareness, and tonic-clonic. The diagnosis was heartbreaking. My parents thought the brain tumour was behind us, that once it was removed, everything would be okay. They weren’t prepared for epilepsy - no one explained that seizures could continue or even begin after surgery. It was very difficult for them to accept.

Epilepsy has, at times, left me feeling hopeless, especially as I’ve always done my best to look after my health: eating well, exercising, sleeping properly. Yet seizures still happen. When I finished school, I dreamt of studying medicine or working with people with epilepsy, but often it feels like I’m the one who needs doctors and nurses.

What’s helped me is focusing on what I can do. Sport has always been my outlet. I’ve competed in weightlifting at a national level, and when I was younger I represented Australia in discus at the Youth Commonwealth Games and World U20 Championships.

Even when epilepsy limited me in some areas, sport gave me confidence and purpose. I first came across the Epilepsy Foundation through an online search, which led me to information about the Walk for Epilepsy. I wanted to find a platform that would allow me to share my journey and hopefully make a difference.

The Foundation has given me the opportunity to share my story and help educate others. That has been incredibly empowering, not only for me but also, I hope, for newly diagnosed individuals and their families. Knowing you can still pursue your goals, even with epilepsy, makes a world of difference. And today, the Foundation continues to support me through connection, advocacy, and opportunities to raise awareness.

Life with epilepsy can be hard and unpredictable, but it doesn’t mean life stops. You can still find quality of life, even if the journey looks different than you expected. So, live your life, chase your dreams. It might not be the path you planned, but it is your path - your journey.”

Epilepsy training vital in early childhood settings

An understanding of epilepsy – what it is, what it can look like and what to do if a child has a seizure – is essential for ensuring a safe environment for children with epilepsy or seizure disorders in early childhood settings.

Currently in Australia, approximately 1 in 200 children has epilepsy with one of the largest cohorts being children under the age of 5. It's likely every early learning centre will have a child with epilepsy in its care at some stage.

Epilepsy Foundation education and training programs aim to empower teachers and co-educators with the knowledge and skills to be able to confidently and competently manage a child's seizure.

Nicole Coulthard, incoming CEO and current General Manager Services & Projects at the Foundation, says knowledge and preparation are critical. "Understanding how to recognise a seizure, knowing each individual child's epilepsy management plan and how to administer emergency medication, if required, is critical."

For Lipscombe Park Kindergarten in Croydon, Melbourne, training has made a significant difference in the confidence levels of staff in managing Jack's epilepsy. Laura Kennedy, Education Support Officer says, *"When the application for Jack came in, we were required to have a medical management plan in place. His mother was very concerned about her child going to kindergarten and being in the care of others, as he is in a wheelchair and non-verbal. She wasn't aware of the Epilepsy Foundation, but we were able to put her in touch and they helped with getting the plan in place that we needed."*

In early 2025, the centre trained all 10 staff in understanding and managing epilepsy, as well as the theory and practice of administering emergency medication, specific to Jack's needs.

Laura says the benefits of training mean staff now feel capable to handle a seizure if it happens. *"We all know where the plan is kept, where the medication is stored and how to use it. To have the knowledge of what to do keeps the staff calm, directed and competent in taking the right steps. It has given them the confidence and reassurance they're going to be okay and they would know what to do if Jack has a seizure. It has also given his mother confidence her child will be safe."*

Nikki Woods, Jack's mother, says, *"I was extremely nervous in my son starting kindergarten with epilepsy. Knowing the staff are fully trained and comfortable with the plan put my mind at ease."*

Laura added, *"It has helped to reduce some of that stigma and fear about what epilepsy might bring into the centre, which has been great for staff wellbeing."*

A small investment in training is a worthwhile one to help ensure children have the best possible start in their education and development into the future. If you would like to learn more about our self-directed eLearning courses or trainer-led sessions, please contact the Epilepsy Foundation. Call 03 8809 0695 or email training@epilepsyfoundation.org.au

Need help? Call National Epilepsy Support Service!

For all your epilepsy support needs including advice, information and referrals, contact our National Epilepsy Support Service.

Phone: 1300 761 487
Email: support@epilepsysmart.org.au Available Monday to Friday, 9.00am – 5.00pm (AEST)

Lighting the nation PURPLE for epilepsy

This year's Make March Purple campaign lit up the nation – quite literally – with buildings, communities, and people turning purple to raise awareness and funds for epilepsy. With the uplifting theme 'Purple Heroes,' we celebrated the courage and resilience of people living with epilepsy, as well as the everyday champions and public figures who are helping change the conversation around epilepsy.

Thanks to your passion and purple pride, we raised more than $257,000 nationally – directly supporting vital services, programs and research for people living with epilepsy.

This year, we were honoured to stand alongside some incredible ambassadors who used their voices and platforms to raise awareness and inspire action:

- Brett Ratten – AFL legend and devoted dad to a child living with epilepsy.
- Dr Emma Foster – Renowned neurologist and researcher working to shape the future of epilepsy treatment.
- Wally Lewis – NRL icon who has bravely shared his own epilepsy journey and championed awareness.
- Matt Preston – Food journalist and beloved TV personality honouring his brother, who passed away from SUDEP (Sudden Unexpected Death in Epilepsy).
- Lachy Gillespie – The Purple Wiggle, who brought fun and heart to the campaign, raising awareness through his family's own connection to epilepsy.

Australians didn't just wear purple – they became purple heroes in creative, bold and sometimes very messy ways, including the Purple Hero Challenge where participants committed to changing their appearance every day in March to include something purple; Purple Grill Challenge where backyard BBQs went purple to raise funds and connect communities; Purple Muck Challenge with brave fundraisers doused in purple muck; and Purple Schools Challenge with schools across the country hosting Purple Hero Days, dressing up, holding fundraisers and learning about epilepsy.

Each of these activities brought people together in fun, meaningful ways, helping to reduce stigma and increase understanding. From the bottom of our hearts – thank you. Whether you fundraised, participated in a challenge, hosted a purple event or simply spread the word, you've helped improve the lives of people living with epilepsy. **Let's carry that purple energy into October for Walk for Epilepsy 2025 – because a hero's work is never done!**

Let's Walk and Talk for Epilepsy in 2025!

Walk for Epilepsy returns this October with a powerful message and an all-star ambassador lineup.

This October, join thousands of passionate Australians as we step out in support of the 1 in 25 Australians diagnosed with epilepsy. Walk for Epilepsy is back – and this year, we're making every step count with the inspiring theme 'Walk and Talk'.

Our goal is ambitious but achievable: together, we're aiming to raise $500,000 nationally to fund vital services, research and education for people living with epilepsy and their families.

More than just a walk, this is a movement to break the silence around epilepsy. Whether you're travelling solo, walking with friends, or forming a team, each step is a chance to spark conversation, share stories and create change.

We're proud to walk alongside an incredible group of Walk for Epilepsy 2025 ambassadors, representing the diverse experiences of the epilepsy community:

- **Neil Balme** – AFL legend who has lives with epilepsy. Neil's openness has inspired others to speak up and seek support.
- **Dr. Emma Foster** – Neurologist and researcher dedicated to advancing treatment, understanding and outcomes for people with epilepsy.
- **Adrian Salvatore** – Epilepsy Foundation client, Special Olympics athlete and all-round inspiration. Adrian lives with epilepsy and an intellectual disability and reminds us that ability, determination and spirit are stronger than any diagnosis.

Whether you walk one kilometre or one hundred, Walk for Epilepsy is for everyone. You set the pace, the path and the purpose.

Let's start important conversations. Let's raise awareness and funds. Let's walk together. Register or donate today at walkforepilepsy.org.au.

Because together, every step makes a difference.

New classifications for epileptic seizures

The International League Against Epilepsy (ILAE) has updated classifications to recognise some seizure types as focal or generalised onset, allow classification when the onset is unobserved, include some missing seizure types, and adopt more transparent names. There are now 4 main seizure classes - Focal, Generalised, Unknown (whether focal or generalised) and Unclassified, and 21 seizure types. Six key changes were made:

1. 'Onset' is removed from the names of the four main seizure classes.
2. Distinction made between classifiers and descriptors. Classifiers reflect biological classes and directly impact clinical management. Descriptors characterise specific features in a seizure type.
3. "Consciousness" replaces "awareness", defined by both awareness and responsiveness.
4. The motor vs non-motor dichotomy is replaced by observable vs non-observable manifestations.
5. Seizures are described by the chronological sequence of signs and symptoms, than solely on the first sign.
6. Epileptic negative myoclonus is recognized as a seizure type.

For more information visit www.ilae.org/updated-classification-epileptic-seizures-2025. If you have questions about your own or a loved one's epilepsy classification/s, call us on 1300 761 487 or email support@epilepsysmart.org.au

Inspired to run for people living with epilepsy

Early this year, 6-year-old Zac was diagnosed with epilepsy, after experiencing two Tonic Clonic seizures in his sleep.

Josh, Zac's dad, shared, *"It was and is a life changing diagnosis for all of us, but obviously more so for Zac. He has taken this diagnosis head on with all the tests, medication and changes as a superstar and he continues to be brave with all the challenges it has brought. With the fantastic support of his medical team, our family and friends, we have turned this diagnosis into a positive one and thought a fundraising opportunity would be fantastic."*

Zac's diagnosis inspired him to make a difference for others. He set a goal to raise awareness and funds for other children and adults also living with epilepsy. Zac spent months training with his dad to be ready for this year's Run Melbourne.

"Zac ran the 2-kilometre kids' dash. He was super excited, with the biggest smile on his face. Every donation that came in he knew it would help others who are also living with epilepsy. Our family and friends were incredibly generous and raised a lot more than we ever expected. I think that is reflective of Zac and the support people want to show to him."

Thank you, Zac, for running for people living with epilepsy. You are a true inspiration!

Make a lasting legacy for people living with epilepsy. Leave a gift in your Will.

Living with epilepsy is unpredictable and challenging. A gift in your Will can help ensure we continue to provide vital programs and services – support, information, tools, education and training, care - that meet today's needs. Your gift will also enable the Foundation to create innovative programs that can address the difficulties and challenges people will face tomorrow.

Writing a Will is one of the most important documents you will ever create. If you have ever considered writing a Will, this can be the time to do so.

Epilepsy Foundation is partnering with two organisations where you can write your legal Will for free, securely online (some conditions may apply). Once you've outlined your wishes and provisions for family and friends, please consider leaving a gift to the Epilepsy Foundation. Your gift is an investment in:

Ground-breaking research leading to a potential cure
Innovative support, information and resources for people with epilepsy
Evolving new treatments aimed at providing greater care for them

More so, a gift in your Will is your legacy of changing lives in the future.

Once you have decided to leave a gift in your Will to the Epilepsy Foundation, you can consider the type of gift you would like to make. This may be, a share of your estate (a residuary gift), a fixed sum of money (a pecuniary gift), or a specific gift such as property, shares, insurance, art or even a piece of jewellery, which can then be sold to support our work.

If you would like to learn more about leaving a gift in your Will to the Epilepsy Foundation you can visit https://epilepsyfoundation.org.au/bequest or call Phil Nicholls on 03 8809 0648.

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

EPILEPSY FOUNDATION

EFINT925

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

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 subscribe to the Fundraising Institute Australia'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 1800 437 453 or email: donations@epilepsyfoundation.org.au

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

Sustainable shopping for a cause

If you live or work in the Kilsyth area, there's a new way to shop sustainably and grab a bargain, all while supporting our cause. Our new Kilsyth Op Shop is open and already proving to be a treasure trove of new and pre-loved affordably priced items.

The Op Shop also offers a convenient pick-up service across Melbourne, Mornington Peninsula and Gippsland, for those wanting to donate their pre-loved items.

Our Op Shop stores are a vital part of our fundraising and awareness-raising efforts and have become vibrant community hubs where people meet, connect and share their love of thrifting while supporting people living with epilepsy.

Drop in your donations of quality items or call Darren for a pick-up on 0425 799 415. And if you're interested in volunteering, visit epilepsyfoundation.org.au/op-shops/volunteer-with-us.

Our new Kilsyth store is located at 243 Colchester Road, Kilsyth South. Open Monday to Saturday, 9.30am – 5.00pm; Sunday, 10:00am – 4:00pm.