



Taking Action

Optimal outcomes for those living with epilepsy

WHERE THERE IS RESEARCH, THERE IS HOPE

While there have been considerable advances in science, there is so much we still don't know about epilepsy. For example, current medication fails to help around three out of 10 people control their seizures.

Epilepsy Action Australia has made research a key focus area and is involved in many research projects that significantly impact the prevention, diagnosis and treatment of epilepsy.

The following personal stories explain why research is so important in providing safer and more effective medications that will improve seizure control.

PREGNANCY COMES WITH CHALLENGES

Whenever someone asked Natalie what she wanted to be when she grew up, she always said "a Mum". Now aged 28, she is about to have that dream come true, but due to her epilepsy the pregnancy has been more difficult than expected.

Prior to her pregnancy, her seizures were reasonably well-controlled with a particular antiepileptic drug (AED), but research has revealed it could cause birth defects in babies.



For Natalie, changing to a different medication has meant a significant increase in her convulsive seizures. She has to take extra precautions to keep her and her baby boy safe, such as immediately going to bed when she feels a seizure coming on.

In what has been devastating news, Natalie has also been told that it is unlikely she will be allowed to be alone with her son for at least six months.

"I understand that my doctors are concerned that I might have a seizure while holding my child but it really hurts to lose that independence. It will be hard to rely on others for so long," Natalie says.

She hopes that research will be able to develop new medications that will be safer and more effective in controlling seizures so that other Mums won't have to face the same problems.



CEO Message

2019 promises to be an exciting and busy year for Epilepsy Action and we are so pleased you are coming on this journey with us. Your valuable contributions and support of our organisation is key to the successful delivery of some of our most ambitious and much needed initiatives this year. These include the National Response Service, which will see 7-Days a Week Support for people living with epilepsy and an Online Medicinal Cannabis Education Resource we have called C4E (Cannabis for Epilepsy).

Your gifts to this appeal will go directly towards much needed research, helping to provide 'hope' for the future of the 250,000 Australians impacted by epilepsy. I hope the stories we are sharing with you in this newsletter are successful in outlining the critical importance of research programs. If your 'budget' can extend a little further, please consider becoming a research advocate (monthly giver) to support these programs into the future.

Once again we are turning Australia purple for epilepsy awareness throughout March, ahead of International Purple Day (26th March). We would love your help in spreading the message that knowledge is power and the community does not need to 'fear' epilepsy. Changing common misconceptions and changing attitudes is important and we hope that Australia can get on board. Check out ways to get involved in Purple Day activities by visiting www.epilepsy.org.au/fundraise/purple-day.

Once again, please accept my sincere gratitude for making a difference in the lives of people living with epilepsy.

Carol Ireland
CEO & Managing Director

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EPILEPSY DEATHS STILL A MYSTERY

It has been four years since Damian, then aged only, 10 passed away from SUDEP (Sudden Unexpected Death in Epilepsy), and his Mum Tina is still no closer to understanding why it happened and why she had never even heard of it at the time.

"I would have absolutely preferred to have been educated and more prepared. I watched Damian die and that's very hard for anyone to go through. If I had known about SUDEP, I could have done more, like learnt CPR. As a Mum that is something I have to live with for the rest of my life," says Tina.



The cause of SUDEP remains a mystery but researchers believe it could be linked to seizures causing breathing or heart difficulties. Sometimes there may be signs a seizure has happened, although, as was the case with Damian, this is not always so.

Tina has worked tirelessly to educate people with epilepsy about SUDEP, appearing in the media, a documentary and print campaigns to spread awareness and ensure people take as many precautions as is possible.

She hopes that her loss may someday help save someone else's son or daughter.

MEDICINAL CANNABIS OFFERS HOPE

Ava, aged 13, is a gorgeous and funny child who loves dancing, going horse-riding and fishing with her Dad.

But four years ago, things were very different for Ava – she was having up to 30 seizures a day and couldn't sleep for more than three hours at a time.

Ava had undergone two brain operations and tried every antiepileptic medication available, and her exhausted and distressed parents, Joelle and Peter could only watch on helplessly as Ava suffered.

So they tried Ava on a few drops of medicinal cannabis oil. The results were swift and life-changing – Ava's seizures had stopped within 10 days and a few months later she was sleeping through the night. Today she is having small seizures only two or three times a week.

And while Ava's health is so much better, the family still faces many challenges regarding the legalities and expense of shipping the product in from America.

While other medicinal cannabis products are legally available on prescription in Australia, they are three times more expensive. Joelle is also reluctant to face the risk of switching to another medication that may not work as well for Ava.

"I hope that with more education and research, medicinal cannabis will one day be recognised as a good safe first-line drug option for epilepsy so that others don't have to face the same difficulties that we are," Joelle says.



FUNDING RESEARCH FOR A BRIGHTER FUTURE

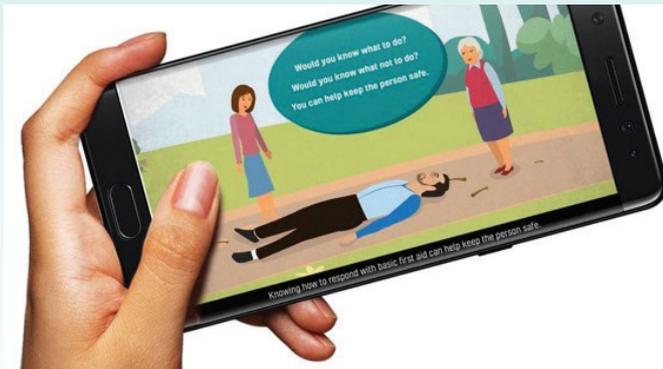
Epilepsy Action is working hard to make sure that the future is brighter for people with epilepsy by funding research and clinical trials in important areas such as safer medications for pregnant women, SUDEP and medicinal cannabis.

WITH THANKS

Epilepsy Action Australia thanks the following trusts, foundations, businesses and Government departments for their support in assisting us with our ongoing mission: to optimise life outcomes for people with epilepsy.

Epilepsy Essentials – Education training in the Sutherland Shire

With Sutherland Shire Council's generous support, Epilepsy Action is delivering Epilepsy Essentials education in the Sutherland Shire area.



Animated first aid seizure videos for children and adults

This year UCB proudly supported us with funding to produce two animated educational first aid seizures animated videos for children and adults. These have 'gone viral' with more than 110,000 views and been shared by organisations in Ireland, Japan, Scotland, New Zealand, the UK and US.

Epilepsy Awareness and Education Program for CALD communities

New materials were developed and launched in Arabic and Chinese (for distribution through the Epilepsy Society of Australia, Australian and NZ Association of Neurologists, and Society of Child Neurologists), along with educational sessions for families and professionals. This was made possible with support from Cumberland Council and the Australian Chinese Foundation.

NSW Health – Western Sydney Local Health District

This funding focuses on providing health education, information and training for individuals, families and carers impacted by epilepsy, and professions and members of the general community.

Department of Family and Community Services

This funding supports services that are vital to assist people with epilepsy lead productive and independent lives. It supports people with disabilities to access services, enhance their rights and to facilitate greater participation in the community.

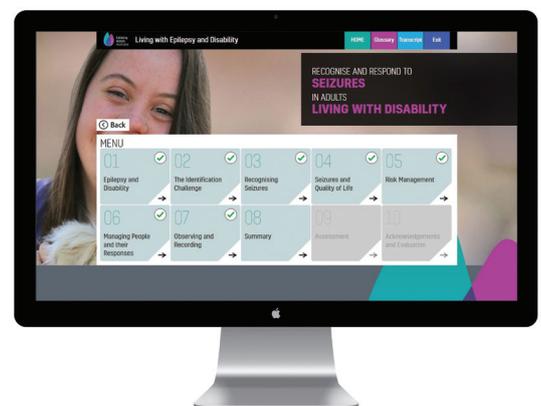
Early intervention project

We were assisted in delivering our vital early intervention programs for children and youth in various locations:



Volunteer speaker – John Sexton and his wife - collecting the cheque from The Lord Mayor's Charitable Trust

- + In NSW and WA supported by Commonwealth Bank of Australia
- + In Cumberland City Local Government Area supported by Dooleys Lidcombe Catholic Club
- + In Queensland supported by the Courier Mail Children's Fund
- + The Lord Mayor's Charitable Trust
- + In the Brisbane area supported by the Lord Mayor's Charitable Trust



Epilepsy and Disability Training Resource

With significant support of The Ian Potter Foundation, Gandel Philanthropy and the John T Reid Charitable Trusts, Epilepsy Action launched its innovative Epilepsy and Disability Training course, first of its kind in Australia.

C4E

With funding from MGC Pharma and NIB Foundation, Epilepsy Action has created, and continues to develop, a simple and effective platform C4E – www.c4e.com.au which provides easily packaged, accessible, user-friendly information on epilepsy and medicinal cannabis."





PURPLE DAY – 26TH MARCH

It's that time of year again where we all go purple to raise awareness of epilepsy.

It's that time of year again where we all go purple to raise awareness of epilepsy. Our campaign Know Epilepsy, No Fear continues to help us combat misconceptions and lack of understanding of epilepsy. We have hope for a world that understands epilepsy, does not fear it and is kinder to those impacted by epilepsy... But we need your help to achieve that.

Epilepsy is a condition with many challenges for those impacted by it. The reactions and ignorance of the wider public is an additional challenge that can have significant impact on those living with epilepsy. This is why Purple Day, the international day of epilepsy awareness, is so important. We stand together with those around the world to show that epilepsy exists, can impact anyone's life, and needs to be understood.

We believe that you are not defined by your epilepsy, nor the epilepsy of your loved ones. We see the strength and courage you display on your epilepsy journey and this really inspires us. We think the world should know about them too. So this Purple Day, share your story with us, your family, friends, colleagues, community and together we will start conversations and increase epilepsy awareness throughout Australia.

During the month of March people will be hosting fundraising events, wearing purple, buying merchandise and making donations to help us spread the word as far as we can reach, and we'd love for you to be a part of this. Find out how you can get involved here:

www.epilepsy.org.au/fundraise/purple-day



TAKING ACTION FOR RESEARCH



Most people relate epilepsy to seizures, but there are many other serious issues that children, teenagers and adults with epilepsy have to face because of their condition, or due to medication side effects. These include memory, language and learning difficulties. Unfortunately, depression, anxiety

and suicidal thoughts are also very common in individuals with epilepsy.

As you have learnt from the stories featured in this newsletter, further research is needed so that these problems can be addressed and managed to ensure a better quality of life for everyone affected by epilepsy including parents and families.

We work collaboratively with world-leading medical and academic institutions across many important areas including:

- + Sudden Unexplained Death in Epileptic People
- + Medicinal Cannabis trials to help control seizures in children
- + Potential long-term effects of anti-epileptic drugs (AEDs) on mothers and babies/children during and after pregnancy

- + Wearable technology, e.g. seizure detection systems; and thermal fabrics that monitor body temperature
- + Complementary therapies with identified potential to manage seizure activity
- + Psychological interventions to enhance quality of life.

You could get involved with us by providing a regular monthly donation, joining our troop of valued **Research Advocates** who truly make a difference to people with epilepsy.

Your donations will be invested directly in support of research projects and initiatives. **Please help us improve lives by becoming a Research Advocate today! Sign up here:**



www.epilepsy.org.au/donation/make-a-donation/ and select Monthly Donation.