



# Taking Action

Optimal outcomes for those living with epilepsy



## THE SUPERPOWER OF A SMILE

**Children with epilepsy are little superheroes in many ways, but their superhuman powers are not always obvious.**

Maybe they are not the brightest in their class – but having to cope with frequent seizures often makes learning difficult. They may not be the strongest or fastest – epilepsy can also affect physical development, and participating in sport is not always possible.

For 11-year-old Jackson, his superpower is his determination to enjoy and embrace his life with a smile despite the many challenges he faces due to epilepsy, developmental issues and autism.

According to his Mum, Renee, he is strong like his idol the Hulk but it is an inner strength he displays each day.

Even though he has serious disabilities and has suffered “hundreds of seizures over the years”, Jackson is affectionate, happy and quick with a smile. He loves to go bike-riding, horse-riding and play in the water.

But there is a lot he can't do and may never have – like the close circle of friends his nine-year-old sister Charlotte has.

*“For Jackson and all of us, there are definitely more restrictions. We don't know when the next seizure will come so we can't do a lot of things other families do. We manage our lives around epilepsy as best we can,” Renee says.*

Jackson was not even three years old when he was diagnosed with epilepsy. For his parents, the diagnosis came as a relief that they knew what they were dealing with. But overwhelmingly there was sadness, especially for Renee who had grown up with a Mum who had epilepsy and understood all too well the challenges ahead.

Renee says that there is definitely more support and understanding for Jackson than there ever was for her Mum “who had a pretty rough time”.

For example, Jackson and Charlotte's school holds Purple Day each year to fundraise and promote awareness of epilepsy. This has helped others accept Jackson's differences, particularly his classmates, the other parents and Charlotte's friends.

**Thank you for your generosity, which has assisted Jackson and his family to find the strength and courage to live the best life possible despite the challenges they face.**



## CEO Message

We've all heard the saying 'not all superheroes wear capes' in a number of contexts but we really wanted to highlight to you the superpowers displayed by some of our bravest kids. Not only do they deal with the normal challenges of growing up, they have the added burden of seizures, yet everyday they are strong and brave. We want you to celebrate their superpowers with us! And we thank you for supporting the thousands of Superheroes we work with every year.

We had a huge Purple Day in 2018! This year we had more fundraising and school events registered than ever before. We also had a record number of people spreading awareness for epilepsy through our "Know Epilepsy. No Fear" campaign and received tremendous coverage in print, online and broadcast media. Thanks to everyone who got involved and helped raise funds and awareness of epilepsy throughout Australia. Every event, donation, purchase and conversation makes a difference to our work with those impacted by epilepsy. We can't wait for 2019! Let us know if you'd like to be involved to keep the momentum going. Simply send the team an email or like us on Facebook to keep in the loop.

I hope you enjoy reading about some of our other successes over the last year, all made possible by you. I also sincerely hope you will continue your incredible support to help us achieve even more for people living with epilepsy. Thank you so much.

**Carol Ireland**  
CEO & Managing Director

# A CALL FOR SUPERHEROES

For children with epilepsy, identifying with a Superhero can help them find courage to deal with the numerous issues in their lives. We recently asked parents to tell us about their child's favourite superhero, and share what powers their children use in their battle against the challenges of epilepsy.

## IRON MAN'S HEALTH BATTLES AN INSPIRATION

Harry, aged 10, nominates Ironman as his favourite superhero because he faces his own challenges with his health, but remains brave and strong to combat crime and terrorism!

While Harry has violent and frequent tonic-clonic (convulsive) seizures at night that leave him exhausted, he stays positive and still wants to go to school next day. And in true superhero form, he is helping others with his epilepsy fundraising efforts.

According to his Mum, Beck, his bravery is his biggest power, but if she could, she would give Harry the power to stop his seizures forever.

*"Then he wouldn't have to suffer the terrible migraines he gets after the seizures, and it would take away the fear we see in his eyes every single time he has a seizure," Beck says.*



## BRAVERY NOT ENOUGH FOR DOMINIC

While six-year-old Dominic may not have a billowing black cape, he is brave just like his idol Batman.

Less than two years old when diagnosed, Dominic faces daily challenges of extreme fatigue and problems focusing in the classroom because of frequent 'absence' seizures.

His superpower lies in his bravery in dealing with these issues without complaint. But his Mum Rani would also like to give him another power.

*"He worries a lot about what others think of him when he has a seizure, so if I could I would give him the power to become invisible when they occur."*

## A LITTLE WONDER IN MANY WAYS

Wonder Woman is the superhero of choice for seven year old Piper, as Wonder Woman fights for those who cannot fight for themselves.

Piper was diagnosed with epilepsy in the first year of her life and the biggest challenge is controlling the violent nocturnal seizures that steal so much of her strength. Despite everything she goes through, her Mum Summer says she always manages to smile.



*"Some days we may wait a little longer, yet we know we'll see that smile, not sadness for the days, hours or minutes that have passed – just Piper's own little sparkle that tells us, 'I'm home!'"*

*"For all she endures without complaint, for the comforting smile she shoots my way, for these reasons and a million more, she is our Superhero," Summer says.*

# WHAT WE'VE ACHIEVED WITH YOUR HELP

Here are some of our achievements this past year, that would not have been possible without your support.

Across Australia

## 6,264

people with epilepsy  
accessed our  
specialist services

## 4,893

participants enrolled  
in our community  
based professional  
education sessions

## 2,786

individuals studied  
via our Online  
Academy courses

Of those who accessed our training:

## 99.42%

reported a better  
understanding  
of epilepsy

## 98.31%

reported that they have  
the skills to provide  
first aid to someone  
having a seizure

## 99.36%

reported they have the  
skills to administer  
emergency medication  
for seizures

**CALD Resources** – Arabic and Chinese communities can now access the latest epilepsy and seizure first aid information in their native language. Thanks to the Cumberland Council Stronger Communities Fund and Australian Chinese Charity Foundation for supporting this initiative.

**SUDEP Resources** – Epilepsy Action Australia established a partnership with SUDEP Action in the UK to raise awareness of Sudden Unexpected Death in Epilepsy (SUDEP) and provide the most current information related to epilepsy-related death. The information provides essential facts about epilepsy and risk, as well as strategies to minimise identified risks.



### First Aid Videos for Adults and Children (Animations)

These fully animated short videos demonstrate what to do if someone has a seizure. One is specifically written for and narrated by children to give the perspective of a child seeing someone having a seizure and responding to keep the person safe. Kindly supported by UCB Pharma.



## 379

Ted-E-Bears and  
education packs were  
sent to families of  
children under age 8



### Epilepsy Youth Conference 28-30 July 2017, Sydney

This was a 'Conference Style' residential experience for young adults (18-25) with epilepsy with a focus on employment, mental health, pregnancy, lifestyle factors (relationships, alcohol and driving), and self-management of epilepsy. Twenty-one young adults from across Australia attended the program.



# WHAT A HUGE PURPLE DAY!



We were blown away with the fundraising efforts of our community of supporters this year! Thanks to Brooks and Crayola we got to honour our top fundraisers in a special way.

**Harry** (who you met earlier in this newsletter) was another top fundraiser. At just 10 years old he got his whole community involved in raising awareness about epilepsy. His recent diagnosis spurred him on to help educate others. With that big smile and generous spirit Harry made a real difference, raising over \$4,000.



Thanks to Crayola we were able to spoil one amazing school with a huge prize as a thank you for their fundraising. Amity College Auburn have been part of Purple Day for numerous years and host their own Purple Day cake stall. The students were very excited to be our top fundraisers and to meet Elly Bear when we visited their school to deliver their prize. Huge thanks to Amity College Auburn school community!



**Bronwyn** has been a huge supporter of Purple Day for many years. She loves purple and wears it any time she can, and is passionate about raising awareness everywhere she goes. Through her support of Purple Day she has connected with people from around the world impacted by epilepsy.



**Kate** and her family organised the amazing 'Walk for Chloe' in memory of their precious daughter who lost her battle with refractory epilepsy at just four and a half months old. Family, friends and community came together to walk, raising awareness and funds to help others impacted by epilepsy.



## LIVING WITH EPILEPSY & DISABILITY

With the significant support of The Ian Potter Foundation, Gandel Philanthropy and John T Reid Trust, Epilepsy Action Australia has recently launched its innovative new Epilepsy and Intellectual Disability Training course.

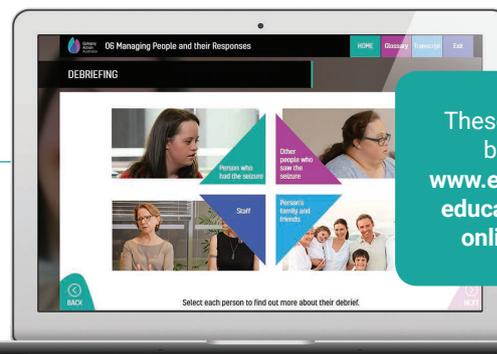
It is estimated that 30,000 Australians living with intellectual disability also have epilepsy and as many as 1 in 4 are misdiagnosed, largely due to inadequate training in recognising and managing seizures by their caregivers. Not only is epilepsy more common in people with intellectual disability than in the rest of the population; the requirement for multiple medications is often higher and they can experience more side effects.

It is easy for an untrained worker to misinterpret seizure activity, as seizures can be subtle or can be mistaken for movements or mannerisms sometimes seen in people with severe intellectual and multiple disabilities. This misdiagnosis and mismanagement can reduce quality of life for the person and their family and, in some instances, can lead to unnecessary death.

In response to this need Epilepsy Action has developed 4 courses specifically crafted for workers in the disability sector, families, carers and general health providers who care for people with epilepsy and disability with the ultimate aim of improving the quality of lives of people living with epilepsy and disability.

The courses include a nationally accredited unit for support workers offered in conjunction with Red Cross College. There are also 3 shorter courses which cover issues such as how to identify seizures, how to reduce risks and how to observe and record seizures. Two of these courses are relevant for people living with epilepsy regardless of whether they have an additional disability.

With the support of



These courses can be found at [www.epilepsy.org.au/education-training/online-training/](http://www.epilepsy.org.au/education-training/online-training/)