



epilepsy  
queensland | inc

# 2018 – 2019 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 Inc

## Our values

We **respect** and **care** about those impacted by epilepsy. We are **accountable** for our actions, **passionate**, and **person-centered** in our approach. We value **collaboration**, are **agile**, and ensure **integrity** in all that we do.

## Customer service charter

Epilepsy Queensland cares about your story and values your experience. We:

- Provide welcoming and supportive care
- Ensure prompt and attentive service
- We strive to provide current and factual information
- Seek and welcome feedback to continually improve our service
- Provide timely and transparent resolution to any complaint
- Walk beside people on their journey with epilepsy

## Our strategic priorities

- Empower individuals and families
- Enhance our community engagement and advocacy
- Ensure sustainability

## Directory

Patron  
Wally Lewis

Chief Executive Officer  
Helen Whitehead

## Board as at 8 November 2019

Chairman  
David Bunker

Treasurer  
Kalvin Booth appointed 28/10/19

Secretary  
Andrew Barnes

Board members  
Charmaine Driver  
Kim Davis  
Katrina Tune  
Sam Bryce appointed 03/12/18  
Treasurer Jane Vidler retired 07/10/19  
Kristin Ramsay retired 03/12/18  
Kos Sclavos retired 03/12/18

# chairman's report



This year Epilepsy Queensland celebrated its 50th Anniversary, truly a significant milestone for any organisation and especially for an organisation that aspires to serve, to advocate and support Queenslanders. This year, like every other year since 1969, Epilepsy Queensland maintained its mission to optimise life for people living with epilepsy and bring epilepsy out of the shadows.

Epilepsy Queensland is an organisation that lives its values: to respect and care about those impacted by epilepsy, to be accountable for its actions, passionate, and person-centered in its approach, and to truly value collaboration, remain agile, and ensure integrity in all that it does.

As Chair of Epilepsy Queensland, this report provides me a personal opportunity to thank our sponsors, our volunteers, board and staff members for everything they do. I say this, not only as an office bearer, but as a father, husband and friend to people living their best lives with epilepsy. This report also affords me an opportunity to reflect on the goals we set for the business, and our journey to achieve the measures we set ourselves - for our community.

Epilepsy Queensland continues to foster a supportive environment for people with epilepsy and their families in their work places, in their education environments and in the broader community. We also maintain a goal to contribute to scientific understanding of epilepsy through research and education. This year the 'Thinking outside the box' Symposium was an inspiration and showcase for research and practice in epilepsy management, and a great network building and community engagement event. Of course, we also seek to ensure long-term sustainability and forward planning. In and through these goals we maintain our dedication to improving the quality of life of people with epilepsy and their carers and families through information, support, counselling, education, training, advocacy and research.

Reflecting on the year that was, some special commendations and thank yous are required. To all our contributors, volunteers and fund raisers, your support is greatly appreciated. We acknowledge the recurrent grant funding provided by Queensland Health and the twelve month grant from Department of Communities, Disability Services and Seniors to assist with the NDIS transition.

To the Brisbane Lord Mayor, Adrian Schrinner, our special thanks for hosting our 50th birthday celebration at City Hall. Thank you also to Wally Lewis for his continued patronage and support. This year I had the opportunity to meet with many of our volunteers and supporters at fund raising events, and at a special morning tea to show our appreciation to the Deputy Premier Jackie Trad for her support. The take away for me has been just how special the people in our community are, the selflessness, the diversity, the commitment. My gratitude for all of you, our members and supporters.

In the year to come the business will focus on building brand, on outreach, especially to our rural and remote communities, and campaigning to raise funds that effectively pay for our services. We remain open to opportunity, so please know that our doors are open, and your contribution is welcome.

Our commitment is that Epilepsy Queensland will go forward, we will manage our financial position closely, we will build capacity and look to develop new ways to provide training and education, and to reach as many Queenslanders as we can, to bring epilepsy out of the shadows

# helping and empowering the community

Epilepsy Queensland aims to empower and support people with epilepsy, their families and carers by providing support services, information and connection to peer groups. Our dedicated services team has a wider impact through a holistic approach, providing training and information to health and disability workers, teachers, businesses and community groups. Epilepsy Queensland is also dedicated to raising awareness about epilepsy to decrease stigma and promote understanding, inclusion and support for people affected by epilepsy and their loved ones.

“ for anyone living with epilepsy, this is a great place to communicate with others that are going through the same thing. A place of understanding and caring. - Bruce ”

“ Trish- Thank you for your time and support in explaining many things [during our call] this morning. I really appreciate the work of Epilepsy Queensland and the dedication of everyone offering the highest level support. - Pauline ”

## Helpline

Our helpline continues to deliver telephone support as a vital point of first contact for people living with epilepsy across metropolitan and regional Queensland. Our dedicated and multidisciplinary team is a trusted source of current information as well as practical and emotional support. As many people with epilepsy may only see their specialist a few times a year, having access to caring professionals and being listened to with compassion and understanding supports positive psychological well-being for people affected by epilepsy.

## Information Services

Epilepsy is a multi-faceted condition that requires an individualised approach. Epilepsy Queensland provides high-quality, often tailored information resources that empower people with the knowledge to manage their condition where possible and to optimise their wellbeing and self-care. This year, we refined our poster for our seizure first aid awareness campaign, which ran throughout the month of September. Epilepsy Queensland also continues to provide Flame, our quarterly newsletter to our members.

“ A special thank you to those staff who organise the 'Flame' magazine for so many readers who not only learn a wonderful amount but also by reading it, don't feel so alone while dealing with the little issues epilepsy might bring with it. - Jane ”



## Regional Services

People with epilepsy and their families that reside in regional Queensland can access support provided by Epilepsy Queensland through our telephone helpline and website. Our services team travel across Queensland on-demand to deliver *Understanding Epilepsy* and the *Administration of Midazolam* workshops, facilitate community meet-ups and conduct NDIS funded services such as assistive technology assessments. Our youth services in regional areas, including meet-ups, have been funded by The Great Elders Cattle Muster, which took place in 2018.

“ Donna- thank you! I think your course was excellent and it was so nice to see our consumers benefit from such important information.” - Kylie, Neurology Clinical Nurse Consultant, Gold Coast Hospital. ”

## NDIS Support

Epilepsy Queensland is a registered National Disability Insurance Scheme (NDIS) provider and assists people with epilepsy through the NDIS process. Our services team provides support to individuals and families to navigate the new system. We offer a free pre-planning support session to prepare for appointments with the NDIA to ensure people with epilepsy achieve the best possible outcome from this process. Our team provide assistive technology assessments and we also provide NDIS information sessions with all the latest news and updates. Further services we continue to deliver include consultation to develop epilepsy management plans and facilitating our E-connect program for teenagers and young adults.

“ Leonie- Thank you very much for all of your work and patience with everything that you have done for Joseph and our family. You have always been approachable and your service and commitment has made such a positive experience for us with the initial NDIS process. You are amazing and so very thorough and it has been an absolute pleasure and delight to have you taking this journey with us. - Alana ”

## E-connect

In June 2019, Epilepsy Queensland facilitated E-connect, a two-day program of self-care and wellness workshops for teenagers and young adults living with epilepsy. The program delivers fun, engaging and age-appropriate activities which provides a supportive environment for peers to connect, share and learn life skills and more about epilepsy. Participants were able to choose from a variety of activities including arts, music, sports and cooking. Positive feedback indicated the workshop was well-received with participants gaining new friendships, new knowledge about seizures and epilepsy, and improved self-care skills.



## Little Poss Children's Programs

The social impacts of epilepsy can be difficult, particularly for children and their families. Epilepsy Queensland has a special club for children living with epilepsy featuring mascot, Little Poss. Little Poss is a possum who also has epilepsy and loves to help children and their family and friends learn about epilepsy through fun activities, information resources and newsletters. Little Poss has a birthday party each year and this was well attended by little ones and families who come together in a safe environment for a fun celebration.

“It's wonderful watching the children come together to celebrate Little Poss' birthday. They really enjoy this loving mascot, who provides an opportunity for them to come together and for parents to connect as well. - Mary-ann



## Epilepsy Symposium

The ninth annual epilepsy symposium “Thinking Outside the Box” took place at The State Library in October 2018. The event was well attended and featured renowned experts from a variety of fields. Topics included autoimmune epilepsy, seizure prediction devices, the changing landscape of epilepsy surgery and the role of venomous animals in the development of medicines for epilepsy.

The symposium provided the opportunity for members of the epilepsy community, health professionals and affiliated organisations to connect and engage in stimulating dialogue about the latest epilepsy research and developments.

“What a great day, thank you to all! I especially liked the session on the venomous animals and their role in treatments. - Cheryl-anne

“Jenny- thanks so much for the training last night. We do a lot of training each year and we believe that the session last night was one of the best training sessions we have taken part in. - Skye Sunkids Children's Centres



## Training

Epilepsy Queensland provides training to community and disability support organisations, health and welfare groups, businesses, education providers, students and more. In-service training continues as a convenient option for service providers and these are responsive and often tailored, and delivered in a variety of formats.

We also offer a suite of online and offline training resources for those that cannot access face-to-face training. The online training option is nationally available through Epilepsy Australia and features modules on understanding epilepsy and emergency medications, understanding epilepsy management plans and the Smart Schools Program.

In-person training can be accessed at one of the monthly workshops at the Woolloongabba office and is also delivered on various dates throughout the year on the Gold Coast. Epilepsy Queensland members are eligible for one of these training sessions per year, free of charge.

## Website and social media

Epilepsy Queensland's digital interfaces including our website, e-news and social media networks allow people to overcome geographic boundaries to access the latest events, news, and research outside of business hours. This provides a forum for discussion where people can engage with others affected by epilepsy.

The implementation of a Social Media Strategic Plan this year has resulted in the increase and re-engagement of our community across Instagram, LinkedIn and Twitter. Facebook continues to be our largest and most active social media community, with strong engagement and growth.

We are close to realising our 2019 goal of a new website, designed for easy navigation with a fresh new look yet the same comprehensive information.

## Seniors Project

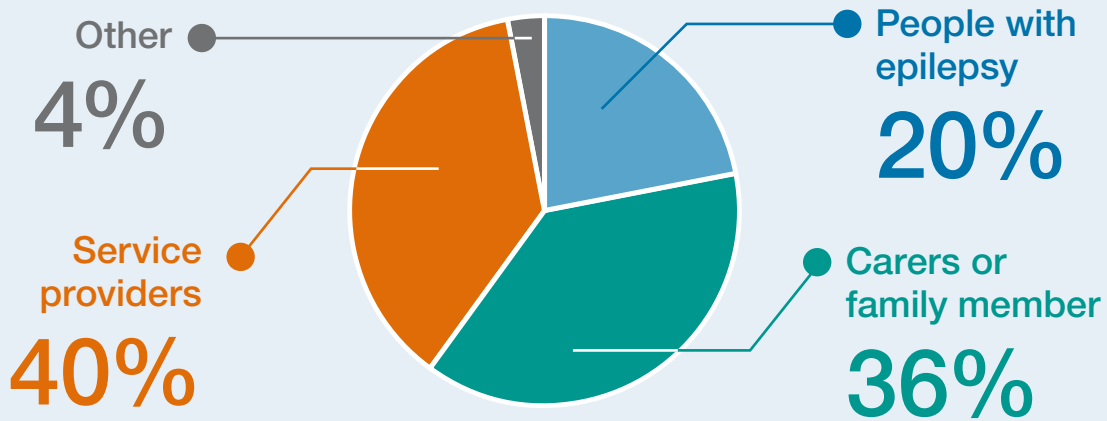
For senior people with epilepsy (aged 65 years and over), everyday living can be challenging with a profound impact on a person's independence and capacity for economic and social inclusion. Despite advanced age now being the most common time to develop epilepsy, this is often not the first condition to be considered when an older person has a seizure. This is due to clinical presentation resembling other conditions common in older people, such as stroke, cardiovascular disease or dementia.

This identified knowledge gap underpins Epilepsy Queensland's seniors project “Faints, falls and ‘funny

turns’- could it be epilepsy?” This one-year project has been funded by a Brisbane City Council grant under its Access and Inclusion Community Partnership Program 2018-2019.

A key part of the project has focused on individual capacity building for older people to identify and learn strategies to overcome barriers to access and inclusion. The project will culminate in the development of a practical resource suitable for use by mainstream and community services- “A Practical Guide to Epilepsy/Seizures in Later Life”.

# support and information



Website traffic **increased** by **17%** to **103,260** unique users

**3,677** Individual contacts

## Training



Training session attendees  
**1,895**

Training sessions for **143** organisations including **17** in regional areas



**476**

Learn Epilepsy / Webinars

Symposium attendees

**161**

## Publications sent

**2,688**

Little Poss newsletters



**3,797** Flame magazine

**49,037** E-News



**2,154** Livewire newsletters

## Facebook



**28% Increase**  
Page likes increased from 5821 – 7426

**59% Increase**

Average post reach increased from 1729 – 2744



# consumer engagement, advocacy and awareness

Epilepsy occurs in one in fifty 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 throughout Queensland.

## purple day

### Bringing epilepsy out of the shadows

Every March we celebrate Purple Day, our major fundraising and awareness event of the year. Purple Day is an initiative dedicated to raising awareness about epilepsy worldwide. It's an opportunity to show those living with epilepsy that they are not alone and to encourage conversations about the condition. We continue to use this opportunity to build awareness across all community sectors in Queensland and beyond and raise funds so we can continue to support people living with epilepsy and provide our vital services. Our Purple Day campaign is supported by large and small corporations, businesses, pharmacies, hospitals, schools, clubs, families and friends in an effort to unite the community towards this very important cause.

### Everyday Heroes championing the cause

Each year people living with epilepsy and their family members and friends take on Purple Day challenges. In 2019 we again had a group of intrepid supporters climbing Brisbane's Story Bridge as it was lit up purple for epilepsy awareness. The group included 17-year-old Chloë Bradford who climbed the bridge for her younger sister Brydie, who lives with epilepsy. The family raised an amazing \$1,323 and travelled all the way from Yarranlea (past Pittsworth) to be a part of our celebrations.

Brisbane Mum, Larissa Winter also took part in the climb for her daughter and Purple Day Ambassador Nickayla. Larissa is petrified of heights and had many a white knuckled moment throughout the climb.

Larissa explains why she took on the challenge. "Epilepsy Queensland provides me with so much support, and there have been many times when I have called up in tears not knowing what to do. Having someone to talk you through it and explain what to do is vital for parents with a child living with epilepsy. Epilepsy Queensland also went out to Nickayla's school to train the teachers on how to handle her seizures. It has made the world of difference to our lives."

We are thrilled and grateful for the long term support of the Winter family, their enthusiasm has made a difference. You don't need to climb a bridge or take on your worst fear to be a part of Purple Day. We are incredibly grateful to everyone who created an Everyday Hero page and shared their epilepsy story with family members, friends and colleagues to raise vital funds.

### Events

Special thanks to the Cairns Hospital Neurology Department for going purple the whole month of March. They raised an amazing \$2,500 hosting a morning tea and selling purple day merchandise on clinic day and at their local shopping centre.

"We make sure that all of our patients know about the services that Epilepsy Queensland provides as they are a major source of support for so many people," says Neurology Administration Officer, Teresia Lallemand.

In Mackay, Palmview Village hosted Purple Day celebrations with 110 residents attending. They were able to raise great epilepsy awareness with local radio 4MK and Channel 7 Mackay News involved. Through their event and Purple Day merchandise sales they raised a fantastic \$2,219.





Queensland students continue to show impressive support with 46 schools and early learning centres across Queensland taking on purple challenges to highlight epilepsy in March. Freshwater Christian College in Cairns have been long time supporters and this year held a purple free dress day raising awareness and funds for Queenslanders living with epilepsy. Thank you to the Morse family for their support in organising this event.

Mt Maria College have a number of students living with epilepsy and their teaching staff access training from Epilepsy Queensland. Thanks to the Unnasch family, they held a Purple Day awareness event attended by Epilepsy Queensland Patron Wally Lewis. The school generously donated \$500 to help support more Queenslanders living with epilepsy.

## Working with retail partners

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. This year the Purple Pharmacy award went to a Sunshine Coast local business, Buderim Pharmacy.

Pharmacist Mel said: “We fundraised all through March and made sure that we wore purple every couple of days. Then on Purple Day (26 March) we decorated the whole pharmacy and brought out a epilepsy selfie frame. Our boss pledged to donate a dollar for every selfie taken towards Epilepsy Queensland.”

“We are proud to be supporters of Purple Day and the staff enjoy getting behind it by dressing up in purple. We all wore purple and I baked a cake and asked for gold coin donations. We also sold Epilepsy Queensland merchandise throughout the entire month. One man loved the pens so much he came back and bought himself some more because they wrote so well!”

Thank you to Followmont Transport who are major sponsors of Epilepsy Queensland.



## Queensland landmarks go purple



One of the highlights of Purple Day is landmarks across the state turning purple for epilepsy. In our 50th year we were pleased to have more illuminations than ever before. Fountains in Mackay, Gladstone and Townsville went purple for the day to raise awareness. The Victoria Bridge, also in Townsville, was illuminated purple, along with trees in Hervey Bay, Town Hall in Maryborough, the Broadbeach sign on the Gold Coast, Toowoomba’s Victoria Bridge was illuminated and in Ipswich the Civic Centre went purple. There were also a number of unique illuminations including the giant whale in Hervey Bay, the water towers in Logan, Gasworks gasometer at Teneriffe and Graincorp silos in Dalby. Thank you to the councils and businesses 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), Victoria and Kurilpa Bridges, City Hall, Treasury Casino, QPAC, Parliament House, Howard Smith Wharves and Suncorp Stadium. We were thrilled to see all of the selfies with these fantastic purple landmarks.

Thank you Brisbane City Council, City of Gold Coast, Fraser Coast Regional Council, Gasworks ULA group, Gladstone Port Authority, Graincorp, Ipswich City Council, Logan City Council, Mackay Regional Council, Office of Speaker of the House, QPAC, Queensland Department of Housing and Works, Suncorp Stadium, Toowoomba Regional Council, Townsville City Council and Transurban.

## Awareness

The 9 News Queensland team were big supporters of Purple Day 2019 helping us to bring epilepsy out of the shadows. Our Patron, Wally Lewis, did a live sports news cross with a number of our supporters dressed in purple and the Story Bridge illuminated purple as a backdrop. The news team including Andrew Lofthouse, Melissa Downes and Garry Youngberry dressed in purple for the Statewide broadcast.

We are extremely grateful to ODNA for pro-bono advertising on their network of digital billboards across Brisbane. The striking purple and green ads featuring our Purple Day ambassadors Wally Lewis and Nickayla Winter reached a large



audience of motorists on busy Brisbane roads. The advertisements were displayed at 17 sites across Brisbane for the two-week period in the lead-up to Purple Day. The estimated exposure was 3.6 million cars per week.

Purple Day messages were also displayed on electronic message boards on the Logan and Gateway Motorways thanks to Transurban from 24-26 March. Estimated exposure was 279,000 cars per day.

We also received pro-bono Purple Day radio advertisements on 97.3 and 4KQ. These advertisements reached an estimated 346,000 people.



## SUDEP Action Day

If a person with epilepsy dies suddenly and no obvious cause can be found, it is called Sudden Unexpected Death in Epilepsy (SUDEP). Each year SUDEP Action Day is held on 23 October and Epilepsy Queensland joins with other epilepsy organisations around the world to promote the day. SUDEP can be a difficult topic to talk about, but SUDEP Action Day encourages us to do just that. We encourage people to know their level of risk and to take action to reduce the risk. This includes maximising seizure control, being sure to never run out of or suddenly stop taking anti-epileptic medication and avoiding known seizure triggers.

## In Memory

Any loss to our epilepsy community is deeply felt, whether it is related to a person's epilepsy or not. Sometimes family members decide to honour the memory of a lost loved one by fundraising and raising awareness of epilepsy in their name. We are grateful to be able to share in these memories and work with families to make a difference.

### Faith's Legacy

On 13 December 2019, Faith Gray from Mackay unexpectedly passed away following complications from a seizure.

The Gray family, their friends and colleagues wanted to do something to support other families affected by epilepsy as well as share their loving memories of Faith and their grief. They created an Everyday Hero page and to date have raised nearly \$8,000.

We are honoured that the Gray family shared these memories of Faith with us.

"Faith Gray was the youngest of three daughters born of Kelvin and Kathy Gray. She was diagnosed with epilepsy after her first seizure at 13 years of age."

"Despite epilepsy setting her back from achieving some milestones, it never broke her spirit. Faith graduated from university with a Bachelor of Learning Design in 2017 and was on the way to fulfill her dream of becoming a special education teacher. She tutored many students, worked as a teacher aide at a local high school and maintained work in her local Coles."

"She inspired all she met to embrace themselves, quirks and all. She seldom let negativity win. All those who knew Faith instantly felt the warmth, kindness and generosity she exuded. She was one of a kind and can never be replaced."

"One of her passions was raising awareness about epilepsy and the difficulty faced by those who live with it. This is why our family has chosen to support Epilepsy Queensland to raise vital funds to help others who have epilepsy cope with their diagnosis. Vital funds also go towards education of workplaces, educators and schools, advocacy work, counselling, NDIS support and much more."

## Bequests – leaving a lasting legacy

A gift in a will is a lasting legacy positively influencing the lives and dreams of future families and individuals living with epilepsy.

This year we received over \$290,000 from generous supporters who left a precious gift to Epilepsy Queensland in their will. Our deepest thanks for this thoughtful gesture that truly is a gift that will keep on giving.



# sustainability

## Raising funds in the community

Development in the community isn't just about raising funds, it's about challenging our partnerships to grow dynamically. Epilepsy Queensland is privileged to receive support from members and companies across our magnificent state. This includes our events Purple Day and the Little Poss Appeal, Tax and Christmas Appeals.

Thank you to each and every supporter and donor, each contribution is ensuring our services continue. We are amazed at the ongoing enthusiasm, energy and good will from supporters. Some of our highlights from supporter fundraising events are below.

### Everesting for epilepsy

Simon Watt lives with epilepsy. He wanted to do something to challenge himself while raising funds and awareness for epilepsy at the same time. On 1 June he took on a superhuman challenge 'Everesting for Epilepsy', cycling up and down the steep side of Mt Coot-tha 45 times, 8,848m the equivalent height of Mt Everest.

Simon used the challenge to raise nearly \$13,000 to help fund our information and support services for Queenslanders living with epilepsy.

Simon shared: "Cycling is my passion however when epilepsy has restricted me from driving it has also provided me with freedom to get from A to B."

Simon started his ride at midnight, cycling in the dark with his incredibly supportive wife Elise and a handful of family cheering him on. As dark turned to light Simon was joined by a great crew of family and friends, some who took turns riding laps with him. The ride meant old friends from as far back as school reached out to support Simon's ride by making donations, sharing his story and completing the ride with him.

Simon completed his ride ahead of schedule in 12 hours 56 minutes.

### Lendlease Charity Golf Day

On a beautiful spring morning, 136 keen golfers came together at Brookwater Golf and Country Club, in support of Epilepsy Queensland and Legacy for the annual Lendlease Charity Golf Day.

After a fun round of golf featuring a few novelty competitions for golfers of varying skill, the very generous participants dug deep for some fantastic prizes spurred on by MC Darren Curtis from Channel Nine. Our board member Katrina Tune spoke from the heart about being a parent of a child living with epilepsy.

Epilepsy Queensland have been the beneficiary of this fantastic event since its outset in 2010. We are pleased to report that the event raised \$66,116 shared equally between the two charities.

Over the years the event has raised an amazing \$318,111 towards Epilepsy Queensland's services for children and adults living with epilepsy.

Lendlease are Australia's largest building business. They not only care about the communities that they live and work in but also value the relationships they have with their subcontractors. Special thanks to Lendlease, the event sponsors and the Golf Day Committee.

### Corporate Partnerships

Epilepsy Queensland enjoys the support of corporate Australia. These businesses are committed to social impact and are integral in making a difference to people living with epilepsy. Our team is committed to building a strategic partnership, funding innovation and developing new skills in your team. Business and industry are at the heart of sustainable solutions that ensure self-reliance and independence for people living with epilepsy.

Thank you to our corporate partners who have helped Epilepsy Queensland grow and maintain our programs and services.



## Appeals

Epilepsy Queensland conducts two major fundraising appeals each year at tax and Christmas time. Our generous donors through direct marketing campaigns contributed significant funds toward the maintenance and growth of our services and programs.

## How you can help

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



Make a donation



Join us – membership



Challenge yourself



Raise awareness



Leave a legacy



Corporate Partnership



Host or attend an event



Join the conversation on social media



Share your story



Volunteer your time

## 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 participating in golf days, we salute you Wally and look forward to continuing to increase awareness and understanding of epilepsy with you.

As we celebrated our 50th year of supporting Queenslanders living with epilepsy in 2019, we also celebrated 10 years with Wally Lewis as our Patron. Many of our members were touched by Wally sharing his epilepsy story at our 2018 Annual Celebration and 50th anniversary launch.

### Board, staff and volunteers

The staff of Epilepsy Queensland are vital to our success in all endeavours. During the 2018-2019 year our full time equivalent was 10.48, a slight increase from 9.68.

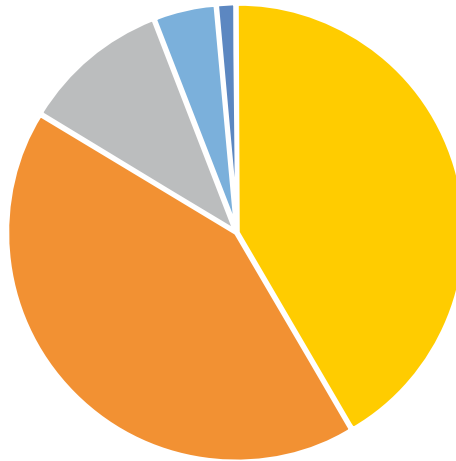
Epilepsy Queensland's Board is the governing body of the organisation, meeting at least once every two months. All members are honorary. Sam Bryce was recruited to join the Board on 3 December 2019. Sam lives with epilepsy and is also a parent of a child with epilepsy. He has a special interest and skills in delivering services to regional areas.

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



# Income

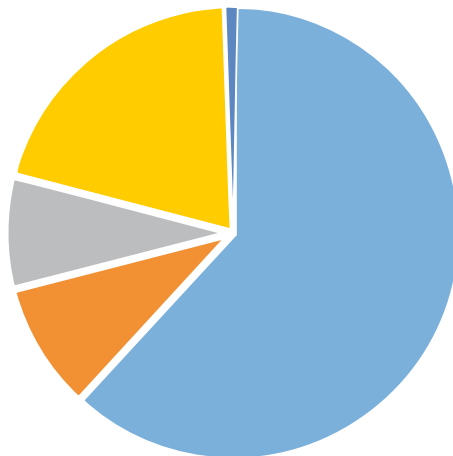
## Income sources 2018/19



- Trading Activities
- Membership, donations and sponsorships
- Interest and other income
- Support and Education Services
- Grant income

# Expenditure

## Expenses 2018/19



- Service Expenses
- Communication/Marketing
- Other expenses
- Administration/Operational expenses
- Fundraising/Campaigns

Epilepsy Queensland thanks all of our donors, members and supporters. Together we are making a difference for Queenslanders living with epilepsy.

## Highlights

- 1202 individual donations received from our generous supporters
- 42 people fundraised and shared their stories through Everyday Hero
- 83 events held during Purple Day and September Sizzle
- 535 financial members adding their voice for Queenslanders living with epilepsy
- \$70,071 raised through Golf Days organised by our generous supporters (Lendlease \$33,058, Peter Meyer \$35,300, Samuel Milne - St Lucia Ladies Golf Day \$1,713)

# Celebrating 50 years of supporting Queenslanders with epilepsy

50 years ago, our founder Doris Kemp, saw the repeated discrimination against her son Robert. Back then, anti-discrimination and disability laws just didn't exist. Doris knew something needed to be done and there wasn't an organisation to assist people with epilepsy and their families in Queensland. Doris put notices in papers and spoke to everyone who would listen. From there the Epileptic Welfare Association in Queensland was formed. This was a brave and bold move and Doris faced a lot of criticism. With hard work and dedication Doris won over even the greatest cynics.

Original committee member Marella Jenkins shared:



*Doris was the association. When she told her son Robert's doctor about the Association she had formed, he initially looked at her as if to say "You poor thing". Later on, after he had seen what the Association was achieving, he acknowledged what a good thing she was doing.*



Doris also had fantastic support from her family – Arthur and Robert Kemp. In 1981, Doris Kemp was awarded an Order of Australia medal for her work – an honour well deserved.

Brisbane Lord Mayor Adrian Schrinner hosted a Civic Reception to celebrate Epilepsy Queensland's 50th anniversary of service to the epilepsy community. Our Patron Wally Lewis did a live sports broadcast from the reception and was thrilled to catch up with some of our original committee members along with some current supporters, donors, ambassadors, volunteers, staff and board members.

In a speech Wally discussed his own experiences of living with epilepsy and how a seizure on air delivering the sports news changed his life. This gave him the push to investigate epilepsy surgery and now Wally has been seizure free for more than 12 years. It also gave him the courage to start speaking publicly about living with epilepsy. For Wally, 2019 marks 10 years as Patron of Epilepsy Queensland.

Wally paid tribute to the original and early members of Epilepsy Queensland who were able to attend and those who are no longer with us. He also spoke about the ongoing need for Epilepsy Queensland and those affected by epilepsy.

*While times have definitely changed, 30 percent of people living with epilepsy still cannot control their seizures with the assistance of medication. Many people with epilepsy and their families are still struggling with the life impacts of epilepsy. Many are still experiencing a lack of community understanding, fear and discrimination - there is much work still to be done. I need your continued support to bring epilepsy out of the shadows. - Wally Lewis*



Thank you to everyone who has contributed to Epilepsy Queensland over the past 50 years and helped us reach out to more Queenslanders living with epilepsy.



# Looking to the future of epilepsy

“In Queensland 100,000 children and adults will be diagnosed with epilepsy in their lifetime. The team at Epilepsy Queensland are doing their best to support Queenslanders, however growing numbers means growing costs. Your support ensures they are not alone.”



*This is a cause close to my heart. We need Epilepsy Queensland to be around to support the next generation, so there is help today, tomorrow and well into the future. - Wally Lewis*

It is a privilege for us at Epilepsy Queensland to come into contact with so many amazing young people who live with epilepsy as well as their family members and friends. We are grateful to all of our young ambassadors who share their stories to build awareness of epilepsy in their schools and in the community.



## Ivy Mcalister - Brisbane

Ivy is 12 and an inspiration to others living with epilepsy. She has dealt with bullying at school but has maintained her trademark sense of humour and has forgiven anyone who has teased her. Ivy has been 38 months seizure free and now focuses on assisting others living with epilepsy by helping to raise awareness and funds. Ivy and her family have participated in the last two September Sizzles raising awareness and funds for seizure first aid. She has recorded an awareness video called ‘Still Me’ and was happy to share her story for the 2018 Christmas Appeal. Ivy won the Epilepsy Queensland Youth Award in 2018.



*One in 10 Australians will have a seizure in their lifetime. Most people don't know what to do if someone has a seizure, but if they do, they can know how to help. It's one of the most common things, so we have to try to raise awareness. Don't be ashamed of epilepsy. Lots of people have it, so it's normal. I have epilepsy, but I'm still me. I'm still Ivy. - Ivy Mcalister*



## Jack Dalton – Dalby

Jack, now 14, was first diagnosed with epilepsy at the age of five. He lives with Jeavons Syndrome and has faced challenges and bullying related to epilepsy and seizures. However, Jack hasn't let his epilepsy get in the way of pursuing his love for rugby league. He is very aware of the need to effectively manage his epilepsy and make modifications to ensure he remains safe. Jack had epilepsy warrior headgear specifically designed to ensure he had the right protection but also to raise awareness of epilepsy at the same time. Jack was inspired by Queensland Reds legend Ben Daley who wore epilepsy awareness headgear to raise funds for Epilepsy Queensland.



*I get bullied a lot and only have a few friends. Mum says that bullies are only scared because they are uneducated or learn it from home and I should feel sorry for them. It still upsets us though - Jack Dalton*



Jack loves cars and all types of machinery, so he hopes that he can get a license and a school-based apprenticeship as a diesel mechanic. He also wants to help make life better for others living with epilepsy by raising awareness and funds for epilepsy services.

The family are big supporters of Purple Day. “It means a lot as the more awareness the better because people seem to live in the shadows for fear of being judged and excluded. We missed fundraising for Purple Day, but organised a purple sock day at Jack's footy club. We were thrilled that the day raised \$2340 to support more families across Queensland affected by epilepsy.” Anna Dalton



# thank you for your support

Across Queensland we say thank you to the organisations and people who have raised awareness, funds, advocated and supported our work every day of the year. Your support from July 2018-June 2019, has ensured the longevity and sustainability of our work. Your contribution no matter how big or small has made a real difference.

Those listed below, in addition to many others, have substantially contributed to helping Queenslanders whose lives are affected by epilepsy.

- Our Patron- Wally Lewis
- Department of Health
- Department of Communities, Disability Services and Seniors
- National Disability Insurance Agency
- Gambling Community Benefit Fund
- Brisbane City Council
- Perpetual Foundation - Gloria & Douglas Mathews Gift Fund
- Cowboys Community Foundation

## Partners/Sponsors

- The Pharmacy Guild of Australia (Queensland Branch)
- Followmont Transport
- UCB Australia Pty Ltd
- EISAI
- The Hon. Terri Butler MP
- Lord Mayor Adrian Schrinner
- The Hon. Jackie Trad MP

## Fundraising

- Lendlease Annual Charity Golf Day
- The Milne Family
- Ipswich 100 Bike Ride - Lions Club of Moggill-Mt Crosby
- Haymans Electrical & Data Suppliers
- Hutchinsons Builders
- Peter Meyer

## Purple Day and Little Poss Appeal

- Our partners at [www.purpleday.org](http://www.purpleday.org)
- Purple Day Founder - Cassidy Megan
- Fundraising Services Team
- The Print Bar
- Our Purple Day Heroes and those who hosted fundraising events
- Story Bridge Climb
- 9 News Queensland
- 97.3FM
- 4KQ AM
- ODNA
- Transurban

## Volunteers and Students

- Annelies Shaw
- Bianca Wrakuale
- Cassandra D'Arcy
- Donna Bones
- Gerrard Gaudiello
- Gus Smith
- Jackie Saunders
- James Henderson
- Jaycee Lai
- Kahren Minter
- Kam Yeomans
- Karen Garland
- Karly Jol
- Lyla Long
- Marie Lyall
- Nicole Cuhney
- Oliver Minter-Stubbs
- Paul Barry
- Sandra Unnasch
- Shannon Bullen
- Krystina Wallis
- Brandon Ræ
- Lauren McLeod
- Shashi Shrestha
- Bridget Nixon
- Wen-chi Chao
- Yiqi Huang
- Ting Jia
- Xiaoying (Christine) Liu
- Jinlin (Frank) Xiong

## Gifts in Memory

- Chris Dicker
- Janet Burgess
- Elizabeth Stapleton
- Edith Elliott
- Trent Long
- Faith Gray

## Speakers and Advisors

- Dr Dan McLaughlin
- Dr Steve Malone
- Prof David Reutens
- Assoc Prof Cecilie Lander
- Dr Sasha Dionisio
- Professor Sean Pittock
- Professor Glenn King
- Professor Terence O'Brien
- Associate Professor Karin Borges
- Mr Peter Jones
- Dr James Wheless
- Assoc Prof Lata Vadlamudi
- Gerrard Gaudiello
- Cassandra D'Arcy
- Liam Warriner
- Dr Harry Singh
- Emily Prain

## For sharing their story or articles

- Luke Eisenhuth
- Jo Adams
- Linda McClelland
- The Milne Family
- Jane Ræ
- Peter Jones
- Marella Jenkins
- Dr Linda Blomster
- Olivia Rowswell
- Kylie Lodge
- Ivy Mcalister

## Communications

- Queensland Newspapers
- GO1
- Plain Design
- Print Systems Australia
- 9 News Queensland
- Queensland Country Life
- ABC Regional

## And...

- Kangaroo Point Holiday Apartments
- IMGA – Mediprotect
- Dr Harry Singh
- Pilot Chartered Accountants
- Epilepsy Australia
- International Bureau for Epilepsy

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