A fun-filled and positive experience at camp

For most families, a weekend away with friends is something to look forward to. But for many families with children with epilepsy, the thought of going away with other people can be a daunting prospect.

So many uncertainties arise: what if the child has a seizure in the company of others; will other families really understand life with epilepsy; will the food be okay; will there be a chance to relax?

All these anxieties prove to be of no consequence for families who have attended our popular getaway weekends. The feedback is overwhelmingly positive and the only complaint seems to be that the weekends are not long enough and there are not enough of them! One young man was even delighted that he had epilepsy because he got the chance to go to one of our weekends. We thought you would like to hear his story.

Six and a half year old Rupert Kerr has left a never-to-be-forgotten picture in the memory of his mum Susie: that of him running along so happily towards the Portsea camp, swinging his arms, and saying how lucky he was to have epilepsy so he could go to the Epilepsy Foundation’s family camp.

At that moment, Susie saw a more confident, happier Rupert who totally came out of his shell to participate in his first Epilepsy Foundation family weekend. Not only did the camp enrich Rupert’s life, it was also of great benefit to Susie who attended the camp with Rupert’s sister India and Rupert’s grandmother.

Rupert was just 18 months old when he experienced his first seizures in quite traumatic circumstances for his family while they were holidaying in Western Australia. Susie recalls being almost ignored in a busy regional hospital while Rupert was having non-stop seizures. It was only when Rupert began vomiting and had a massive seizure that more attention was given to him. Even then, staff at the hospital neglected to tell Susie that it was highly likely that Rupert would have a seizure in two weeks time – and that’s exactly what happened.

From that time on, Rupert has experienced uncontrolled nocturnal focal seizures that leave him tired and fatigued in the morning. Rupert also has a history of severe eczema and allergies, so getting the right medication to help control his seizures has been difficult. Susie says that the epilepsy has proven to be emotionally difficult for him and that’s why the camp was such a highlight for her.

Susie knew nothing about the services that were available through the Epilepsy Foundation – in fact she knew nothing about the Foundation at all. It was only about two years into seeing a neurologist that he suggested that Susie might check out the Epilepsy Foundation. She did, and her first contact was an information session run by the Foundation at which Dr Ingrid Scheffer was speaking.
From the CEO

Even though it is well into the New Year, this is my first opportunity to wish all our supporters, donors, and people living with epilepsy, a happy 2016.

As each year turns over, it is a chance to reflect on the past year’s achievements and challenges, and it is also a time for renewal as we venture into the New Year. At the Epilepsy Foundation that means a time to renew our commitment to continue vital support services for people with epilepsy, to educate and inform the community, and to put an end to the stigma and discrimination that affects the life opportunities of so many people with epilepsy.

I am sure that you will be inspired and motivated by the reading in this issue of InTouch with Epilepsy. From the wonderful story of Rupert, to the work being done by our Education and Training unit; from our research projects, to the international day of epilepsy awareness, we begin the year with great optimism and hope that the community is beginning to see epilepsy in a different light. Maybe in 2016, we will make even bigger steps towards ending discrimination, and to changing perceptions about epilepsy.

As you read this issue, I encourage you to pay particular attention to the way in which you can be involved with Purple Day activities. We know that every person who wears a purple pin, a ribbon or t-shirt shows the rest of the community that they want to see an end to discrimination, and better support for people living with epilepsy. Your individual donation or fundraising efforts will really help us reach our Purple Day target. I thank you in anticipation of your support.

As we move forward into the rest of 2016, I want to express my sincere appreciation to every one of you who supports our work – donors, volunteers, partnering organisations and clients. We can have the best organisational plans and aspirations, but it is only through your support that we can really change life for individuals and families who live with epilepsy.

With your support – and our work – we really can make a difference in 2016.

What other families say about their weekend camp experience:

"Almost overnight, things started happening for me," says Susie. "I began to ask questions of the neurologist and felt much more of an advocate for Rupert. It was definitely an empowering experience". When the camp was advertised in a Foundation bulletin, Susie put in an application to attend, but still had reservations about whether it was the right thing to do and whether Rupert would cope. David Clunn, the camp co-ordinator reassured her, and the rest is history as they say.

Not only was Susie concerned for Rupert, she was also anxious for herself. "I still find it difficult to speak about his epilepsy – I guess that’s a coping mechanism for me," says Susie. "So it was confronting for me too to be with people who were willing to speak about their children’s epilepsy."

Susie lists many benefits from attending the camp. First and foremost, she learnt more about the services the Foundation could offer families and which she has since used. She got to know the Foundation staff and met other parents. She heard their stories about their experiences of having a child with epilepsy, some of whom experienced more difficult, and sometimes less difficult epilepsy than Rupert.

As for Rupert, he came into his own on the weekend. As Susie says, "He really felt it was his camp and we had come along with him. It was such a boost to his self-confidence. He totally came out of himself and was totally comfortable with everyone else." Rupert ventured off by himself to the dining hall, talking to people he had never met before. Even the massive 18 metre swing held no fear for Rupert; he was first onto it and was thrilled with the experience.

Rupert and Susie’s experiences are similar experiences to other families who attend the family getaway weekends. To be realistic about it, for many families who have a child with epilepsy it can all seem too difficult, and often confronting, to take a child with epilepsy into a new environment with new faces when sometimes seizures and behaviour are unpredictable. But at the end of the weekend, the story is the same as Rupert and his family felt – a fun-filled adventure for the children, and a positive experience for the parents.

Rupert and his sister have since spoken about the camp a lot, says Susie, and that says a lot about the impact it had on them. Susie’s mother who was over from Western Australia was invited to join them and as Susie says was ‘blown away’ by the camp and the people who work and volunteer for the Foundation.

As has been proven so often, family getaway weekends might seem just a lot of fun, and they are. But more than that they are a coming together of families with shared experiences of living with epilepsy, of acceptance, of learning and inclusiveness.

“We wanted to understand other people’s challenges and share our experiences. We have done that, and so much more.”

“Fun, relaxing, able to relate to families that had similar issues to our own.”

“[We loved] the inclusiveness, not needing to apologise for your children’s challenging behaviour.”

“We feel like we are not travelling a road on our own.”
Impact through education and training

If you take a close look at the info graphic (right), you will see that in 2014–15 alone, more than 4890 people received training or education about epilepsy and the management of seizures.

Schools and disability settings were major participants in that training, with families, hospitals and other groups actively participating. Those numbers translate to 4890 people in our community who can make a difference to the lives and life opportunities of people living with epilepsy.

Across every sector of our community, the role of the Epilepsy Foundation’s Education and Training unit is to provide the training, to create greater understanding and knowledge, and to improve the circumstances of the life of the person for whom they are doing the training.

It will come as no surprise that almost every time you read an Epilepsy Foundation story about a person’s experience with epilepsy, that the person’s life was improved through assisting them with some form of training or education about epilepsy and seizures.

Whether that story is about a parent who has learnt how to administer midazolam to their child when they experience a severe and prolonged seizure. Or about teachers and young people in schools who have learnt about seizures and the impact of epilepsy on learning and behaviour.

It might be about carers working with people with a disability who need more understanding about seizures in their clients. Or it could be about parents attending a conference to learn more about a severe form of epilepsy called Dravet Syndrome.

Janita Keating, Service Development Manager, says the Foundation is focused on providing education and training that has the most impact on improving life for people with epilepsy.

“There are really two layers of training and education that we provide: the first is a primary group, that is, the people who have epilepsy, and the second layer of training is for those who support the person with epilepsy. That could be their family, school, carers, or workplaces,” says Janita. “We strive to gain maximum impact from all our training and education work by ensuring that the outcome is a better quality of life for people with epilepsy.”

“In addition, our partnerships, for example, with schools, disability organisations, hospitals and government are very important in enabling us to reach the people who benefit most from training”.

The Foundation’s Education and Training unit welcomes the opportunity to be of assistance to any school, workplace, disability organisation, early childhood centre or health professionals who would like training or further information about epilepsy. Contact the Education and Training unit at the Foundation on 03 8809 0600.
**Research that makes a real difference**

The Epilepsy Foundation's current research projects aim to improve the quality of life for Australians and their families living with epilepsy.

Two important research programs are currently being conducted by the Foundation. One is a longitudinal survey into the social impact of epilepsy. This survey is repeated every three years and enables us to track if people's lives are improving or worsening.

Through this research, for example, we now have the evidence to show that people with epilepsy find it hard to complete education and to find full-time work. This evidence proves extremely important when going to government to advocate for improved services to assist people with epilepsy.

A second major piece of research the Foundation is undertaking concerns older people with epilepsy and is being conducted with project partners, the National Ageing Research Institute (NARI) and the Council on the Ageing (COTA). This project aims to improve services and support to older people, carers and workers, particularly with a view to enabling older people to stay in their own homes for as long as possible.

The findings from the Foundation's research are used to ensure our client services are really meeting the needs of people with epilepsy. We also use our research to argue for better government support for people with epilepsy, and to create awareness about epilepsy in the Australian community.

For further information about our research projects and how you can be involved with our research, go to www.epilepsyfoundation.org.au and follow the research link.

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**Leaving a bequest**

Including a gift in your Will is one of the most special and powerful things you can do. After providing for family, friends and other important needs, many people choose to leave a bequest to a cause close to their heart.

When you make a bequest to the Epilepsy Foundation, you extend your commitment to people with epilepsy into a lasting contribution to our work. Bequests help build our reserves to ensure the long-term financial viability of the Foundation. No matter how large or small, your bequest will make a big difference and transform lives.

To make a bequest, you must express your intentions clearly. The best way to do this is through a clearly written and up-to-date Will. Your solicitor or legal representative will help ensure that your Will meets all legal requirements and that your wishes are interpreted accurately.

Contact Helen Smith for a copy of our bequest information booklet on 03 8809 0664.
Op Shop treasures now at Bentleigh

Opportunity shop lovers, rejoice! Our Bentleigh Op Shop has been open for six months, and is proving a great find for op shop hunters and the local community alike.

The newest of our op shops is located in the vibrant shopping strip at 351 Centre Road, Bentleigh. It is the perfect store to visit when you are looking for hidden treasures, or to grab a bargain from the great recycled clothing, furniture or home wares range.

In addition to its every day treasures, the store offers weekly specials and an excellent range of seconds and samples that come on a monthly basis from supporting businesses. The Foundation is most appreciative of the support of the Bentleigh community over the past six months and looks forward to offering many happy years of service in the community.

The store has a fun, vibrant, energetic feel about it. Our manager, Effie and the team will be more than happy to help you find what you are looking for.

Opening hours are from Monday to Friday 9.30am to 4.30pm and Saturday from 11am to 4pm. Donations are always welcome and we would welcome more volunteers to assist us. Please call Effie on 03 9557 8401 if you are interested in volunteering, or for donations of furniture please call 0425 799 415.

Register your interest in the China Challenge

Want to be part of the adventure and experience the majesty and mysticism of the Great Wall of China? Register your interest to join us for the Epilepsy Foundation China Challenge in April 2017
Contact events@epilepsyfoundation.org.au

Visit us online at:
www.epinet.org.au

facebook.com/epilepsyfoundation
@epilepsy_fdn
EpilepsyVictoria

Purple Day merchandise now available from our online shop
www.purpleday.com.au

Epilepsy Helpline 1300 852 853
Get ready, get involved, go purple!
March is Epilepsy Awareness month

This year, Purple Day, 26th March, falls on the Easter Saturday holiday, and that’s an even better motivation for getting involved.

Whether you’re staying at home or going away with friends or family, there are many ways you can be involved in raising awareness of epilepsy. A purple wrapped Easter egg with a very cute purple puppy dog would be a perfect gift!

If it’s just too difficult for you to do something special on the 26th, don’t worry, you have the whole of March to organise an event, wear purple, buy great merchandise or start your own fundraising page. March is Epilepsy Awareness Month during which people in their workplaces, in schools, and in local communities show their support for people living with epilepsy.

Purple Day was the initiative of a nine year old girl, Cassidy Megan, who began a grassroots movement in 2008 to highlight the worldwide prevalence of epilepsy. Not only is Purple Day a visible sign of support, it also assists the Epilepsy Foundation to reach its target to raise $200,000 to fund vital support services.

Everyone has their own special motivation and reason to get involved in Purple Day. We would love for you to join us. You may want to support a family member or friend who has epilepsy, remember and honour a loved one who has died from epilepsy, or simply want to raise awareness of the prevalence of epilepsy in the community.

How to be involved
There is simply no excuse for not showing your support for Purple Day. There are many ways you can become involved to show your support for people living with epilepsy. For example, you can:
• go purple on Purple Day, wear a pin or t-shirt
• purchase Purple Day merchandise
• make a donation
• sell our merchandise
• create an online giving/fundraising page
• host your own event like a morning tea or dress up/theme party.

Whether you make an individual donation, buy Purple Day merchandise, or join others in your workplace, school, community centre or your home, every Purple Day contribution makes a difference.

Merchandise is available for sale at:
• www.purpleday.com.au
• our head office in Surrey Hills
• our opportunity shops located in Blackburn (82 South Parade), Bentleigh (351 Centre Rd), Parkdale (258 Como Parade West) and Cranbourne (2 and 10 Lurline St).

Want to do more?
Order a box of merchandise to sell, or simply donate, call us on 03 8809 0600 or visit www.purpleday.com.au to get started.

Spread the word
Why are you supporting Purple Day? If you are comfortable talking about it, let people know by:
• talking to friends and neighbours
• posting your support on social media
• like and share our Facebook page www.facebook.com/epilepsyfoundation
• letting the local press know about your event
• speak to your local sporting and cultural associations.

Your message may strike a chord with someone and create more awareness of epilepsy. It might even encourage them to make a donation to the Foundation’s work which supports people living with epilepsy.

Register your interest at www.purpleday.com.au

Purple Day for Epilepsy

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