



# Taking Action

Optimal outcomes for those living with epilepsy

## Finding her voice

**Erin Malone's epilepsy made her feel isolated at school, but with the help of Epilepsy Action Australia, the 18-year-old has learned to speak up for herself – and she's keen to show other teens they're not alone.**

The first time Erin Malone had a seizure at school was "embarrassing and hurtful".

"I could feel a seizure coming on, but I didn't know how to tell people. Then I dropped to the ground and had the seizure. All the kids and staff were standing around. There were a couple of kids that actually had videos of it, and they posted online. That really brought my confidence down."

Erin had her first seizure when she was 13. She was in year 7, that awkward year when children transition from being the big kids at primary school to the youngest and smallest in high school. It was a lot to deal with. So, she kept quiet about it.

"When I first got it, I felt like I was the only person who had it," she remembers. "I worried if I told other people, they would treat me differently. I was getting bullied at the time as well, so I just didn't want to make it worse."

Finding Epilepsy Action Australia online as a teenager came at the right time for Erin, who had been struggling with her mental health. She was invited to attend two youth conferences this year, and given

the chance to do something she'd shied away from before – speak publicly about her life with epilepsy.

"There were a few tears (from the audience) which is normal but also a lot of congratulating," she says. "It's a very supportive environment which is what I love about it."

She believes the conferences have made a big difference to her confidence. "It makes you feel like you're not alone. It's a heartwarming feeling."

She believes schools need to be much better prepared for children with epilepsy, not just for their physical safety, "but for their mental safety as well". Erin is now setting herself on a path to be there for people with epilepsy herself, starting TAFE this year to become a Registered Nurse.

"I eventually want to get into nursing people with epilepsy, so I can understand myself more and help other people."

**Above all, Erin's proud of her newfound self-assurance. "I'm really grateful for Epilepsy Action Australia, it's made me feel so much more positive."**



# CEO MESSAGE



Welcome 2024!

Another new year is upon us and this year

I am embracing new beginnings and taking on new challenges with passion and enthusiasm alongside the Epilepsy Action Australia team. I always think that it's nice to reflect on the year that has been, the stepping stones to this moment and where we are right now, but I love the thought of celebrating the "what's next". Sometimes those moments can be scary but sometimes they are also exhilarating!

Starting school is a big milestone for any child, but when you are starting school with epilepsy – it's a whole new world to navigate and challenges to face. Just like it is for those finishing school and starting work, furthering study or even starting a new job. Epilepsy Action Australia is there to support people with epilepsy as they face these exciting and daunting times! Our specialist nurses are at the end of the phone or email to provide the support and encouragement to face those challenges thanks to the generosity of our donors. You can read more about the work we are doing in this newsletter.

As always at the beginning of the year we start turning our world purple! International Purple Day is on March 26th and we hope that everyone will celebrate by making the entire month of March purple. There are many ways to get involved, see the back of this newsletter or visit our website to support this initiative.

Epilepsy Action Australia is also celebrating some new additions to our Board of Directors, we have five new Directors that joined our Board late last year, all with different skills to support our cause. We have shared a story about how two new Directors, David and Erin Oudshoorn have helped raise awareness for epilepsy and our cause in the corporate sector through a recent company event. You can also read about all our new Director appointments here: <https://bit.ly/3vDvjJs>

I hope you enjoy reading this newsletter and that 2024 brings you happiness, opportunities and unforgettable moments. Please accept my sincere gratitude for continuing to make a difference in the lives of people living with epilepsy.

**Carol Ireland**  
CEO & Managing Director

## How to transform a corporate event into a night with real impact

In a remarkable show of community support, MaxCap's 2023 Dealers & Developers Conference went beyond the typical corporate event, transforming into a unforgettable evening of generosity.

David Oudshoorn, MaxCap's NSW business leader and our ambassador, encouraged his organisation to consider incorporating a charitable component to the event. As one of our ambassadors and a recently appointed Board Member he nominated Epilepsy Action Australia as the event's beneficiary, marking their inaugural inclusion of a fundraising component.

David's wife, Erin, joined him for the evening and bravely shared their family's moving story of their daughter Luella's battle with severe epilepsy. Erin's heartfelt speech captivated the audience of 200 property industry professionals, leading to an outpouring of donations.

"Erin and I were so touched and humbled by the support we received from my peers," shared David.

The conference provided a platform for Erin and David to raise awareness about epilepsy and its real-life impact. Attendees were deeply moved, describing the event as the most heartwarming they had ever experienced.

"I would really encourage any organisation to consider incorporating a charitable element to their corporate events. EAA made the process easy by providing a QR Code that we placed on tables encouraging attendees to donate without any pressure."

Knowing our event will have a lasting impact, leaving a legacy we can be proud of, is priceless."

MaxCap's dedication to community engagement serves as a great example other organisations can easily follow to create an event with impact that can also support corporate social responsibility commitments.

**As organisations plan their annual events, we hope MaxCap's story inspires you to consider incorporating a charitable element to your next workplace event. Epilepsy Action Australia are available to support your efforts, offering volunteer speakers and other assistance. Contact [epilepsy@epilepsy.org.au](mailto:epilepsy@epilepsy.org.au) to discuss how your event can make a lasting impact by helping people affected by epilepsy.**





# Epilepsy Youth Conferences

Recently, 30 young people living with epilepsy took part in our latest Youth Conference in Newcastle, made possible by a generous grant from Newcastle Permanent Charitable Foundation.

These conferences are the centrepiece of our 'Youth Peer Support – Connecting Young Australians with Epilepsy' program.

The two-day event focussed on empowering young people to reconnect with community, build confidence to seek support, and form connections with other youth experiencing similar life transitions and barriers as a result of their epilepsy.

This conference helped give young people with epilepsy a voice, whilst tackling common issues around isolation, discrimination and anxiety. Attendees learned about managing their epilepsy, techniques to look after their mental health and worked on sharing their story.

"Our previous National Conference survey results showed that, 80% worry people will view them differently if they find out about their epilepsy, 85% feel isolated and or anxious, and 80% felt epilepsy was a barrier to finding employment," shares our CEO, Carol Ireland.

"Attendees also said they often 'hold back' due to fear of seizures and judgement, which has significant consequences on their capacity to live meaningful, independent lives."

Registrations of Interest now open for our next Conference!

**Our next Youth Conference will be on 11-12th May in the NSW regional area of Wagga Wagga. All meals and accommodation costs will be covered for eligible attendees. Young people aged 16-24 are encouraged to register their interest to attend here: [bit.ly/3TWUcd6](https://bit.ly/3TWUcd6)**



## How confident are you that you know what to do?

One of our key priorities is delivering the very best education and training nationwide for people with epilepsy, their families, caregivers and the wider network of people involved.

### All Australians should know how to recognise a seizure and what to do.

Unfortunately, most people believe a seizure is when someone drops to the floor and convulses (known as a tonic clonic seizure). However, there are many other types of seizures – how well could you recognise a seizure? Would you know what to do? Do you know seizure first aid?

We have an extensive number of online tools and resources to deliver flexible, user friendly education and training options. Our Online Training Academy provides vital and practical information about epilepsy and seizures for a variety of audiences.



**Scan the QR Code and sign up for a course using the code TAKINGACTION to get \$10 off any course if you sign up before 30 April 2024.**



# EVERY **33 MINUTES** A LIFE IS TURNED **UPSIDE DOWN** BY EPILEPSY



**WILL YOU HELP US MAKE  
MARCH PURPLE THIS YEAR?**

This Purple Day, Epilepsy Action Australia encourages you to join the Make March Purple movement to raise awareness and much needed funds in support of the 250,000 Australians living with epilepsy.

Make March Purple is a national campaign supported by epilepsy organisations across Australia. We want to ensure epilepsy is in the spotlight for longer than one day alone and encourage you to have conversations with your employers, colleagues, clients and company stakeholders throughout March to break the stigma often associated with the condition.

**Get involved and help us turn things around by hosting a community fundraising event or online fundraiser to Make March Purple!**

If you have any questions or need advice on the suitability of an activity, online fundraiser or event, please contact us on 1300 37 45 37 or by emailing [epilepsy@epilepsy.org.au](mailto:epilepsy@epilepsy.org.au).

**Scan the QR Code to learn more:**



## THE IMPORTANCE OF MAKING A WILL

Donations in support of the work of Epilepsy Action Australia have a major impact on the lives of thousands of people a year by helping them manage their condition. Sometimes, donors take the opportunity to continue their support through a gift in their Will.

A bequest is a very special gift! If you would like a free booklet on The Importance of Making a Will, which covers changes to legislation surrounding inheritance, please call our office on **1300 37 45 37** or email your request to [epilepsy@epilepsy.org.au](mailto:epilepsy@epilepsy.org.au)





Epilepsy  
Action  
Australia

life changing impact



WITH COMPLIMENTS

XX Month 2024



Supporter ID

Mrs Sally Sample  
999 Sample Street  
Sampleville NSW 0000

Dear {SALUTATION},

Thank you for your ongoing impact through our regular giving program. I have enclosed your copy of our Taking Action newsletter to keep you up to date with the work your generosity makes possible.

Yours sincerely,

*CA Ireland*  
Carol Ireland  
CEO & Managing Director

Epilepsy Action Australia respects your privacy. Your details are protected by us under the Privacy Act. Please see our website [www.epilepsy.org.au](http://www.epilepsy.org.au). If you do not wish to receive mail from us, please call 1300 37 45 37 to advise.

**National Epilepsy Line 1300 37 45 37 – Available Australia-wide • PO Box 384 NORTH RYDE BC NSW 1670 • [www.epilepsy.org.au](http://www.epilepsy.org.au)**

Epilepsy Action Australia ABN 61 000 533 791 • CFN 11390 (NSW), 48861 (VIC), CH1411 (QLD), 1131 (SA), 21416 (WA), CFN 19001032 (ACT), F1A-162 (TAS)