

KEEPING YOU

in touch

WITH EPILEPSY

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spring

It's time to get away!

Families living with epilepsy often find it an isolating experience, particularly if they don't know anyone else dealing with the same issues.

Involvement in Epilepsy Foundation events – like the annual family respite weekend and adult getaway – can change everything.

Suddenly parents have a new support network of people who can truly relate to what they're going through, and children find themselves surrounded by a whole new group of friends!

Here's a quick look at two 2016 events.

Family Respite Weekend, March

A total of nine families with a child under 18 with epilepsy attended this three day-two night event in Anglesea. With the support of staff and volunteers, participants took part in a range of fun and challenging activities, such as a giant swing, rock climbing, arts and crafts, face painting, a family disco and a treasure hunt.

Parents and children alike enjoyed relaxing and spending time with like-minded people.

Champion volunteers

Volunteers and supporters like you are the heartbeat of the Epilepsy Foundation. Without people willing to give their gifts and their time, there's no way we could reach people living with epilepsy.

One incredible volunteer who we've recently nominated for the leadership category of the Victorian Premier's Volunteer Champions Award 2016, is a lady by the name of Catherine Wise.

A senior manager at ANZ bank, Catherine first approached the Epilepsy Foundation in 2013 to see if she could use her company paid volunteering day with us.



"Kids loved the activities and we had the chance to chat with other families," one parent reported.

Adult Getaway, April

Set against a backdrop of sea, sun and sand, 29 men and women – aged between 20 and 71 – enjoyed the annual Adult Getaway to Portsea in April.

The weekend's program included a high ropes course, flying fox, arts and crafts, bushwalking, yoga/meditation, disco and an epilepsy information session.

"I loved the sea, the togetherness, making very friendly conversations," one of the weekend's participants said.

If you or your family would like to participate in next year's events, please register your interest by emailing dclunn@epilepsyfoundation.org.au

Since then, Catherine has not only become our 'go-to' corporate volunteer, she's also brought many other ANZ staff along to volunteer days.

ANZ volunteer teams led by Catherine have cleaned, painted and fitted out three epilepsy opportunity shops, including the new shop in Port Melbourne, and supported Purple Day preparations.

Best wishes Catherine – and the other seven ANZ staff nominated in the Premier's Award teamwork category.

And thank you to all volunteers and supporters who continue to make the world a better place for people living with epilepsy!

Front cover: Emily is living with epilepsy. She loves to dress up as a fairy and pick flowers, especially pink ones.

To help children like Emily donate now at www.epilepsyfoundation.org.au

The importance of Epilepsy Smart Schools

One of the key ways the Epilepsy Foundation creates better understanding and awareness in the community about epilepsy is through providing training for teachers.

With your support, the Epilepsy Smart Schools program has run successfully for over four years and an innovative online version of the program – which will bring even more schools on this important journey – is currently in development.

So how important is it for schools to have this training? The Epilepsy Foundation's Education and Training Manager, Debra Parker, takes a moment to explain:

“Getting a good education is the critical start in life that all children deserve, as it forms the foundation for a fruitful future in the community.

An Epilepsy Smart School is one that understands epilepsy and puts in place inclusive practices to support a student with epilepsy to achieve their academic potential and develop positive social relationships. It takes a whole of school approach – working with the student with epilepsy, other students, teachers, staff, parents and the school community.

Say YES to new friends and better self-confidence

What do young people living with epilepsy really want out of life?

To feel normal. To be able to study, work and enjoy social activities just like everyone else. For people in the community to really understand epilepsy.

These are just some of the things young people expressed at the first ever gathering of the Youth Epilepsy Support (YES) Group late last year.



The Epilepsy Smart Schools program aims for schools to achieve the following:

- All students with epilepsy have a current Epilepsy Management Plan and policies and procedures are in place to ensure inclusive and safe practices.
- School staff understand the possible impact of epilepsy on students and ideally take part in epilepsy training.
- Students are also given the opportunity to learn about epilepsy, using resources from our website.”

Your continued support for Epilepsy Smart Schools – including supporting our innovative online version of the program – will allow more reach to more schools more quickly. Thank you!

Since then, the group – which includes 18 young people and parents – has run a successful Purple Party and started planning events for the coming year.

Your support helps keep this vital group together; providing a valuable network for young people aged 12-24 who have epilepsy to extend their social networks and build self-confidence. Thank you!

Helping you remember those you've lost

On Sunday 22 May, more than 150 family members and friends gathered at our eighth Biennial Memorial Service, held at St Mark's in Camberwell.

Parents Glenda Johns and Andrew Miller spoke profoundly of the loss of their daughter Rosie to epilepsy, while Epilepsy Foundation's Helen Smith and ambassador Joffa Corfe read moving poetry.

Associate Professor Doug Crompton, a neurologist and epilepsy specialist, spoke about the progress being made into sudden deaths related to epilepsy, and Teddy Tahu Rhodes accompanied by Helene Hatton shared some beautiful music.

Candles were lit in memory of those who have passed and families took time to share photos, stories and memorabilia with each other.

If you or your family would like to participate in our next memorial service (2018), please email memorial@epilepsyfoundation.org.au.



The day the world shone purple

On March 26, a day dedicated to increasing awareness about epilepsy, many famous buildings, as well as schools, workplaces and individuals 'went purple' all around the country.

In Victoria, the night skyline shone bright with Melbourne's Federation Square and Arts Centre spire lit up in purple, as well as Bendigo's iconic Alexandra Fountain and Mooropna Water Tower in Shepparton.

Channel 10 Masterchef 2015 contestants Jacqui and Ashleigh auctioned off a personally-cooked dinner for 10 on 3AW – raising \$3,000 for the Epilepsy Foundation – while the Avoca Beach Surf Lifesaving boat turned its nose purple. And AFL's best-known supporter and Epilepsy Foundation ambassador Jeff 'Joffa' Corfe pulled a purple puppy out of his hat for the media.

Thank you to everyone who shone a light on epilepsy during the month of March. Your support helps to break stigma, create awareness and improve the lives of people living with epilepsy.

Middle Right: Federation Square lights up for Epilepsy
Bottom Right: Jacqui and Ashleigh raised \$3,000



Maree's passion for training

Epilepsy Foundation trainer Maree has a passion for teaching people about epilepsy.

Having worked with countless families and schools over the years, Maree knows that helping people understand epilepsy not only empowers them to deal with it more effectively; it also reduces stigma.

“Knowledge is the key to understanding and supporting [people with epilepsy] so that they are able to get the right help,”

When it comes to schools, most of Maree's initial contact occurs because teachers find out they need training to administer Midazolam medication to students with epilepsy. But she knows there's much more to truly understanding epilepsy.

As well as teaching schools how to deliver medication during seizures, Maree helps teachers understand how epilepsy might affect a child and their individual needs.

“We don't provide just Midazolam training, we provide epilepsy training prior to that; it comes as a package,” Maree explains. *“You do see the awareness increase amongst teachers. You see those light bulb moments where you talk about the student who might be drowsy ... it's about bringing all the pieces of the puzzle together.”*

Importantly, Maree also helps children, families and schools see what is possible for children with epilepsy.

In fact, it was Maree who worked with Sami – the year 10 girl whose story you may have read about recently – helping create a situation where she could attend a school trip to the Great Barrier Reef.

“[That involved] helping the school understand what support they need for that child to be able to go on a camp,” Maree says.

“And obviously it's not just about the experience of the camp;

it's about being connected with her peers and not being left out and isolated because she can't do certain things because of her epilepsy.”

For families learning to care for children with epilepsy, Maree's advice is also crucial.

She's there to show parents – as well as grandparents and other family members – how to administer Midazolam but more than that, she also provides encouragement and advice for the journey ahead; empowering them to advocate for the bright future their child deserves.



Above: Maree loves to educate people about epilepsy

A trip of a lifetime. And you're invited!

Together with adventure travel company Inspired Adventures, Epilepsy Foundation CEO Graeme Shears and a group of intrepid explorers are getting ready to trek the Great Wall of China in April 2017.

And because the trip is also a fundraiser, every step taken on the wall helps provide the best quality of life for Australians living with epilepsy.

"I'm excited about trekking the Great Wall ... and meeting all the great people that join the adventure," says CEO Graeme. "I will be approaching friends and family to support the challenge and raise funds to support people living with epilepsy."

Says Pat Tomlinson of Bendigo: "I have decided to participate because I like to raise awareness for different causes. Especially one that is so close to me."

My plan for raising enough money is to rely on the help of friends, family, and the community. I plan on hosting movie/trivia/bowling nights."

To find out more, or to join this trip, contact danny@inspiredadventures.com.au or visit www.inspiredadventures.com.au/events/epilepsyfoundation-china-2017



Dreaming of a career in retail?

Then the Epilepsy Foundation's new retail training program is just for you!

Aimed at helping women with epilepsy find a meaningful career in retail, the program will teach you about merchandising, window dressing, styling, relationship building, making sales, using the cash register and banking procedures through experience working in our Epilepsy Op Shops.

Not only will you gain retail experience in a safe and supportive environment, our op shops are full of treasures that raise money for people living with epilepsy.

You will also get help to refine your interview skills and assist you to find the job that's right for you. **To find out more, call Tracey Lindskog – Epilepsy Foundation Retail Operations Manager – on 0405 220 132.**



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