2016 – 2017 Impact Report



Optimising life for people living with epilepsy and bringing epilepsy out of the shadows.

our mission	Epilepsy Queensland's mission is to optimise life for people living with epilepsy and bring epilepsy out of the shadows.
our goals	 To create a supportive environment for people with epilepsy and their families To empower people with epilepsy and their families To contribute to the scientific understanding of epilepsy through research, education and its application To ensure health, welfare and other services respond appropriately to the needs of people with epilepsy and their families To ensure appropriate policies for people with epilepsy are included in public policies in all sectors To ensure the long-term sustainability of Epilepsy Queensland
our role	 An estimated 100,000 Queenslanders will acquire epilepsy during their lifetime. We will be here for them, providing: Information Support and counselling Community awareness and education In-service training for staff of health, education and disability organisations Advocacy Resource development Research
our strategic priorities	 Empower individuals and families through information, education, support, awareness and advocacy Enhance our community engagement and advocacy Sustainability
Patron	Board as at 22 November 2017

Wally Lewis

Chief Executive Officer

Helen Whitehead

Chairman Steve Eltis

Deputy Chairman Elsewerth Ephraums

Treasurer Jane Vidler

Secretary Andrew Barnes

Board members

David Bunker Kim Davis Kos Sclavos AM Vivienne Johnson Louise Foley (Retired: 03/12/16) Noel Johns (Retired: 03/12/16) Kristin Ramsey (Appointed: 30/01/17)

chairman's report



As Chair of Epilepsy Queensland Inc (EQI) it gives me great pleasure in presenting the 48th annual report of the organisation. I hope you find our new Impact Report a more insightful way to share with you a summary of our year.

In 2017, the key highlights and activities for EQI have been:

- Another wonderful and highly successful Purple Ball
- A very well attended symposium
- Continued preparation for the progressive rollout of NDIS
- A significant role in the rollout of Medicinal Cannabis into Queensland
- Changing staff roles to reflect new organisational priorities in marketing and service development.

At this time, I would like to pay tribute to the supporters, sponsors, donors, Board, Patron, staff and volunteers for their continued dedication, support and enthusiastic efforts. We simply could not provide the highly valued service to Queenslanders with epilepsy and their families without the contributions you each make.

As many of you know, our CEO has battled some serious health issues this year and the EQI team has had to carry a significant load while Helen has been away. I am especially proud of how the staff have risen to the challenge to produce another strong year of providing advice and advocacy for our clients.

Finally, I am very pleased to advise that the process to progressively renew our Board has continued this year. Kristin Ramsey, a lawyer in the employment and industrial relations field joined the Board in January. I would like to thank outgoing Board members Elsewerth Ephraums and Vivienne Johnson for their outstanding contributions to the organisation over several years, particularly their efforts in fundraising and increasing the profile and reach of EQI in the business community. From a personal perspective, after seven years on the Board it is time for some fresh eyes and ideas from a new Chair, and so I will not be seeking another term on the Board. I wish to thank all those many people who have supported me during my tenure as Chair.

As always, I would also like to thank our Chief Executive Officer, Helen Whitehead, for her leadership of the organisation during these rapidly evolving times and for the all the support she has provided to the Board and to me personally. I know Helen and the EQI staff work very hard to deal with the multiple challenges of client service delivery and fundraising, so on behalf of the Board I'd like to finish by again paying tribute to their efforts.

Steve Eltis Chairman

helping and empowering the community



Epilepsy Queensland is a trusted provider of information and support services relating to epilepsy. Epilepsy Queensland's dedicated services team have an impact on people with epilepsy, their families and other members of the community that support their journey including support workers, teachers, and health workers.

94% of people who responded to our annual survey indicated that the most important service Epilepsy Queensland can provide is information, support, and counselling.

Helpline

Our helpline continues to be the primary point of initial contact for Queenslanders living with epilepsy. Support and counselling help with the many stresses that epilepsy may bring – having an understanding person to listen plays an important role in maintaining psychosocial well-being. Thank you to Alison, the lady who took my call today. Our conversation gave me a more informed strength to approach my daughter's new doctor today. We made some progress. Thank you for your support. - Andrea

Friceless information for new people having just been diagnosed. This has been a wealth of knowledge.

- Sharyn

Regional Collaborative Services

Throughout the year, we continued our relationship with Spark NeuroCare. Spark NeuroCare is a collaboration of six not-for-profits who have joined together to ignite the power of coordinated care for people living with progressive neurological disease. The Townsville and a new Toowoomba office offer locally based NDIS services with the ability to access our specialist epilepsy expertise.

A biz thank you to Trish for all of your wonderful help! You are amazinzly kind and I am zrateful to Epilepsy Queensland, particularly you, for everythinz you've done to help me through a very hard time. - Joy

Information Services

Accessible information about epilepsy that is specifically tailored to the individual's situation empowers people with epilepsy to live confidently and manage seizures. During the year, our information resources were updated to reflect the new classification and terminology of the International League Against Epilepsy.



Family Support

Our family support program is now even more important as families of children with complex needs find themselves looking to the future with regards to support through the NDIS. We have a new Services Development Officer on the team whose role includes helping people with epilepsy in Queensland to navigate the NDIS. People living with epilepsy and their carers are now able to access support from Epilepsy Queensland staff in pre-planning for the NDIS and Epilepsy Queensland is a registered service provider.

Little Poss Children's Programs

Developing epilepsy at any age can be difficult, particularly so in the childhood years. Epilepsy Queensland has a special program for children, incorporating mascot Little Poss. Through newsletters, information resources, and activities Little Poss helps children with epilepsy, their siblings and friends to learn about epilepsy in a fun way. Little Poss's birthday party was again well attended by a number of little ones and parents, who love to be a part of the Little Poss Club.



"

A very special thank you to your team for sending out the Little Poss newsletter and Birthday card, you have made my daughter's day! She has been struggling to adjust with her increase in seizures and feeling very alone during this time. Thank you again, it makes such a difference. - Steph

"

The Little Poss children's program also encourages young people who have a loved one living with epilepsy to make a difference by helping to raise awareness in their schools and communities. Paisley and her brother Noah have known Little Poss for over ten years. These photos were taken at the Little Poss party in 2007. Now in high school Paisley features



on the front cover with our Patron, Wally Lewis presenting her with the Epilepsy Queensland Youth Award in 2016. She continues to make a huge difference, in not only her brother's life, but also the epilepsy community itself.

Paisley has continued to advocate at her school over the years and has promoted Purple Day and Little Poss Appeal – she was particularly thrilled when Kelvin Grove College came on board this year. Like most siblings, Paisley is proud of her brother and proud to be out and about in public raising awareness. Paisley is always explaining to people she meets about Noah's epilepsy.

"

Easily the best epilepsy education event in the country. Consistently of a high standard year after year - exceptionally well organised and great speakers."

Epilepsy Symposium

In November 2016, Epilepsy Queensland held its Annual Epilepsy Symposium, 'Thinking outside the box'. The focus was 'Enhancing seizure control' and our highly regarded speakers throughout the day engaged the audience with topics such as epilepsy surgery, medicinal cannabis, managing the impact of epilepsy and directions for future research in epilepsy.

Seizure First Aid

In 2017 Epilepsy Queensland held an appeal focused on raising funds for our seizure first aid program and as a result of generous support, were able to update our resources and conduct additional training. Our tax appeal told the story of Larissa Winter on ANZAC Day 2017. Through seizure fist aid training she was able to provide potentially life changing assistance to a baby having a seizure. The resulting campaign had a reach of nearly 50,000 through social media and enabled us to undertake two additional seizure first aid trainings.

Seizure first aid awareness is very important for helping people to feel safe and being able to educate the community has always been a key focus. It is never more heartening to hear when our awareness efforts make a difference.

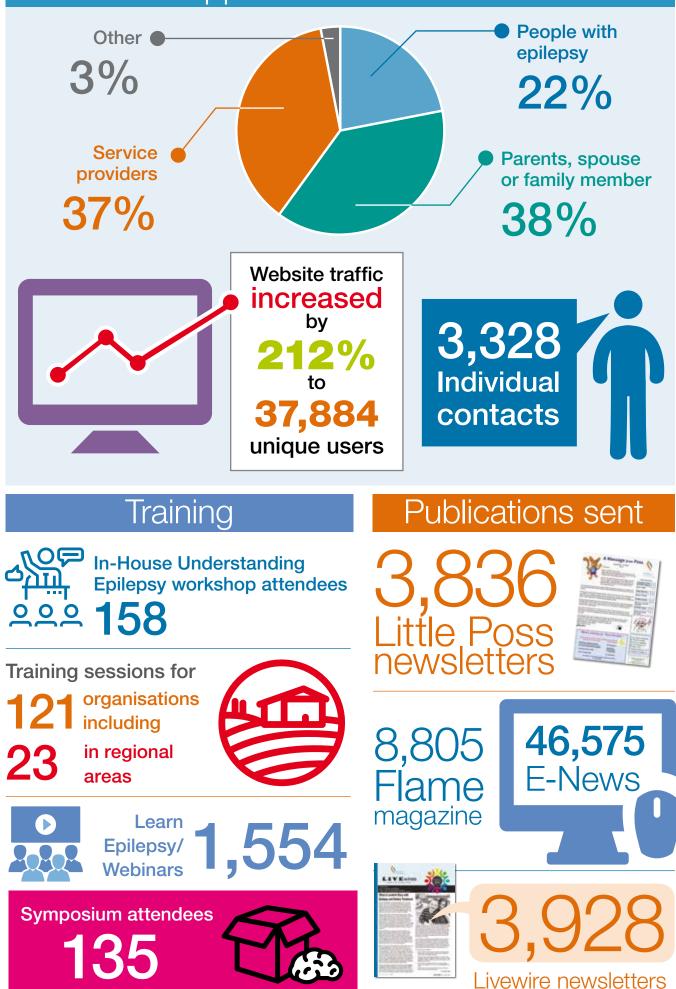
Training

Epilepsy Queensland educates health workers, disability support staff, and teachers about epilepsy to assist them in their various roles supporting people with epilepsy. Face-to-face training at the service provider's own organisation continues to be a high priority, although increasingly these groups are also accessing our webinars and online learning courses. Our website "Learn Epilepsy" is currently being redeveloped.

Those who attend our introductory workshops in Brisbane and the Gold Coast develop an understanding of epilepsy as a complex condition as well as raising seizure first aid awareness in a positive way. Thinking me box!

Alison did a fantastic job. She is a great training presenter. Thanks to her presentation and the information from the family. Staff are feeling much more knowledgeable and better prepared. Hopefully we never have to use it! - Desley

support and information



consumer engagement, advocacy and awareness - bringing epilepsy out of the shadows

Epilepsy occurs in one in 50 people in our community, yet there are widespread misconceptions. For many people the social stigma that comes from community fear and misunderstanding can be more difficult to deal with than the condition itself. Through people sharing their stories and hosting events we are able to build awareness and reduce misunderstanding in local communities throughout Queensland.

We participated in expos and conference information displays, including the APP conference attended by over 6,500 pharmacists.



Epilepsy Queensland has worked with the Department of Health on the introduction of medicinal cannabis.

purple day

Facing the challenges of stigma and awareness

Purple Day was founded in 2008, by nine-year-old Cassidy Megan of Nova Scotia, Canada. Motivated by her own struggles with epilepsy, Cassidy started Purple Day in an effort to get people talking about the disorder and inform those with seizures that they are not alone.

Epilepsy Queensland is proud to have introduced Purple Day to Australia back in 2009, with the aim of bringing epilepsy out of the shadows and raising funds for epilepsy support services in Queensland.

Heroes taking on challenges

Each year we are incredibly grateful for the support of our Purple Heroes for Epilepsy during the month of March.

Brave 16-year-old Rhiarnie Coyne, cut off her hair for her brother and cousin who both live with epilepsy. Rhiarnie and her Mum Natalie organised the cut and morning tea for epilepsy.

Rhiamie said: "I remember when my brother Jack had his seizures. I felt scared and helpless. I remember watching Mum crying. My bizzest fear was watching the ambulances (sic) working on Jack. If I can help make a difference and bring epilepsy out of the shadows I will be happy."





Events

It seemed like the whole town of Pittsworth turned purple with a number of businesses showing support through displays in shop windows, a sausage sizzle, cupcakes and a Purple Day merchandise stall organised by Ann Thompson and her band of volunteers.

Many supporters also hosted morning teas for epilepsy. Special thanks to the Cairns Hospital Neurology Department and the Lady Cilento Children's Hospital Neurology and ketogenic diet teams for hosting fantastic and delicious Purple Day events.

Merchandise and support of pharmacies

Each year the Pharmacy Guild of Australia (Queensland Branch), support Purple Day and the Little Poss Appeal and encourage pharmacies across Queensland to do the same. Some of those pharmacies really go the extra mile to show their customers living with epilepsy they are not alone, by dressing up in their most outlandish purple outfits and wigs. This year the Purple Award for Pharmacy went to a Sunshine Coast local business, Pelican Waters Pharmacy.



Purple pledge



Queensland landmarks go purple

The Purple Pledge Project is an Epilepsy Queensland initiative to raise awareness of epilepsy and dispel the myths surrounding the condition. Renee Williams from Bargara took on the challenge of getting 200 signatures for the Purple Pledge. She was thrilled to present Epilepsy Queensland Acting CEO Natalie Lee with over 300 signatures collected mainly at a stall at Bundaberg Base Hospital. Her efforts raised significant awareness as she was featured in the Bundaberg NewsMail, as well as the local ABC Radio and Channel 7 News.

This was a significant achievement for Renee as she had not previously revealed her epilepsy to even close friends. Now Renee has become a strong advocate for building understanding of epilepsy in the Queensland community.



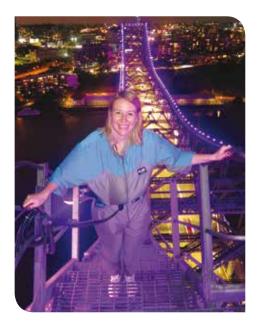
One of the highlights of Purple Day is landmarks across the state turning purple for epilepsy. Fountains in Mackay, Bundaberg and Ayr were purple for the day to raise awareness. Thank you to the councils in these areas and our volunteers who advocated for these local awareness raising strategies.

Brisbane lit up purple for epilepsy including the Story Bridge (which also carried our banner), Brisbane City Hall, Treasury Casino, QPAC and for the first time the Roma Street Parklands Wall of Water. We were thrilled to see all of the selfies with these fantastic purple landmarks.

Racheal Johnson faces her fear of heights!

Brisbane resident Racheal Johnson is terribly afraid of heights, but took on the Story Bridge Climb for her daughter Isla on Purple Day as the bridge lit up purple. Racheal wanted to raise as much money as possible so that others continue to have access to the same vital services that made such a difference when her daughter was newly diagnosed. She did a fantastic job raising \$1,532!

Racheal said: "After attending a workshop with Epilepsy Queensland and having spoken to them over the phone a number of times, I was amazed at how knowledgeable and supportive they were. I really wanted to give something back to them. I wanted to do something out of my comfort zone as many times Isla is faced with appointments, examinations and tests that she doesn't want to do! So I decided to conquer my fear of heights."



Racheal conquered that fear and helped to bring epilepsy out of the shadows on Purple Day.

Community engagement

It may not be Purple Day every day, but with the support of the epilepsy community, we strive to raise awareness of epilepsy year round. Our presence continues to grow on social media as we have new people liking and following our page on Facebook. Through the community liking and sharing our content, we are able to spread awareness to more people. Our aim is to reach more than 5,000 page followers by the end of 2017. We are pleased to say that we are very close to that target.

In January 2017, 23-year-old Caboolture resident Britney Stubbs had her first seizure behind the wheel of her car, causing her to crash. Fortunately, no one was injured, including Britney, but the effects of epilepsy on her life have been significant.

Despite these challenges, Britney is not the type of person to let epilepsy get the better of her. Instead, she shared her story and shaved her gorgeous head of hair to help others who have just had a seizure or are newly diagnosed with epilepsy. Britney and her Mum, Linda raised funds through an Everyday Hero page, donations from a local cafe and a raffle at Linda's market stall.

Linda Stubbs commented on Facebook about Epilepsy Queensland's support: "Excellent support network for my daughter who is suffering from epilepsy. Also for myself as a very concerned mother who is going through this struggle with her."





sustainability

Raising funds in the community

Thank you to everyone who has supported Epilepsy Queensland during the financial year through membership, donations, regular giving, art unions and raffles, merchandise sales, fundraising and events. It is only through your generous support that we are able to continue to provide services to Queensland children and adults living with epilepsy. Here are some of our highlights for 2016/17.

Purple Ball

Epilepsy Queensland's 2017 Purple Ball launched our awareness campaign for the month of March, with a fantastic evening of purple glitz, glamour, fundraising, fine dining and entertainment.

Guests were treated to a wonderful night of magic, music and entertainment with special mention to our MC Andrew Lofthouse and Auctioneer Chris Bombolas. The highlight for many people was a heartfelt speech from 10-year-old Purple Day Ambassador Nickayla Winter who received a standing ovation. Nickayla left everyone feeling that you can't let epilepsy get in the way of living a happy and fulfilling life.

Once again, our Purple Ball raised awareness about epilepsy and vital funds of in excess of \$35,000 to help people with epilepsy and their families. Our heartfelt thanks go out to our sponsors, supporters, donors, volunteers, staff, board and the initiator of the Purple Ball, Elsewerth Ephraums.



Toowoomba Epilepsy Charity Golf Day



Peter Meyer is a passionate advocate for epilepsy, hosting his annual Toowoomba Epilepsy Charity Golf Day in December 2016 at Middle Ridge Golf Club. We are extremely grateful to Peter and his wife Susan along with their supporters for raising nearly \$60,000 to support vital epilepsy services.

A host of sporting heroes shared their stories and teed off with local supporters. Brian Lara, widely acknowledged as one of the best cricketers of all time, took to the greens along with former Australian Cricketer Greg Ritchie. They were joined by Epilepsy Queensland's Patron Wally Lewis.

We thank Peter for his ongoing support personally and via his business eComputing, sponsoring Epilepsy Queensland's 2016 awards and donating prizes for the Purple Ball.

Lendlease Charity Golf Day

Lendlease are long-time supporters of Epilepsy Queensland and their August 2016 event raised a record breaking \$86,000. Their fantastic contribution was shared equally between two charities, Epilepsy Queensland and Legacy. In seven years, the event has raised an amazing \$492,000 for Queensland charities.

The day is always highly entertaining fostering healthy competition and fun between colleagues and their teams. After their spirited round of golf the very generous participants were whipped into a frenzy of giving by the always entertaining Rupert McCall, Epilepsy Queensland's Patron Wally Lewis and auctioneer extraordinaire Scott Gemmell from LJ Hooker New Farm.



We look forward to continuing this wonderful relationship with Maria Bran and the Lendlease Golf Day Committee at future events.

How you can help

Your support, no matter how large or small, has a positive impact on the lives of Queenslanders living with epilepsy.



Join the conversation on Facebook



Make a donation



Join us - membership



Challenge yourself



Volunteer your time



Leave a legacy





Share your story



Join the conversation

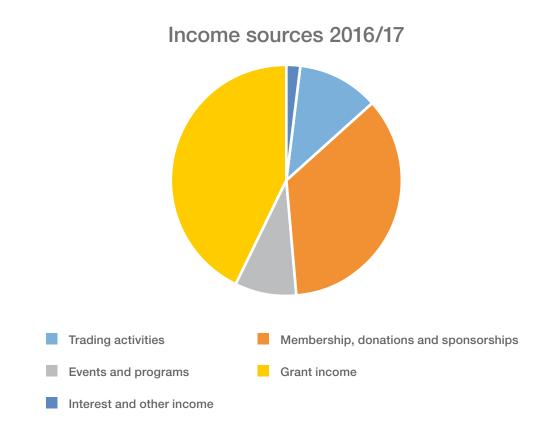


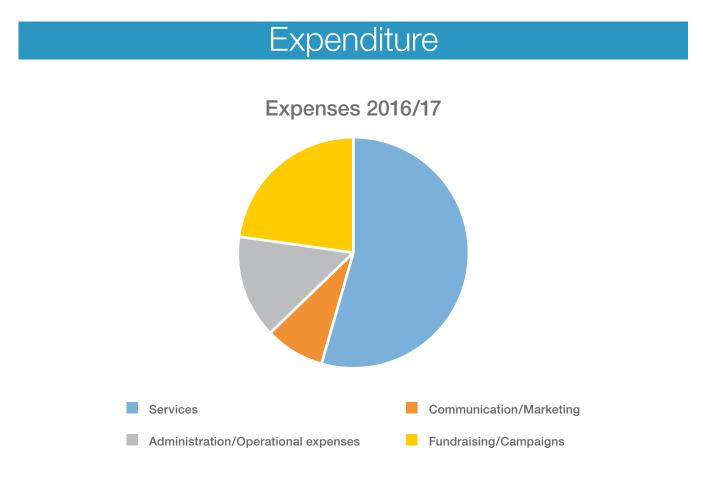
Raise awareness

Strategic review

Epilepsy Queensland has been undertaking a strategic review of its operations. With the changing funding environment in which we work and the developing needs of people living with epilepsy and their families, such a review is key to our ongoing sustainability and positioning for the future.

Income





our people

Our Patron

Once again, throughout the year, our amazing Patron Wally Lewis has helped to bring epilepsy out of the shadows. Wally is always happy to share his experiences and take the time to speak with people from all walks of life, who often share a similar story.

From attending events on behalf of Epilepsy Queensland, to gearing up auction bidders, participating in golf days, presenting the Awards at our AGM and advocating for Epilepsy Queensland, nothing is too much for this warm and generous man. We salute you Wally and look forward to continuing to increase awareness and understanding of epilepsy with you.

"

I think it is fair to say that every child born with epilepsy and every family with such a child or those trying to help such a child would have been hugely indebted to you for the informative but also very touching way in which you thoroughly addressed the challenges, but also hopes, for this ailment.

- David on a speech ziven by Wally Lewis at their club.



"

In february 2017 Wally celebrated 10 years of freedom from seizures after epilepsy surgery in 2007. His 10year anniversary received significant coverage in the media helping to bring epilepsy out of the shadows.

"



Board, staff and volunteers

The staff of Epilepsy Queensland are vital to our success in all endeavours. Some roles have been restructured in line with our strategic review, particularly in the areas of Services Development and Communications/Marketing. During the 2016-2017 year our full time equivalent was 9.68, a slight increase from 9.37.

Epilepsy Queensland's Board is the governing body of the organisation, meeting at least once every two months. All members are Honorary. Kristin Ramsey was recruited to join the Board on 30 January 2017. Kristin is a lawyer with specialist expertise in employment and industrial relations.



Our volunteers are highly valued participants in all areas of the organisation's operations including pro bono specialists, our team of office volunteers, speaking ambassadors, fundraising and events. Their generous contribution of time and expertise is of monumental benefit.

vale



Robert Kemp

We are saddened to report that Robert Kemp died on 5 April 2017. Robert was the son of Arthur and Doris Kemp OAM who was the founder of Epilepsy Queensland.

After he left school, Robert was employed in a number of jobs but the effects of epilepsy were not widely understood and his services were terminated frequently and unfairly. At that time, there were no laws to ensure equal employment opportunities for people with disabilities and there was a great deal of ignorance about epilepsy. Doris vowed to change things and the Epileptic Welfare Association of Queensland was established in 1969.

For a long time the Association operated out of the Kemp family home and Doris was the driving force behind the organisation for many decades.

Robert lived independently at home after his parents died until he was ready to retire to a nursing home. He had a close and loving connection to family and a happy disposition. Robert had a range of social interests including billiards and the Irish Club. He loved music and held season tickets to QPAC. He had a great sense of style and dressed in a black dinner suit with fancy shirt and bow tie to match on these occasions.

We miss Robert's presence and look forward to honouring his legacy during our 50th Anniversary year.



John Wellings

Former President of the Association, John Wellings died on 19 August 2016. John Wellings was elected to the Managing Committee of the Association in 1977. He held the position of Senior Vice President and then President from 1985 to 1993.

A warm hearted and caring person, John gave unstintingly of his time and expertise to the Association.

John was a lecturer in Early Childhood Studies and his family have kindly agreed that we name our Education Award in his memory. The Pam Wellings Memorial Award for a volunteer is named in his wife's memory.



thank you for your support

We sincerely appreciate the help that so many people and organisations have given us from July 2016 to June 2017. Those listed below, in addition to many others, have substantially contributed in some way to helping Queenslanders whose lives are touched by epilepsy.

- Our Patron Wally Lewis
- Department of Health
- Department of Communities, Child Safety and Disability Services
- Gambling Community Benefit Fund
- Australian Communities Foundation

Partners/Sponsors

- The Pharmacy Guild of Australia (Queensland Branch)
- MedAdvisor
- Royal Brisbane and Women's Hospital
- UCB Pharma Australia
- SciGen
- EpiAssist
- The NeuroCare Network/Spark
- NeuroCare
- EISAI

Fundraising

- Ipswich 100 Bike Ride Lions Club of Moggill-Mt Crosby
- RUSH CBD 2016 Melbourne Cup on the Green
- The Good Guys
- Specsavers Optometrists
- Lendlease Annual Charity Golf Day
- Southside Eagles Football Club
- Peter and Susan Meyer
- The Bernborough Club
- Kedron Wavell Services Club
- Janelle White and Family
- Hume Doors & Timber
- Walker Wayland Australasia
- Our Everyday Heroes and Bridge to Brisbane participants

Purple Day and Little Poss Appeal

- Our partners at www.purpleday.org
- Purple Day Founder Cassidy Megan
- Followmont Transport
- The Pharmacy Guild of Australia (Queensland Branch)
- Brisbane City Council
- Fundraising Services team
- The Print Bar
- Our Purple Day Heroes and those who hosted fundraising events and/or sold merchandise

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2017 Purple Ball

- The Pharmacy Guild of Australia (Queensland Branch)
- Andrew Lofthouse
- Chris Bombolas
- Winter Family
- Victoria Park Golf Club
- QT Mutual Bank
- Mercedes-Benz Brisbane
- Firefly Events & Project ManagementMusicanHub

Volunteers and Students

- Paul Barry
- Martin Bevis
- Jannie Bijkerk
- Amanda Budd
- Andrew Budd
- Rozanne Burley
- Cassandra D'Arcy
- Georgia Edwards
- Tracey Francis
- Karen Garland
- Gerard Gaudiello
- Carolyn Gibbs
- Melanie Gilchrist
- Zeta Gilchrist
- Matthew Gunders
- James Henderson
- Breeze Hunter
- Trent Long
- Marie Lyall
- Justin MacDonald
- Isabella Mastrogiacomo
- Oliver Minter-Stubbs
- Amelie Nicholson
- Della Nicholson
- John O'Doherty
- Keith Phillips
- Jackie Saunders
 Annelies Shaw
- Annelles Snaw
 Gus Smith
- Gus Smit
- Shelley Sparrow
- Chris SuttonBen Trigger
- Bianca Wrakuale
- Kam Yeomans
- Margaret Tiainen
- National Australia Bank staff
- Suncorp staff

Gifts in Memory

- Rachel Burley
- Karen Carrigan
- Cameron Dallinger
- Samuel Milne
- Verena Smith

Speakers and Advisors

- Prof David Reutens
- Dr Lindy Jeffree
- Joshua Marks
- Dr Kate Thompson
- Angela Spencer
- Yvette McMurtrie
- Anastasia Suraev
 Jordvn Stuart

Kimberley Irwin

Dr Paul Pun

Dr Geoff Wallace

Dr Cecilie Lander

Dr Sandra Petty

Dr Karin Borges

Dr Steve Malone

Emily Prain

Michelle King

Michelle Hiller

John Manuel

Koka Trevor

Sandra Gurr

Ruth Blackburn

Dr Karin Borges

Renee Williams

Selena Anderson

Communications

Wuhoo Creative

Dr Harry SinghIMGA – Mediprotect

Epilepsy Australia

Jan Taylor

News Corp Australia

Queensland Newspapers

Ann Thomson

• PR Print

Channel 9

• GO1

And...

Gerrard Gaudiello

Kelly and Tiffany Burgess

Sally and Natalie Morse

Larissa and Nickayla Winter

Goodstart Early Learning Centre – Idalia

Kangaroo Point Holiday Apartments

Darling Point Special School

Pilot Chartered Accountants

British Epilepsy Association

Epilepsy Therapy Project

International Bureau for Epilepsy

15

Linda Ray

Dr Dan McLaughlin

For sharing their story or articles

Christine and Chloe Clarke



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...bringing epilepsy out of the shadows