



Our mission

Epilepsy Queensland's mission is to optimise life for people living with epilepsy and bring epilepsy out of the shadows.

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.

Our strategic priorities

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



Directory

Patron

Wally Lewis

Chief Executive Officer

Helen Whitehead until 24/07/20

Chris Dougherty appointed 07/09/20

Board as at 14 January 2021

Chair Sam Bryce

Deputy Chair Kim Davis

Secretary Lousie Prychidczuk
appointed 25/11/20

Treasurer Calvin Booth

Board members

Charmaine Driver

Katrina Tune

Andrew Barnes

William Tuffley appointed 4/12/19

Simon Watt appointed 4/12/19

Murray Fairgrieve retired 8/1/21

David Bunker retired 20/1/20

Chairmans Report

Sam Bryce



Last year our wonderful organisation celebrated 50 years of service to the people of Queensland. For those 50 years we have pursued our mission to optimise life for people living with epilepsy and to bring epilepsy out of the shadows.

In this our 51st year the Board on behalf of members, started to consider what we might need to look like to be here to serve Queenslanders for another 50 years. The organisation commenced a renewal process to evaluate our services and the impact we have on our stakeholders.

Like most organisations across the world, the COVID-19 pandemic certainly had an impact on us. It changed the way we work, the focus of our activities and had some impact on our fundraising efforts. However, seen through the lens of a renewal process, the team took to new ways of working with cautious optimism and found a new rhythm and focus that will serve us well into the future.

Financially, our organisation remains solid with another year of surplus delivered in a very challenging environment. This is in no small part because of the generous contribution of our donors. In particular, I would like to acknowledge the Cameron family who, in memory of their beautiful son Jack, have raised \$218,675 as at 30 June, as part of Jack's Last Gift.

Our CEO Helen Whitehead tendered her resignation in May 2020. Helen's impressive 28 years of service to Queenslanders in this role will most likely never be matched

again in our organisation. Her commitment to optimising the lives of people living with epilepsy will be a lasting legacy that our organisation can be proud of.

A lot has happened in the 12 months to June 2020 and I am immensely proud of the way the organisation has responded, by drawing back to the core purpose of our existence and living our values: to respect and care for 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.

A special mention to my colleagues on the Board who without fail gave tirelessly to the organisation during a year of change and big decisions that will impact our work for many years to come. Our search for a new CEO coincided nicely with emerging from COVID lockdown and bringing together of the renewal process into Strategic Planning processes. We went back to the basics of understanding the needs, wants and desires of our members, the epilepsy community and broader stakeholder groups so that we can bring hope to the 30,000 people living with a diagnoses at the moment, and the 3,000 more that receive one every year.

At the time of writing this report, which is a little later than normal, I am excited about the progress the organisation has made under our new CEO and I look forward to seeing the team deliver the impact people living with epilepsy deserve.

Helping and Empowering Our Community

Joanna and Theo's Story

Joanna's son Theo, was diagnosed with epilepsy after what appeared to be a straight forward pregnancy and birth. Her world changed five hours after Theo's birth when he stopped breathing and started having multiple seizures.

"Newborn life is busy at the best of times, and I was navigating how to be a mother for the first time and a mother to a baby with epilepsy. It wasn't until the dust began to settle that I realised I was struggling. Joanna rang the Epilepsy Helpline for support.

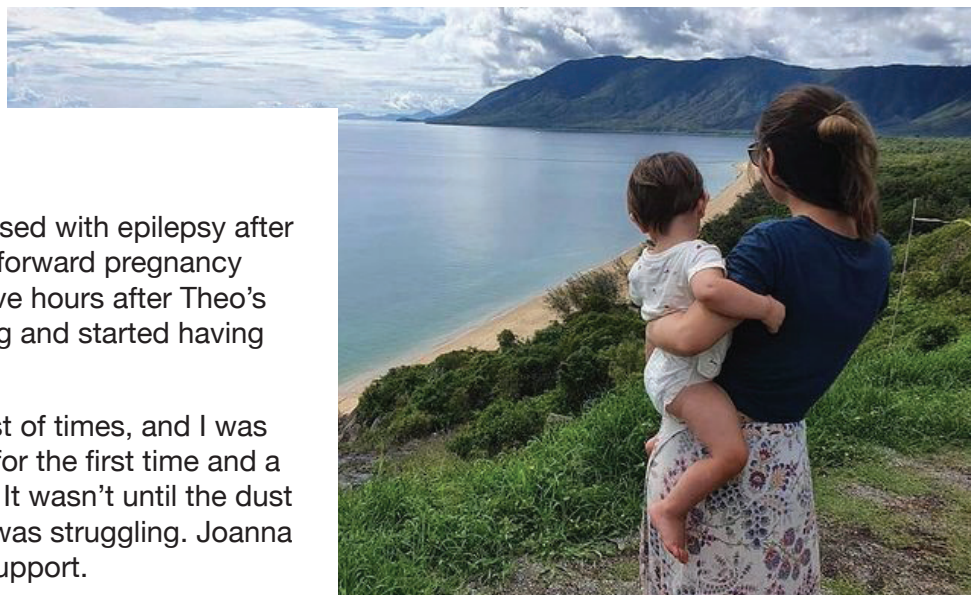
She shares: "When I rang Epilepsy Queensland they told me about opportunities to connect with other people, a wide range of valuable information as well as fundraisers and other events to attend. I found a huge sense of compassion and support from people in the same boat and I realised that I am not alone. I felt so supported and understood.

"It brought tears of relief to my eyes. To find others who were happy to share their battles, I also found mothers, like me, fighting for their children. The social media community added some lightheartedness to what initially felt like a very dreary diagnosis. Everyone is positive and supportive and you feel safe to share your story or seek guidance," Joanna shared.

"There is support all around, so don't be afraid to use it. You will develop welcoming relationships with medical staff, and discover a world of support if you connect with Epilepsy Queensland."

Joanna relayed: "Theo has been seizure-free for more than a year and has been medication-free since mid 2020, despite doctors predicting that he would be taking both Topamax and Keppra well into his primary school years. Now we are looking forward to integrating Theo into a full-time daycare next year, worry-and seizure free!

We were fortunate enough to take him on his first flight for a Christmas holiday - a huge achievement as we felt confident to be hundreds of kilometres away from hospital without medication.



We have a special relationship with a wonderful organisation that has kept us strong. Epilepsy Queensland armed us with the tools, education, and courage I needed to support my son in his superhuman strength (he is far stronger than I'll ever be!) Epilepsy Queensland has been the life ring that has kept us afloat."

Joanna shares: "A potential risk of his diagnosis (myoclonic seizures due to birth trauma) was developmental delay. Theo will be two in February and is very typical for his age - feisty, cheeky and full of love! He is strong willed, which is something I can't help but admire as it was this strength that pulled him through his NICU days. Whether he is fighting for his life or another biscuit, Theo never gives up!"

Joanna is a strong advocate for raising epilepsy awareness and giving back. She has been an active fundraiser and advocate during Purple Day and Seizure Smart September. Joanna shared Theo's story for our 2020 tax appeal and provides updates via social media.

"How blessed we are to share Theo's inspiring story of overcoming the seemingly impossible. I hope it helps spark light and courage for others. In darkness there is always light (even if you can't see it yet, keep going!) Thank you to EQI for supporting epilepsy heroes," Joanna shared.

Helping and Empowering Our Community

Madaline's Story

Madaline Guilk embodies the spirit of determination and is focused on giving back. The nineteen-year-old from Ipswich, lives with a rare form of epilepsy called Jeavons Syndrome and Autism Spectrum Disorder (ASD). Proud Mum Amy says: "Madaline hears the word "NO" all the time but she wants a big successful life."

Madaline was diagnosed with occipital lobe epilepsy at age four, after experiencing eyelid myoclonia (brief and repeated jerks of the eyelids). Madaline also experienced absence seizures and her first tonic-clonic seizure at 11 years old.

When Madaline was in the final stages of completing her Year 12 schooling it became necessary for her to change to an anti-seizure medication with less risk to women of child-bearing age.

After starting the new medication Amy noticed that Madaline's eye flutters increased, her moods intensified and she was in and out of hospitals for a month. At the time, "it was thought that Madaline had been in a state of non-convulsive Status Epilepticus (prolonged seizure activity) for four days," Amy relays.

Madaline's speech was slurred, she was saying strange words and unable to walk. The doctors wanted to induce a coma and told Amy: "This is as bad as it is going to get."



Amy says this was a very intense time. "It was awful, everything felt doom and gloom. I had a daughter previously full of life that couldn't get out of bed."

It was decided Madaline should stop her medication and resume her previous medication, and within five hours, she was out of Status and progressively improved.

Amy engaged with Epilepsy Queensland via our helpline. She says: "Just to have someone to clarify things, to understand what you are talking about without having to explain. It helped to not feel so afraid."

Madaline can now focus on a brighter future. She graduated from high school, which was not always a given due to her health challenges. She has a passion for child care and is working towards a Cert 3 in childcare qualification at TAFE. She is currently enjoying being on placement.

"Being in a classroom environment at TAFE and having so much going on can be hard for Madaline. She gets through it with support from the NDIS and her TAFE teacher and placement people are amazing. It helps that Madaline is such a likeable person and people want to help her," Amy shares.

She says "The information received from Epilepsy Queensland helped us get funding to get Madaline the help to go to TAFE and out and about in the community."

The phone support from Epilepsy Queensland is what got me through as I was a complete mess. We also did training about seizures. As a family we are so grateful to Epilepsy Queensland."

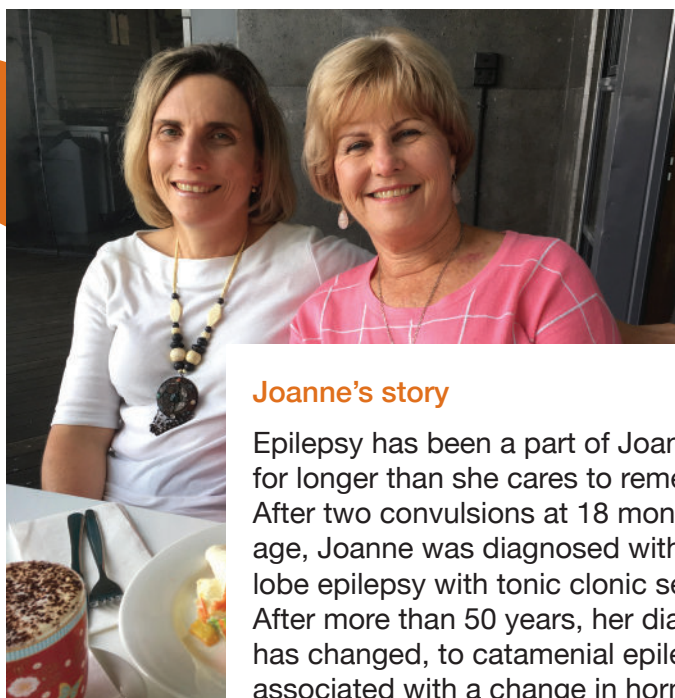
There's a lot to admire about Madaline. She has completed a bikeathon raising \$1,505 and volunteers with Meals on Wheels twice a week.

"Madaline is very social and loves to have a purpose," says Amy. "Recently a friend of Madaline's has been diagnosed with epilepsy and Madaline was able to talk about her experience."

Happily, September 2020 marked one year seizure-free for Madaline. The family celebrated with an afternoon tea, collecting \$250 to donate to Epilepsy Queensland.

Amy and Madaline also appreciate the personal stories shared by members of our community. "These stories got us through so much. It reminds us that we are lucky. If Madaline's story gives one person hope then that would make us very happy."

Helping and Empowering Our Community



Joanne's story

Epilepsy has been a part of Joanne's life for longer than she cares to remember. After two convulsions at 18 months of age, Joanne was diagnosed with temporal lobe epilepsy with tonic clonic seizures. After more than 50 years, her diagnosis has changed, to catamenial epilepsy, associated with a change in hormones.

School was challenging as understanding of epilepsy was low and the kids were cruel, calling her names like "fit".

Desperate to find a solution, Joanne turned to surgery. She shares: "Between the age of 18 and 20, I had operations on my left temporal lobe. Unfortunately, they were unsuccessful and as the focus of the seizure is now more towards the speech and memory part of the brain, I am no longer a candidate for surgery."

This was a huge blow for Joanne affecting her mental health. "After the surgery, I had self-esteem issues and was really bad for two years. At 20, I had anorexia and feel I put my family through a lot," Joanne says.

Joanne believes we can support people with epilepsy to live well by educating the community.

She shares: "The greatest challenge has been people accepting me. It makes socialising challenging and has affected my self-esteem. With other conditions such as diabetes and cancer, people accept you and have some degree of empathy."

Joanne made contact with Epilepsy Queensland after reading the Wally Lewis book and found a whole community of support.

"Reading about his experience and attending Purple Day in Brisbane was a big help. I have had a lot of contact and support through the Epilepsy Queensland Helpline. Whenever I need to speak to someone, they are always there. I feel like I can talk through things and they have

suggestions when I needed a referral."

Joanne is not one to give up and is proud of what she has achieved. She shares: "My biggest win has definitely been in employment. I am a cleaner at the local hospital. This has allowed me to live independently. I bought my own unit and have lived by myself for 20 years."

Joanne knows there are still battles ahead but the team at Epilepsy Queensland are just a phone call away. "Around 18 months ago, I had a change of medication and it wreaked havoc with my seizures. During one seizure, I fell off the toilet and cracked three ribs. I found it really challenging weaning on and off medication."

Joanne hopes for more independence after approval to access the National Disability Insurance Scheme (NDIS). She shares: "Over the years, I have had three attempts, the first two failed but with a change of neurologist and additional support from the hospital social worker, I have now been approved. Epilepsy Queensland have helped with recommendations for a medic alert and key lock outside my apartment. Now, ambulance and police can access my house in an emergency. The NDIS also approved a taxi allowance to help me get around and eight hours per week with a support worker. The support worker takes me to appointments and makes life much easier."

Despite her own struggles with epilepsy, Joanne remains passionate about creating change in the community to assist others.

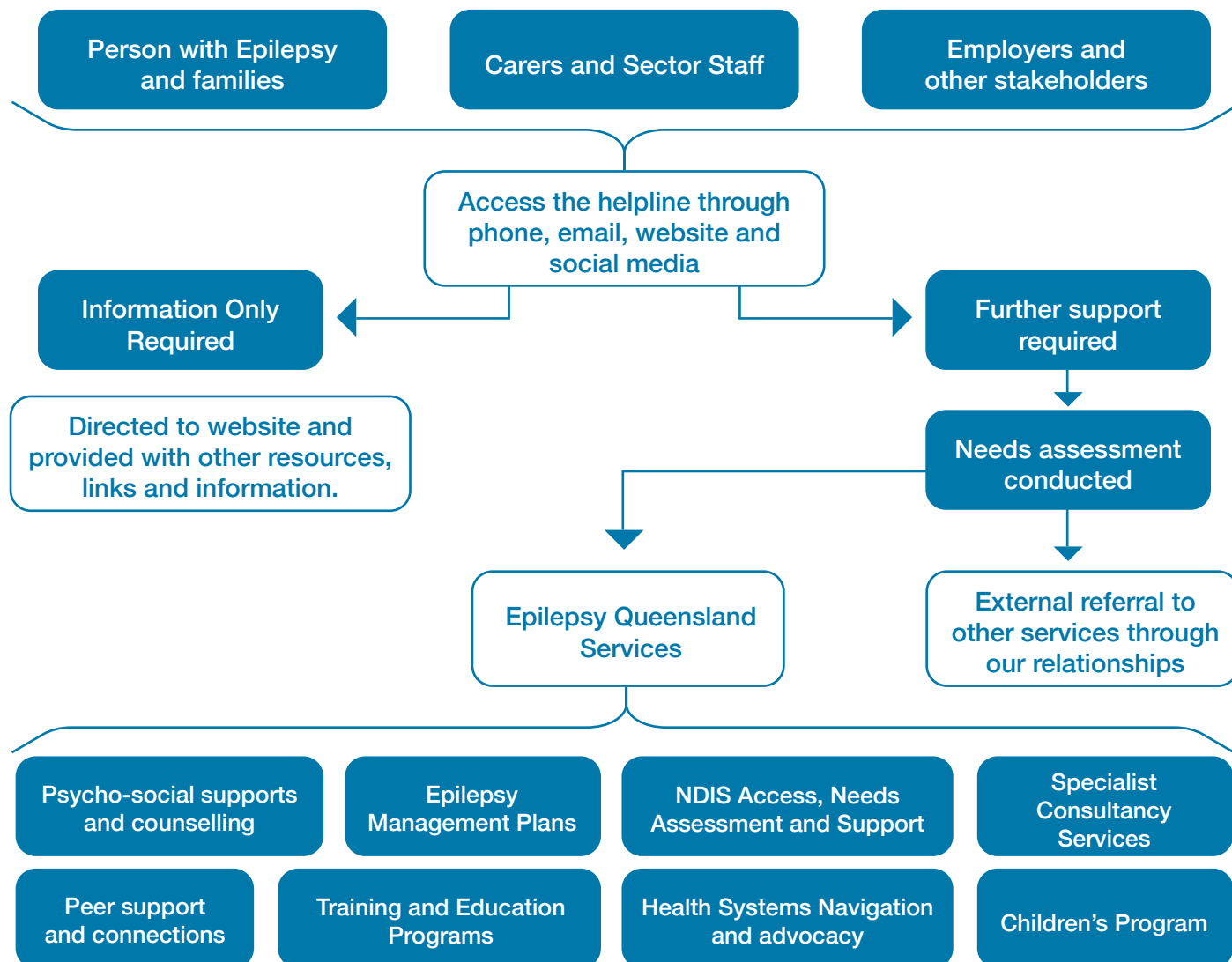
"My aim is to help Epilepsy Queensland grow bigger. I fundraise to help get more information and education out there. Building understanding and educating about epilepsy in the community is one of the most important things Epilepsy Queensland does. I think if you educate people, you can remove the barriers. I'd like to see more people learn seizure first aid, so they can help if someone has a seizure."

Helping and Empowering Our Community

What we do

At the core of what we do is our information, referral and support helpline. This is where we have a direct impact on people living with epilepsy, their families and carers. Our multidisciplinary team ensure we can provide a holistic wrap around service and maintain strong relationships with referral partners to extend the experience for people who access our services.

"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



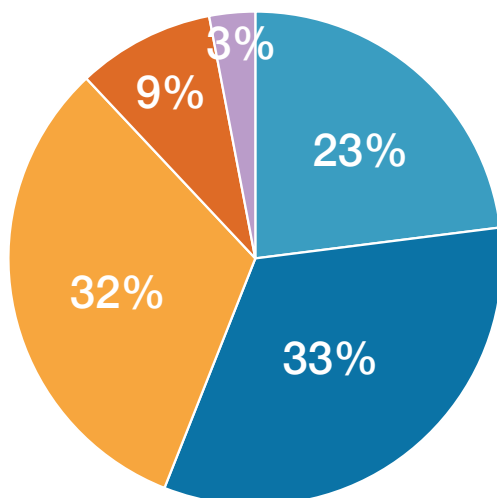
Helping and Empowering Our Community

How we have impact



3,883

INFORMATION & SUPPORT INTERACTIONS PLUS MANY MORE THROUGH COMMUNITY AND INDIVIDUAL SUPPORT GROUPS



- PEOPLE WITH EPILEPSY
- FAMILY MEMBERS
- SERVICE PROVIDERS
- SCHOOLS (INCLUDING KINDY'S AND CHILD CARE)
- OTHER



67

NDIS RELATED SUPPORT INTERACTIONS – A 3 FOLD INCREASE ON LAST YEAR



27

SUPPORT GROUP SESSIONS (3 FOLD INCREASE ON LAST YEAR) REACHING 146 PARTICIPANTS (4 FOLD INCREASE ON LAST YEAR)



350+

HOURS OF TRAINING DELIVERED

131 FACE TO FACE SESSIONS
23 DELIVERED VIA ZOOM DUE TO COVID
REACHING 2048 PARTICIPANTS
385 ADDITIONAL PARTICIPANTS IN E-LEARNING PROGRAMS

Community engagement and advocacy

Lakeisha's story

Lakeisha “Lucky” Patterson was diagnosed with epilepsy at the age of five, after copious unexpected daily falls and a traumatic eight minute seizure. In primary school, Lakeisha was severely affected by her epilepsy and her Mum Sherryn was told, that due to brain damage from seizures Lakeisha wouldn't achieve much, would require constant care, and would need to attend a special school.

Lakeisha shares “Fortunately, I have an absolutely incredible mum who never stopped fighting, in fact, I think that words like that fuelled her fire, making sure I got help to achieve my best. With her support I eventually found a specialist who understood me, found medications that worked, an amazing school and support network, as well as Epilepsy Queensland - all who guided us along my epilepsy journey.”

At the age of 15, Lakeisha won her first medal for Australia at the Glasgow Commonwealth Games. Now 22, Lucky is a Paralympic, World Para Swimming Championships and Commonwealth Games swimming gold medallist. She is also studying for a Bachelor of Communications at QUT.

With all of her achievements, you could be forgiven for thinking that Lakeisha is not affected by epilepsy, cerebral palsy and micrographia, but this just isn't the case.

“My epilepsy affects me on a daily basis. Medication leaves me fatigued, my balance, memory and cognition can be impacted and there are lengths of time when I am unable to drive. Having cerebral palsy left hemiplegia can also be a contributing factor,” Lakeisha says.

Lakeisha has not only experienced physical challenges. She explains: “Unfortunately, there is a stigma, surrounding what people with disabilities can achieve in life. Growing up with numerous medical conditions, I have experienced this discrimination time and time again.”

Lakeisha shares how Epilepsy Queensland helped her family.

“Epilepsy Queensland has been a lifeline in my epilepsy journey. Their knowledge and support towards my mum in the early days, was particularly helpful. For a single-mum who had already survived many obstacles to give her three daughters the best opportunities in life, my epilepsy diagnosis was incredibly stressful.

Since then Epilepsy Queensland has been the go-to source, unlocking solutions for a better lifestyle. Their updated and concise information supports families and individuals facing the same challenges my family did. They do a fantastic job of raising awareness and education to bring epilepsy out of the shadows.”

Giving back to others in the community is Lucky's passion, generously sharing her story at events, through her social media and in the media.

“People in our community are more aware of what epilepsy is through communication and education,” Lakeisha shares.

Lakeisha is optimistic about the future and encourages others to share their stories to create positive change: “Community attitudes have changed towards epilepsy. The stigma and discrimination sometimes associated with epilepsy and other medical conditions, is diminishing as people have greater understanding. This is a positive, and continues to improve as brave individuals share their stories and organisations such as Epilepsy Queensland, spread awareness.”



Community engagement and advocacy

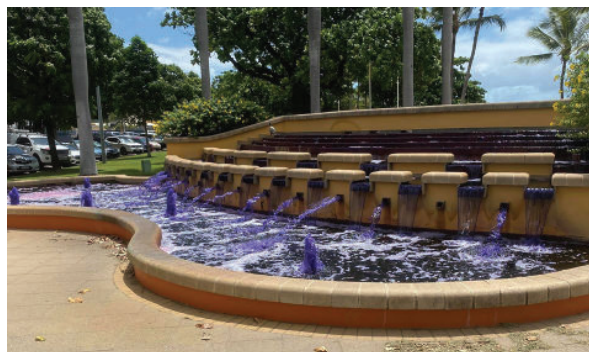
Purple Day

Thank you to our Purple Day partners, the Pharmacy Guild of Australia (Queensland Branch) and Followmont Transport for your support.

The Pharmacy Guild of Australia promote Purple Day to their members, asking them to sell our merchandise. More than 100 pharmacies across the State signed up to celebrate purple day.

Congratulations to the winner of our Purple Pharmacy of the year Agnes Water Pharmacy. This wonderful pharmacy sold our merchandise, held an Easter colouring-in competition and staff dressed in purple!

Followmont Transport have generously been transporting Purple Day merchandise around the state for more than 10 years and once again came onboard in 2020.



Purple Heroes

Thank you to our Purple heroes who managed to hold their events before social distancing came into force and to those who held virtual and online events. We had some wonderful purple activity, including purple schools, shopping centre stalls, Everyday Hero pages BBQs, morning teas and even a virtual art auction.

Queensland landmarks go purple

For Purple Day 2020 we had purple illuminations and fountains across the State. Thank you to the following Government Departments, Councils and organisations: Ayr Fountain, Brisbane City Hall, Forgan Smith Building – UQ, King George Square, Kurilpa Bridge, Newstead Gasometer, Parliament House, QPAC, Story Bridge, Victoria Bridge (Brisbane), Munro Martin Parklands (Cairns), Graincorp Dalby West Silos, Ipswich Civic Centre, Mackay fountain, Graincorp Carrington Port silos (Newcastle) Oxley Street fountain (Townsville).



SUPPORT: Naomi Dullison with son Emmett, 8, who has epilepsy. The Brand Foundation will run purple in support of Epilepsy Awareness Day. PHOTOS: ALAN TAYLOR

Go purple for a good cause

ELIZABETH SILVESTER
Epilepsy. He was having up to 50 seizures a day. After showing Emmett's doctor a video of his seizures, Ms Dullison said her son's diagnosis was a tough time for her and her husband Ben Dullison. "I would see his eyes rolling when he was having a seizure and I said to the doctor, 'Is it behavioural or is it something else?'" she said. "When Emmett was first diagnosed, I didn't know but Epilepsy Queensland was great and they gave us lots of resources where there was no local support." The now 8-year-old has just started Prep this year at St Clare's Catholic School and has been controlled on his medication for the past two years. Ms Dullison credits Purple Day as an opportunity to make connections within the local community to bring epilepsy out of the

Awareness

Thank you to Nine News Queensland who did a live weather cross with a view of the Story Bridge lit up purple and to our Patron Wally Lewis and the news team for sharing a special Purple Day message.

Seizure Smart September

One in 10 people will have a seizure during their lifetime. Our mission is to have one person in every household, school and workplace know seizure first aid.

During the month of September each year, we share tips and stories about seizure first aid through social media, email, publications and our interactions with the community.

The campaign also focused on how to recognise different types of seizures as not all seizures are the same and can present very differently from one individual to the next.

With the support of our community, we shared their stories, social media posts and resources. Together we were able to increase awareness of seizure first aid and help build a supportive community for people living with epilepsy or seizures.



152

social media posts
across Facebook,
Instagram and Twitter



227,816

Combined social
media reach



11,136

Combined social
media engagement

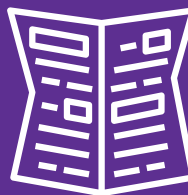
Our Community Impact

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.



60,289

e-news with average subscriber
rates increasing by 14%



3,029

children's program
newsletters with participants
increasing by 11%



399

children's program birthday cards



2,963

Facebook average reach per post



79%

Increase in Instagram followers

Sustainability

Strategy and brand review



For over 50 years Epilepsy Queensland has been the peak epilepsy consumer organisation in Queensland. Our hope is to do more for the 28,000 people in Queensland currently diagnosed with epilepsy and to be there for the 3,000 people that will be diagnosed this year alone. Your stories are what motivate us to be better. It is also your stories that will help us to build broader community awareness and understanding to break down barriers for people living with epilepsy.

Following the celebration of our 50th year last year the Board, through its new CEO and in consultation with people living with epilepsy, their family members and our exceptional staff team, conducted a strategy and brand review. We found above all else, people wanted us to bring hope. Hope to live well, hope for a cure, and hope to reach more people impacted by epilepsy everyday.

We will do this by implementing a robust impact measurement framework so we can track the impact we have on Queenslanders living with epilepsy.

Vision

We are the beacon of **hope** for people living with, and impacted by epilepsy in Queensland

We envision:

An **individual** understood and supported to live life well

A **community** aware, removing barriers and in search of a cure

An **organisation** financially strong, ready to deliver and measure impact

Values

We are **Brave** – we recognise that people living with and impacted by epilepsy demonstrate tremendous bravery everyday. We must be brave in our approach to all activities in pursuit of our vision.

We are **Agile** – we evaluate and respond to change, over rigidly following a plan. We work collaboratively with the people we serve and other stakeholders to iterate and drive more meaningful impact for our work.

We are **Transparent** – We inspire hope in our community through evidence based support and actively engaging in, and supporting, research to live well. We openly share our knowledge and the cost of our impact.

Sustainability

Fundraising Highlights



Lendlease Charity Golf Day

In 2019, Epilepsy Queensland (EQI) celebrated 50 years of supporting Queenslanders living with epilepsy. This would not be possible without the support of corporate partners like Lendlease, who care about the communities where they live and work. This year marked our tenth year of partnership with Lendlease in Queensland through the Lendlease Charity Golf Day.



Lendlease has raised over \$395,000 in 10 years, awareness of epilepsy with their employees, contractors and members of the construction industry.



Many months of planning headed by General Manager Brad Protheroe, attracted 33 teams and over 160 players to support EQI as well as event sponsors including Gold Sponsor, Stowe Australia.



Thank you to Lynn Cowie-McAlister for speaking to the players, sharing how her daughter Ivy has fought to overcome the challenges associated with epilepsy.

Motorbike Ride 4 Epilepsy

Thank you to everyone who participated in the Motorbike Ride 4 Epilepsy in August 2019.

Special thanks to our volunteers and ride organisers Mark and Sandi Unnasch whose son Jack lives with epilepsy. Mark and Sandi are passionate about raising awareness and funds to ensure all families have the information and support they need. We are also grateful to sponsors Revolution Rider Training, Trident Trades and Labour Hire, Action Formwork, Mount Franklin, AEG Powertools and The Mad Hueys. Together 35 riders raised \$5,167 for Epilepsy Queensland's support services for families.

The Unnasch family also raised \$4,000 with the support of Hutchinson Builders, via employee barbeques on the building site of the Fortitude Valley State Secondary College.

St Columba's Primary School Mothers Lunch

When a school community comes together for a good cause, wonderful things can happen. In October 2019, 300 guests were invited to The Calile Hotel to enjoy a special St Columba's Primary School Mothers' Lunch. Epilepsy Queensland was the beneficiary and are extremely grateful.

The day included a number of activities, raising a generous sum of over \$17,500 for Queenslanders affected by epilepsy. We would like to thank Katrina Tune, Carla Di Fabio, John O'Connor, Michelle Kneen, Melissa Bates and Damon Tune for their tireless efforts to make this event a huge success. A special mention goes to Pikos and Brisbane Screenprinting and Displays.

Samuel Milne Memorial Golf Day

The Milne family and Schneider Electric organised a great day with Ian Healy playing the course and Wally Lewis stopping by for a meet and greet prior to tee-off. Donations of \$17,463 received on the day included \$10,000 from Haymans Electrical.

2019 Bridge to Brisbane \$6,673

Epilepsy Queensland was represented by 25 teams and individuals who participated in honour of family and friends affected by epilepsy. Together our supporters raised \$6,673. Special thanks to #Faith'sLegacy, the Epilepsy Angels, Team realestate.com.au, Team Trent Long and Team Sammy Milne.

Sustainability

The Lorimer family's story

The Lorimer family have been long time supporters of Epilepsy Queensland, with mum Noretta and 14-year-old daughter Natalie both living with epilepsy. Noretta has had the condition for over 30 years, the result of brain surgery at the age of 17. Natalie was diagnosed with a form of Dravet Syndrome when she was five, experiencing febrile seizures as an infant but as she grew, the seizures continued, causing her parents to seek a medical opinion.

Natalie experienced tonic-clonic seizures and what her dad Paul describes as “little phase-outs” up to 20 times a day. Paul explains medication has been good at controlling her epilepsy, however, as Natalie grows, she experiences breakthrough seizures which indicates it's time for a medication adjustment.

Epilepsy impacts the family in many ways. Noretta has had strokes and is unable to hold a driver's license. As is characteristic of Dravet Syndrome, Natalie has developmental delays, requiring additional support at school and in daily life. Continuous medication management is also a big part of the family's daily routine.

The Lorimer family first learnt about Epilepsy Queensland via social media around the time Noretta had her first stroke.

Paul initially decided to participate in our “Spring Challenge” event, giving up coffee for three months. “Because I've been with the same employer for over 20 years and am surrounded by very, supportive people, the response was massive,” says Paul. The final tally raised was over \$3000. Shortly after the family became part of our regular giving program, donating each month to Epilepsy Queensland. Paul explains that being raised in a household with a philosophy around giving and where supporting community was encouraged, instills a spirit of generosity.

“I do what I can, when I can,” he says.

It is these values that Noretta and Paul seem to have passed on to their daughter, who Paul says has “a heart of gold.” After the COVID-19 pandemic saw many Purple Day events cancelled, the Lorimer's, and particularly Natalie, decided they still wanted to help.

Natalie did chores and odd jobs around the house and collected her earnings for six months. She donated the \$571 she saved to Epilepsy Queensland and visited the office in-person to make the donation.

Paul describes how excited Natalie was about the visit.



“Doing the chores, setting a goal and deciding to make this contribution, I really saw Natalie progress. The more this is built into her life, the more she will understand she can have an impact.”

Paul hopes this will be the start of a lifetime legacy for Natalie. “I know Epilepsy Queensland relies on funds to increase understanding and raise awareness “It's reassuring to know there is support out there. Through our involvement with Epilepsy Queensland, it has been wonderful to see the benefit provided to so many people in the state.”

In the future, Paul says his ultimate hope that a cure will be found. “But until then, I would like to see greater awareness as greater awareness leads to greater understanding, which leads to tolerance and empathy.”

Paul would like those impacted by epilepsy to know they are not alone. “There are more people with epilepsy than you think. Everyone needs support at some time. You don't have to hide.”

Sustainability

In Memory - Jack's last gift

We are saddened by the loss of a young member of our epilepsy community, Jack Cameron, along with 16-year-old Archie Gouldson as passengers in a car incident. Our thoughts are with Jack's parents Nick and Sarah and older sisters Georgia, Jemma and Meg. Jack Cameron was an extraordinary young man. At the age of 10, the country boy from Ardno, Mount Abundance (near Roma) was a sports champion excelling at Rugby League, swimming and running.

"Jack sent a huge NRL crowd at Suncorp Stadium into raptures of delight last year when he carved up the field playing for the Carnarvon Cubs," James Nason wrote of Jack in a Beef Central article.

The article continues "Earlier this year he qualified to compete in the Queensland Schools State Swimming Championships. The times he was clocking in training had placed him in strong contention for a top-three finish."

"Jack also had his eye on a record closer to home, training to break the Roma and District Schools under 12s 800 metre record, a mark set 36 years ago, by his father Nick," James said

His sporting prowess was paralleled by his abilities on the farm. "He was already capable of mustering on his own and was raising his own herd of more than 100 poddies. Jack was also breeding his own goat herd and was showing early entrepreneurial skills by selling manure to local gardeners"



Jack was diagnosed with epilepsy at the age of two, which was controlled by medication and he continued to be seizure free. Two of Jack's older sisters are also living with epilepsy.

Jack touched many people's lives and was an amazing friend. The family set up a tribute to Jack to allow people to share their memories and make a donation to Epilepsy Queensland. We have been overwhelmed by the support for the Cameron Family and Epilepsy Queensland. As at 30 June \$218,675 in donations have now been received on Jack's tribute page <http://bit.ly/EQJacksLastGift>.

Epilepsy Queensland Chairman Sam Bryce said: "This is the largest single fundraiser in the history of our organisation. Jack's last gift will be a lasting legacy in memory of Jack. He was a remarkable young man who will be missed by many people."

"We are sincerely appreciative of the Cameron family, for wanting to make a difference for other people impacted by epilepsy at a time of tragedy. Jack's last gift has been an opportunity for people to show their support for the family and share memories of Jack," Mr Bryce said.

He continues "The money raised will create a lasting legacy for Jack enabling us to assist many more families. More than 200,000 Queenslanders will be diagnosed with epilepsy in their lifetime. The donations will enable us to provide vital help through our Epilepsy Helpline, training in schools and workplaces, counseling for families newly diagnosed with epilepsy, advocacy and community awareness."

Thank you to everyone who have contributed to making Jack's Last Gift a reality.

\$218,675

donated to June 30;
1347 donations; average donation
of **\$162** and growing by the day.

Sustainability

Our supporter impact

1,635 supporters \$318

through 2,678 contributions raised a total of \$520,460 to support our vision

Average contribution per supporter

\$115,090.90

White Household on the passing of Graham White

\$11,794.09

Gloria and Douglas Mathews Gift Fund

\$10,000

Advisernet Insurance

Top five supporters

\$10,000

McTaggart Household

\$5,414.17

AgTrade / AUSTREX

\$125,000

through bequests from two friends of EQI





Epilepsy Queensland is made up of brave, passionate and highly capable people across our organisation. All committed to optimizing the lives of people touched by epilepsy. With an average tenure of 6 years, we maintain an impressive corporate knowledge to ensure our information is relevant, contemporary and accessible.

Our commitment to quality service delivery is demonstrated in the investment in Quality Systems and our accreditation against the Human Services Quality Standards and the NDIS Practice Accreditation Standards. This commitment embeds our philosophy of continuous improvement and our team works hard to ensure we always find ways to have more of an impact on our community.

Our Board brings together a strong mix of skills, knowledge and experience to ensure strong and effective corporate governance to the organisation on behalf of our members. Almost 50% of our board members also have lived experience of epilepsy which ensure we find the right balance between a sustainable and financially strong organisation and meeting the needs of the community we serve.

With over 1000 hours of collective effort in the last financial year our volunteers continue to provide strong support to our work and much needed capacity to meet our workload demands. Ranging from our team of regular office volunteers to highly skilled pro-bono specialist and students on placement we are extremely lucky to call them part of our workforce, and could not have the impact we do without them.

Finally, to acknowledge the 10+ wonderful years of our Patron – Wally Lewis is championing the cause of epilepsy awareness, and of Epilepsy Queensland. As we celebrated 50 years in 2019 and no matter how many times members and other stakeholder have heard his story, they continue to be touched by the passion and commitment to our organisation.

Sustainability

Our people

11 FTE

multidisciplinary paid staff with an average tenure of 6 years

300 hours

of collective governance from our board adding \$15K of value

600 hours

of core volunteers adding \$32K of value

4 students

with an average of 100 hours placement adding \$17K of value

Financials

Income

In FY20 we saw a year on year increase in overall revenue by 23% to \$1.83M. This is largely as a result of stimulus measures relating to COVID-19 (Jobkeeper) and also recognition of an additional one-off grant from Queensland Health, of which the expenditure will carry over into FY21.

Of particular note is the decrease in supporter income (down 6% overall). Whilst this is common across the sector during the COVID-19 pandemic, it is something of increased focus for the organisation as we seek to serve more of the 30,000 people in Queensland currently living with a diagnoses of epilepsy.

Our income goals of the next strategic cycle include both increasing our supporter income and our fee for service activities (service delivery & education) to lessen our reliance on Government grant income over time.

Expenditure

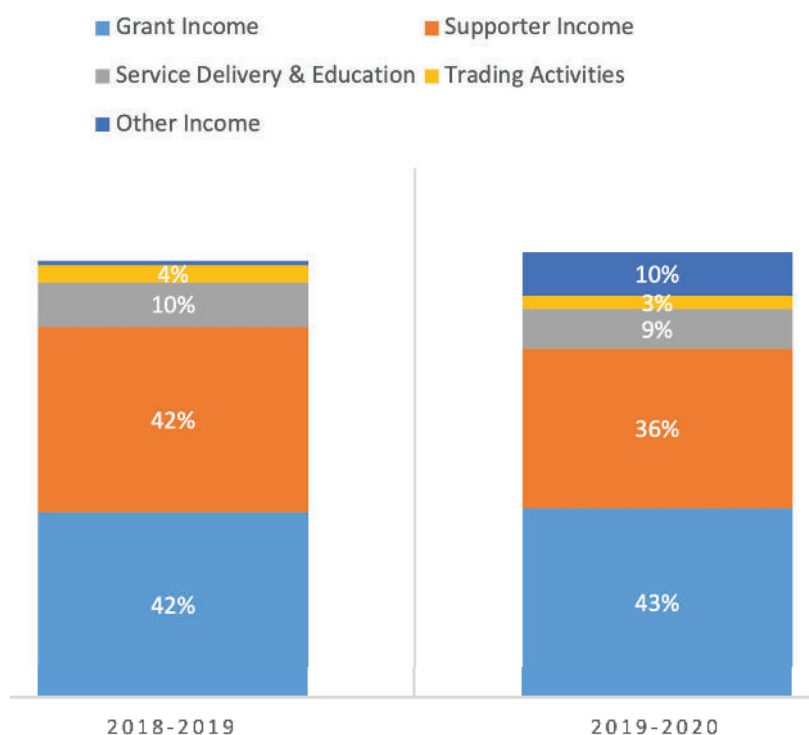
Whilst our income increased by 23% year on year, expenditure only increased by 15% to \$1.62M. This additional surplus in FY20 is largely a result of a one-off grant from Queensland Health which expenditure will be carried over into FY21.

FY20 saw an increase in operating expenses as investments in operating from digital platforms were made to enable ongoing service delivery during restrictions associated with COVID-19. We expect this to return to normal over the course of FY21 and will continue to maintain operating expenses at less than 10% as a benchmark.

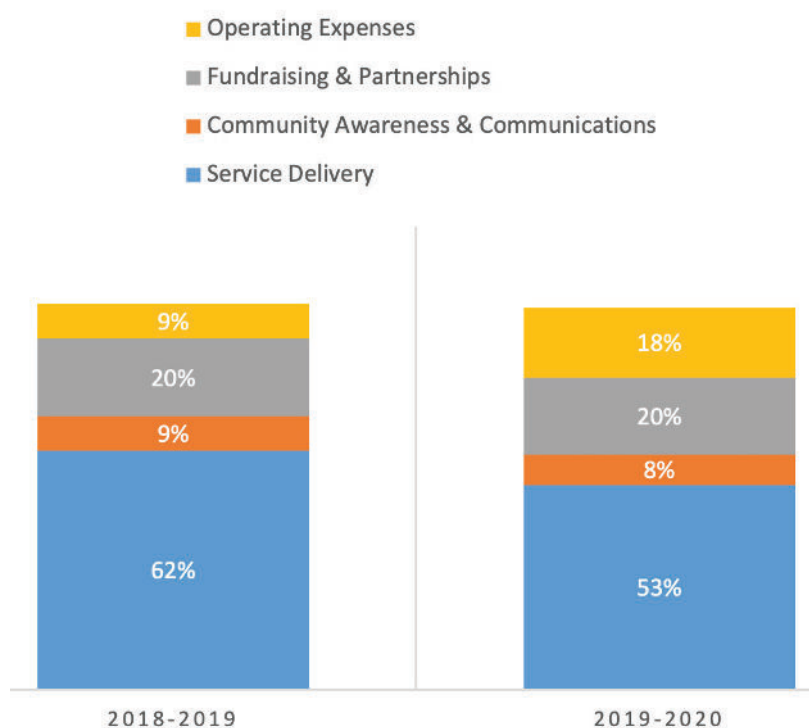
A full copy of the audited financial report is available on our website

<https://www.epilepsyqueensland.com.au/about-us/epilepsy-queensland/annual-reports>

SOURCES OF INCOME



DISTRIBUTION OF EXPENDITURE



Thank you for your support

Government and philanthropic supporters

- Department of Health
- Department of Communities, Disability Services and Seniors
- National Disability Insurance Agency
- Gambling Community Benefit Fund
- Brisbane City Council
- Cowboys Community Foundation

Purple Day and Symposium sponsors

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

For sharing their story

- Jack Dalton
- Vince Cheah
- Maria Rawson
- Matt Butler
- Samantha Nixon
- The Fairleigh family
- Jeska Valk
- Julie Grantham
- Gerard Benedet
- Joanna Marshall
- Madaline Guilke
- Joanne Scott
- Lakeisha Patterson
- The Lorimer family
- The Cameron family

Partners

- Epilepsy Australia
- International Bureau for Epilepsy





PO Box 1457, Coorparoo DC 4151
Level 2, Gabba Towers, 411 Vulture Street, Woolloongabba 4102



07 3435 5000 or 1300 852 853



07 3435 5025



epilepsy@epilepsyqueensland.com.au



www.epilepsyqueensland.com.au