



EPILEPSY
queensland

Impact

**REPORT
2021**



Our vision of hope

Epilepsy Queensland was formed through the passion of people living with epilepsy, parents, medical and allied health professionals, educators, and others whose motivation was to help. The original purpose that united them was “to enable epileptics to take their place in the community, to enlighten the general public, and increase understanding of problems associated with epilepsy”.

One of the main drivers was to increase understanding of the impact of epilepsy for employers. This was championed by founder Doris Kemp, whose son Robert had been employed in several jobs but was sacked repeatedly once his employers found out about his epilepsy. At the time there were no laws to protect people with disabilities from unfair treatment, and discrimination was a commonplace occurrence.

While times have changed, 30 percent of people living with epilepsy don’t achieve seizure control with medication. Many people with epilepsy and their families are still struggling with the ‘whole of life’ impacts of epilepsy. Many are still experiencing a lack of community understanding, fear, and discrimination – there is much work still to be done.

Following our 50th anniversary in 2019, our organisation embarked on a journey to ensure we remain contemporary, relevant, and able to meet the growing and changing needs of you, our community as we seek to be your beacon of hope.

We started by speaking to some of you to understand

what aspects of our work you valued and how we could better serve you. From this we created our new vision, impact statements and associated values that will guide our behaviours. Some of you experienced the launch of this vision in February 2021 on International Epilepsy Day.

Our new Outcomes and Impact Framework will help us measure and evaluate our activities to ensure they deliver to each of our impact statements which are:

- An Individual understood and supported to live well
- A Community aware, removing barriers and in search of a cure
- An Organisation financially strong and ready to deliver and measure impact.

We also heard of your ongoing connection to the flame. The symbol of the lit candle was adopted as the logo of Epilepsy Queensland during the first year of operation in 1969. Originally an illustration by Haro Hodson for the British Epilepsy Association, our logo evolved to a flame in 1995 and then to our current logo in 2006.

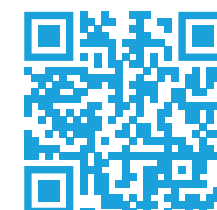
“A brightly burning candle, of course. It’s perfect. A symbol of hope, of enlightenment - that’s the one,” Hodson was told.

Their Founder Irene Gairdner said: “A lit candle can be seen from a distance, even on the darkest night.”

For us, the significance of the flame continues today. It represents our vision to be the beacon of hope for our community.



LEARN MORE
ABOUT OUR
VISION OF
HOPE



Foreword

We are excited to present to you our impact for 2020-2021 and our progress on delivering to our vision of being the beacon of hope for people living with, and impacted by epilepsy in Queensland.

Our new look and style helps bring to life the incredible stories of our community, some of which are presented in this report.

A truly #brave and #agile team within the organisation, and supported by our Board, have navigated through significant change all while delivering more than 3,500 instances of service to our community, record-breaking fundraising results and more uptake in media coverage than ever before.

1 in 10 people will experience a seizure in their lifetime. 30,000 Queenslanders currently live with an active diagnosis of epilepsy. Every year, 3,000 more people are diagnosed.

Whilst we are very proud of the impact we have had on our community this year, we know we can and will do more. We are grateful for the ongoing support of the Queensland Government and by working together we are confident we can deliver our exciting initiatives.

More importantly we are grateful to you, our community, our supporters, and our partners. We welcomed Awareness Partner – Brisbane Roar to the fold this year, we formalised a research partnership with the University of Queensland and we welcomed a number of new corporate partners that are celebrated in this report.

We hope you enjoy reading about our community and their journey this year and look forward to your ongoing engagement in and support of our work.

Chris Dougherty
Chief Executive

Samuel Bryce
Chair

30,000

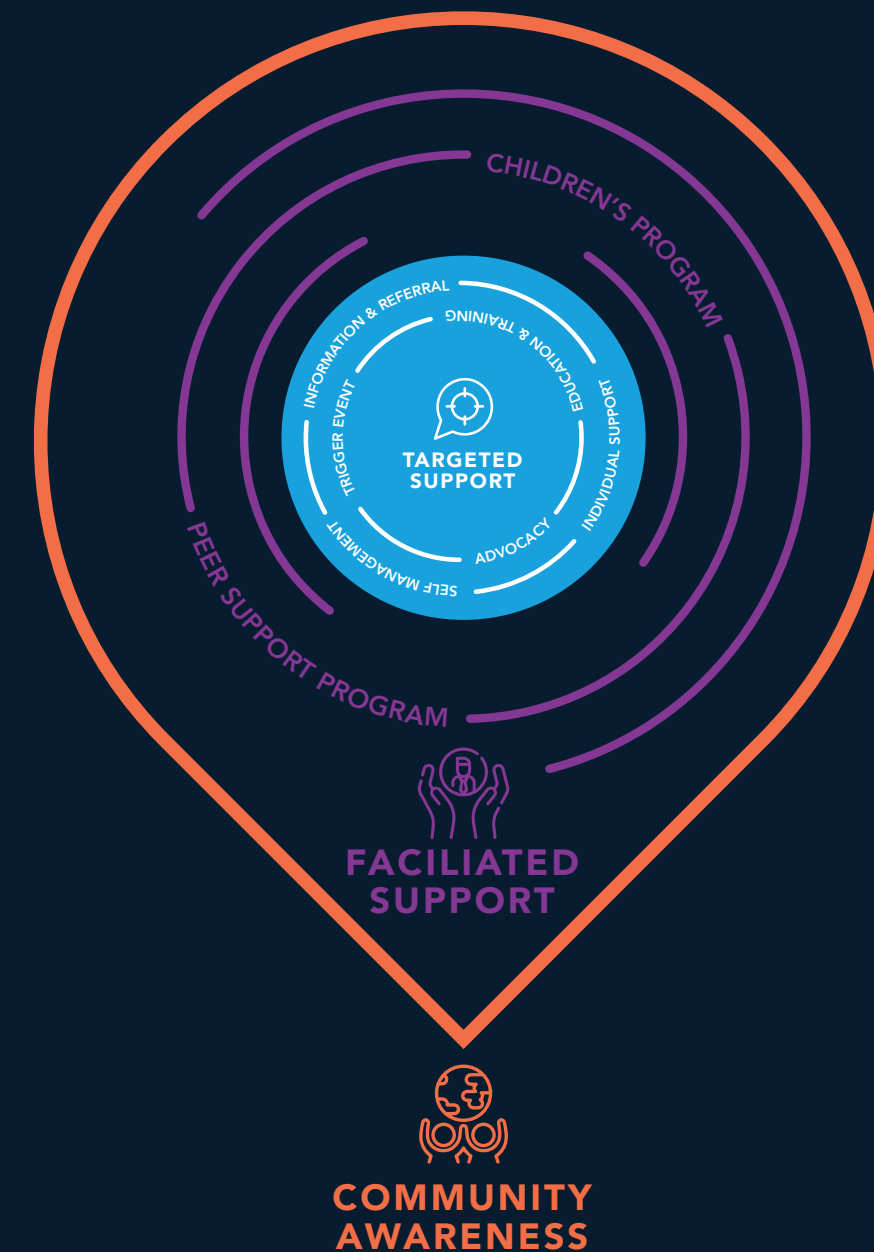
Queenslanders currently have an active diagnosis

1 in 10
will experience
a seizure

3,000+
diagnosed every year



OUR SERVICE MODEL



Over many years our work has evolved from a typical information and referral service (which is still very important today) to a more holistic model that layers targeted individual supports when needed from experts, with facilitated supports in programs such as our Little Poss Children's club. We have often seen our work in community awareness and by extension, our fundraising work as distinctly separate.

Our new Service Model brings this together.

Targeted Supports are when someone needs us the most. Something will change in their life, perhaps a new diagnosis or a breakthrough seizure, where they need access to our professional and expert team to guide them through to gaining control of seizures, building self-confidence and living well with their epilepsy.

Facilitated Supports, including a reimagining of our Children's Program this year, will soon include a comprehensive peer support program. We will design and implement programs and training, empower and coach our community to support each other through the daily impacts of living with epilepsy.

Community Awareness is the key to our long term impact to ensure individuals do live well with their epilepsy. The more we make people aware and remove barriers across the community, the less it interrupts their everyday life. This is why we will design and implement an integrated multi-year strategy to bring this to life, and something everyone in our community can get involved in.

OUR NEW LOGO

For Epilepsy Queensland, the significance of the flame continues today. It represents our vision to be the beacon of hope to people living with, and impacted by, epilepsy in Queensland. We are pleased to unveil our new, contemporary logo that honours our past with the connection to the flame and our traditional

colours of blue and orange. We have also incorporated the colour purple, which in more recent years has represented epilepsy awareness in the community. Purple Day and the Make March Purple campaign is the ongoing celebration of the achievements of people living with epilepsy.



Quabbha Family



Abigail had her first noticeable seizure at three days old. Abigail and her family are from Ingham, North Queensland and the equipment to facilitate a diagnosis was not available in their township. Subsequently, dedicated Mum Danica requested a referral to Brisbane Paediatric Neurologist, Dr. Shah. After a particularly violent seizure, Abigail was officially diagnosed after a 24-hour EEG at 20 months old with multi-focal epilepsy.

Danica says "the day she was diagnosed was a mixture of relief, guilt and heartbreak. I was glad to have a name for what was happening but at the same time was questioning whether we did something wrong to cause this and wondering how her future would look. We mourned the loss of a normal childhood for her. Our family needed support, so I phoned the Epilepsy Queensland Helpline".

People who call the Epilepsy Queensland Helpline will be looked after by our caring and knowledgeable team members who are specifically trained in epilepsy management and are there to provide understanding, information and support when it is needed most.

"Having someone to talk to who has first hand experience and deals with epilepsy all the time has

been amazing and so beneficial to our family," says Danica.

Abigail, now 4 years old, has had significant challenges related to her condition, including many life-threatening episodes. She has tried many medications, unfortunately they don't often impact the severity or length of her seizures. Some side effects the family have witnessed include severe mood swings, rages, sleepiness, appetite changes, and cognitive dampening. As Abigail became older, the frequency of her seizures intensified.

Danica recalls another especially tough time: "We had a two week period where Abigail experienced over 120 clinical seizures, not counting her sub-clinical activity. I honestly thought at times during those two weeks we wouldn't be going home and that was by far the toughest time in this journey thus far."

Danica says: "We have been super lucky that Abigail's childcare centre at the time, was able to apply for an aide for her to keep close watch and ensured all the employees completed Epilepsy Queensland's training in Understanding and Managing Epilepsy and the Administration of Midazolam

““

Epilepsy Queensland helps so many cope with a sometimes devastating diagnosis, connecting them with much needed resources. As a family who has medical bills like you wouldn't believe, it takes the pressure off us knowing that thanks to generous supporters of Epilepsy Queensland, help is a phone call or email away.

””



Helpline

3,563
calls answered

3 in 5
are new customers

30%
people with epilepsy

32%
family members

38%
service providers





5,200+

hrs of training delivered

196

live sessions

1,061

additional reached by
e-learning

2,530

participants reached

Sammie & Evie

The birth of a child is a joyous occasion, but for new mum Samantha, of Tingalpa, the start to her daughter Evie's life in April 2019 was also the start of Samantha's life with epilepsy. Just five hours after Evie's birth, Samantha experienced her first seizure, with a second following four hours later. After just a few days, a diagnosis of epilepsy was delivered.

Samantha describes some of the greatest challenges of this time: "Having my independence completely stripped away from me, adjusting to a whole new diagnosis as well as being a new mum. I wasn't allowed to drive for seven months and had to have constant surveillance for the first month of my daughter's life. I felt nothing like the sharp person I was. I felt like a shell – empty."

Samantha was also troubled by side effects from her epilepsy and antidepressant medications: "The anti-seizure medication side effects took a good eight months to go away. These included the feeling of my brain being "doughy", unable to focus, forgetfulness, and some mood swings."

"I'm now on a Ketogenic Diet (a treatment option for epilepsy) and that has helped with my focus and all over body health. I have also started working with a personal trainer. I have found I need to manage my sleep and keep my stress levels low."

Whilst Samantha wishes she had connected with Epilepsy Queensland sooner, she says recent contact through the Epilepsy Queensland Helpline and Instagram page has helped her to feel less alone with what she has gone through.

Samantha shares: "Epilepsy Queensland exists because people like me have felt very isolated and scared. I was at the point I felt that I was lost, that I had no one else to turn to. I thought no one else understood."

"Returning to work, I wanted to feel confident in the whole new person I was. I wanted to feel educated and empowered living with epilepsy. Epilepsy does not define me. Epilepsy Queensland has, and always will, offer me support and education. Their Instagram page is so informative, warm, and approachable. I really love it."

Samantha and her husband Mitchell also enrolled in the Epilepsy Queensland course *Understanding and Managing Epilepsy*, plus the *Administration of Midazolam*.

She shares: "Best course I ever did! I feel so much more confident since completing. It was nice to feel educated and in control. So proud of myself and Mitch. We feel more prepared for the future in case anything unexpected happens to me, someone we know, or a stranger."

Samantha shares her hope for the future: "I hope to become more confident and share my story with others who are finding it hard to find the light. I want to be more and more educated on epilepsy and get more involved in anything I can to help spread awareness of this common but very misunderstood condition."

"I now work with a very supportive childcare centre that my daughter attends three days a week. They all know I have epilepsy and I'm very open about it. As a centre they have done their epilepsy training. So far I'm very happy and smashing goals."



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I feel so much more confident, educated and in control since completing the course. I'm proud of us. We feel more prepared for the future.

”

Training In Action

Townsend School Bus Services is a Queensland family business that has been providing school bus transport for students with a disability for over 30 years. Each of the 120 modified buses has a dedicated carer on board to ensure the health and safety of the students.

Owner, John Townsend shares the impact that Epilepsy Queensland's training has at his workplace.

"Many of the children who travel on Townsend buses have a diagnosis of epilepsy. It is important to us and our team that they are professionally trained to react and respond if a child experiences a seizure while on board, especially if the child requires an emergency medication. They feel much more confident in caring for the students.

Epilepsy Queensland has been delivering Managing Epilepsy and Administration of Midazolam to our team for over 10 years now. We generally book in for a tailored training session designed specifically for Townsend Buses, with up to 20 staff members involved in each session. We do this sometimes six times each year so that new staff are trained and existing staff have their knowledge regularly refreshed.

The training helps our team to respond to epilepsy with the most appropriate first aid, and helps our carers identify if a child might be about to have a seizure. We see the benefit, both for the children we care for, but also for the staff that we employ. The welfare of all the kids who travel with us is a priority – regardless of if they have epilepsy or not. Knowing that our team are trained correctly in seizure response is good for everyone.

A recent experience that comes to mind relates to a young lady on one of our buses. She experiences seizures on most days and every now and again these can be severe enough that an ambulance is called. This young lady has a one-on-one carer with her on every bus trip. Recently this carer was ill for a period of time and I had several relief carers take her place over the course of three weeks.

The communication between these carers, the parents and the school enabled us to continue to provide an excellent standard of care and a seamless transition between staff members. This is due mainly to the high standard of training provided by Epilepsy Queensland."



I endorse and highly recommend the training provided to my staff by Epilepsy Queensland.

It builds confidence within our staff, not only with the administering of Midazolam, but also with seizure recognition, procedures and record keeping.

DAVID RAPP



Training & Education



4,500+

hrs training to organisations

2,267

participants reached

70%

disability
providers

20%

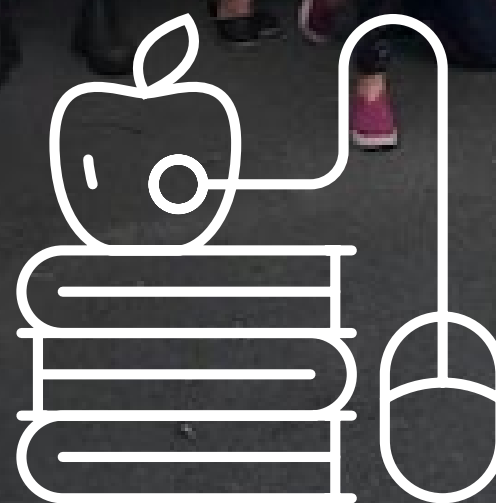
education
providers

9%

healthcare
settings

1%

employers



Brett's Story

Brett, 25, has been living with epilepsy since he was born, after a difficult birth in which his mum was whisked away for an emergency delivery. With support and understanding, Brett has built a busy and rewarding life, proving living well with epilepsy can be possible.

Brett says he experienced frequent tonic-clonic seizures in his early years, which his mum and sister found scary to witness when he was so small. He takes two different anti-seizure medications and said it took some time and adjustment to get the dosage right.

He experienced his last tonic-clonic seizure at 12 years old at his auntie's place when his mum was away on a retreat. Brett continues to experience focal seizures, which he describes as "staring into space, going blank."

He describes some of his frustrations with people's misperception of epilepsy: "People think they are protecting you, but this means you don't get the same opportunity for growth. You mention epilepsy and people run for the hills."

Brett describes Epilepsy Queensland as "cool cats. They are like a second family, where they understand what you are going through."

Brett attends E-Connect, a program for teens and young

adults, and really appreciates being able to meet new people and build skills for different life situations. "Leonie (Services Development, Living Well Team) and the other attendees make me feel included and I have fun."

He also participates in the weekly Zoom social group. "If it wasn't for Epilepsy Queensland, I wouldn't have met new friends. Working and my other commitments mean I have less time to socialise."

Brett has worked for Woolworths since 2013 and is a very community-minded and charitable person who is involved with several non-profit organisations. He raised funds for the Salvation Army Bushfire and Drought Relief Appeal and also travelled to Fiji with Samaritan's Purse Australia as part of "Operation Christmas Child".

In the future, Brett hopes to help establish a group to enable people to rally together and connect parents.

"When growing up as a child, Mum didn't really have support. Mum is really deadly. She is my hero and has always been there to make sure I am OK."

Brett wants to convey there is support available through Epilepsy Queensland: "Having an army of angels behind you makes you feel like you can do anything. They want to see you flourish."



“

Having an army of angels behind you makes you feel like you can do anything. They want to see you flourish.

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Peer support

384

hours of peer support

192

participants reached

SUDEP Awareness

Sudden Unexpected Death in Epilepsy (SUDEP) is when a person with epilepsy dies suddenly where there is no clear cause of death determinable after a postmortem examination. This may be with or without evidence of a seizure, witnessed or unwitnessed. Australian research suggests that SUDEP is underreported, but regardless a shocking 280 Australians die each year.

Epilepsy Queensland encourages a conversation between a person living with epilepsy and their specialist about SUDEP and what they can do to reduce their risk. Many families are not told about the risk of SUDEP by health practitioners. We also offer supports to families who experience a SUDEP death and we actively support research in this area.

We work with families impacted by SUDEP to raise awareness in the epilepsy and broader community. After the tragic passing of several young Queenslanders from SUDEP, we worked with the Courier Mail and a number of regional outlets on features and interviews with the families.

We are sincerely grateful to the Tibbotts, Fairleigh, Lehtonen and other brave families for sharing their stories and working with us to advocate for more SUDEP research and awareness.

Australian research suggests that SUDEP is underreported, but regardless a shocking

280

Australians die each year.

VALE - ROSEMARY JUNE PANELLI

30.6.1952 – 27.4.2021

Today, Sudden Unexpected Death in Epilepsy, or SUDEP, is being studied around the world. Rosie, along with colleagues from Epilepsy Australia, took a key role in producing and editing a book called "Sudden Unexpected Death in Epilepsy: A Global Conversation." People who knew Rosie knew that she was a woman of extraordinary energy and commitment, especially around SUDEP.

Rosie was widely respected around the world for her work in public health, where her legacy will live on as part of the story of remarkable women in epilepsy in Australia. She was truly, widely loved.

Dr. Rosemary Panelli, Rest In Peace.

FOR MORE INFORMATION AND SUPPORT

Epilepsy Queensland Helpline – 1300 852 853

SUDEP Action – sudep.org

Beyond Blue – 1300 22 46 36

5 May

Online Epilepsy Memorial Day

A day to pay tribute to and remember those we have lost to epilepsy. SUDEP Action launched this special day enabling the bereaved community to connect around the world.

A common misconception about epilepsy is that it is not a life-threatening condition. Sadly, this is not the case. A recent Deloitte report estimates 342 Australians lost their lives to epilepsy in 2019-2020. SUDEP is the most common cause of epilepsy related deaths, however, members of our community also pass away due to drownings, falls, other accidents, and suicide.

Each year Epilepsy Queensland staff and volunteers symbolically light a candle to keep the light of those lost to epilepsy burning, ensuring that their memory still lives on and burns bright. Within our own epilepsy community, we also use the Epilepsy Queensland candle as a symbol of hope, bringing light to epilepsy. Joining together on this day to remember, reflects our hope and our combined strength into the future.



VALE MADDIE GILL

Maddie Gill was diagnosed with absence seizures when she was in primary school. She was a passionate epilepsy advocate raising awareness and funds each Purple Day.

Maddie was healthy, she loved life, and was building a strong future for herself. She was in her final year of studying marketing and advertising at QUT and also worked part-time at a dental clinic. On 5 December 2020, Maddie's young life was taken from her by SUDEP.

Courier Mail journalist, Sophie Chirgwin, writes: "Maddie Gill was vivacious with a zest for life. The 22-year-old, with an unforgettable smile, was a born storyteller."

While still grieving, Maddie's family vowed to honour her legacy by raising epilepsy and SUDEP awareness for Epilepsy Queensland.

The family and their supporters created an "In Memory" fundraising page and have so far raised over \$15,000 to support SUDEP awareness support and research. The community of Mount Perry also rallied with Maddie's family and friends to Make March Purple for Epilepsy.



VALE JUDAH LEHTONEN

Judah celebrated his 21st birthday in November 2020. Just two months later, on 2 January 2021 he passed away from SUDEP. He was diagnosed with epilepsy at the age of 18. His epilepsy was managed with medication and to his parents Mick and Louise's knowledge he only had two seizures since.

His family are calling for more research into, and awareness about the deadly condition among people with epilepsy. His mother, Louise, told 7 NEWS if her son had been aware of the risk, he would have done more to reduce the chance of it happening.

Judah had just been promoted at his job at Carl's Jr restaurant Rockhampton. He was loved by many and had a bright future.

Dad Mick says: "He was extremely caring, very empathetic. He made everyone feel comfortable and he was accepting. He was gifted musically and loved the outdoors."

In March the family raised \$4,391 for Epilepsy Queensland via a Facebook fundraiser.

Louise shares: "For my birthday I asked for donations to Epilepsy Queensland, particularly research into the phenomenon of SUDEP. I've chosen this nonprofit because their mission means a lot to me, as I lost my beloved son, Judah Jonathon Lehtonen in January to SUDEP."

VALE ANNA FAIRLEIGH

Anna Fairleigh was a talented sportsperson playing soccer, netball and competing in rowing state titles. She was a huge Gold Coast Titans fan, a love she shared with her father. She was passionate about graphic arts and was close to completing her degree.

October 2, 2019 was meant to be a celebration for Tanya and Chris Fairleigh's 21st wedding anniversary. Unfortunately, it turned into a nightmare when they found their beloved 20-year-old daughter Anna had passed away from SUDEP. They had known about SUDEP, but didn't think it would happen to Anna. Diagnosed at age two, her epilepsy was well controlled by medication and she had been four years seizure-free.

The Gold Coast Titans raised \$2000 for Epilepsy Queensland in memory of Anna and had planned fundraising and awareness activities for Epilepsy Queensland during their first home game in March 2020. Unfortunately, due to the impact of COVID-19 on the NRL, this was postponed. Chris and Tanya continue to raise funds for SUDEP awareness, research and support. In March 2021 Chris donated \$1500, a percent of the earnings from his landscaping business. The logo for the business "Go Anna" was created by Anna's aunt, Susan Cooper, in her memory.





“

Epilepsy Queensland has helped me find the right neurology service, navigate the NDIS and helped me secure an assistance dog. They have helped me stay connected with my peers, especially throughout COVID.

”

Renee's Story

Renee, 22, has been living with epilepsy for over a decade. They experienced their first seizure in 2009, but wasn't diagnosed until two years later in 2011.

Renee first got involved with Purple Day four years ago and became an advocate for Epilepsy Queensland in Bundaberg. They then started to access our services.

"Epilepsy Queensland has helped me find the right neurology service, navigate the NDIS and helped me secure an assistance dog. They have helped me stay connected with my peers, especially throughout COVID."

Renee keeps busy with many interests: "My time is mainly spent writing for my medical-related blog, writing for my free independently published book series featuring characters with epilepsy and my art."

Renee recalls a particularly memorable day, which they describe as both their worst and best day: "I had my most intense seizure ever that took me out for about a month and a half. Not nice. At the time I was still hiding my condition the best I could. That same day, in my foggy state, I accidentally told mum to message people who didn't yet know to update them on what happened. Their responses showed me I didn't have to hide anymore as they were really kind, caring, and supportive. That day changed how I live my life."

Since this time, Renee has connected with Epilepsy Queensland and has become a terrific advocate for epilepsy.

Renee is a #MakeMarchPurple ambassador for Epilepsy Queensland and is a previous recipient of our Role Model Award. They often facilitate our Zoom Social Group each Wednesday afternoon and has also undertaken numerous

fundraising activities for our organisation. For our Make March Purple for Epilepsy campaign Renee created the "My Hair, I Care Challenge". Renee raised vital awareness and \$1,550 for Epilepsy Queensland. They coloured their hair 15 different shades, one for each \$100 raised for our organisation.

They reflect, "My future is ever-changing and unpredictable but one thing I know for sure is I'm going to be the best advocate and peer mentor that I can be."

"My vision for the future is to be known as a great advocate who is able to see the impact they're having on the world."

Renee believes transparency is a key to people understanding epilepsy in the community. "We can be transparent by being honest with the public and people with epilepsy about what epilepsy is, how it impacts people, how it will impact your daily life and your furthering of self within the community."

Renee would like to see more neurologists and GPs referring people who are newly diagnosed with epilepsy or still in the process of diagnosis.

They share: "When someone is diagnosed with cancer they are automatically linked in with the Cancer Council. I wish it was a thing for every other diagnosis. My mum and I were left to find Epilepsy Queensland on our own and it took us some years and it took us longer to reach out. Because we didn't know if we had anything worth talking to them about. If we were told on day one, "Here's Epilepsy Queensland, go look them up, give them a call, tell them you've just been diagnosed," we would have had so much more help with my journey."



Community Awareness

80%
LinkedIn

75%
Instagram

16%
Facebook

7%
Twitter

Seizure Smart September

One in 10 people will have a seizure during their lifetime. With this in mind, our aim is for one person in every household to know seizure first aid. Our Seizure Smart September campaign aims to raise awareness in the community of what to do if someone has a seizure. We share the basic tools of seizure first aid that could help save a life.

The campaign also focuses 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.

Together we were able to raise awareness of seizure first aid and help build a supportive community for people living with epilepsy or seizures.

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 aim of seizure first aid is to keep the person safe whilst maintaining their privacy and dignity. Through Seizure Smart September we aim to reduce stigma and fear in the community when someone has a seizure. By building community awareness of what to do to help someone having a seizure, we remove barriers to living well with epilepsy.

Epilepsy Queensland have a range of quality resources available for work, home or school. For more information about seizure first aid including tonic-clonic (convulsive) and non-convulsive seizure types can be found at: <https://bit.ly/GetSeizureSmart>.

60

social media posts

295,531

facebook reach in 2020

12,986

social media engagement

“ I have lived with epilepsy since birth and want to show my support for a cause close to my heart. ”

HARRY



Make March Purple

Make March Purple for Epilepsy is a time for us to celebrate as a community. It's also a great opportunity to raise awareness of epilepsy and remove barriers by building understanding through sharing our stories.

AWARENESS RAISED

27

articles

13

radio interviews

4

TV interviews

1

podcast



430,657
people reached



157,412
impressions



40,439
impressions

750,000

viewers/week reached
digital TV - Anzac Square

69,314

people reached
with facebook ads

34%

increase in
page views

3,470

people reached
with google ads

34.6%

increase to our
website

RAISING FUNDS

109

fundraising events

130k+

raised

3000

purple plush sold

965

individual donations
received

45

schools
participated

31

bridge climb
participants

MAKE MARCH
PURPLE
FOR EPILEPSY



Queenland
Illuminates
Purple

25

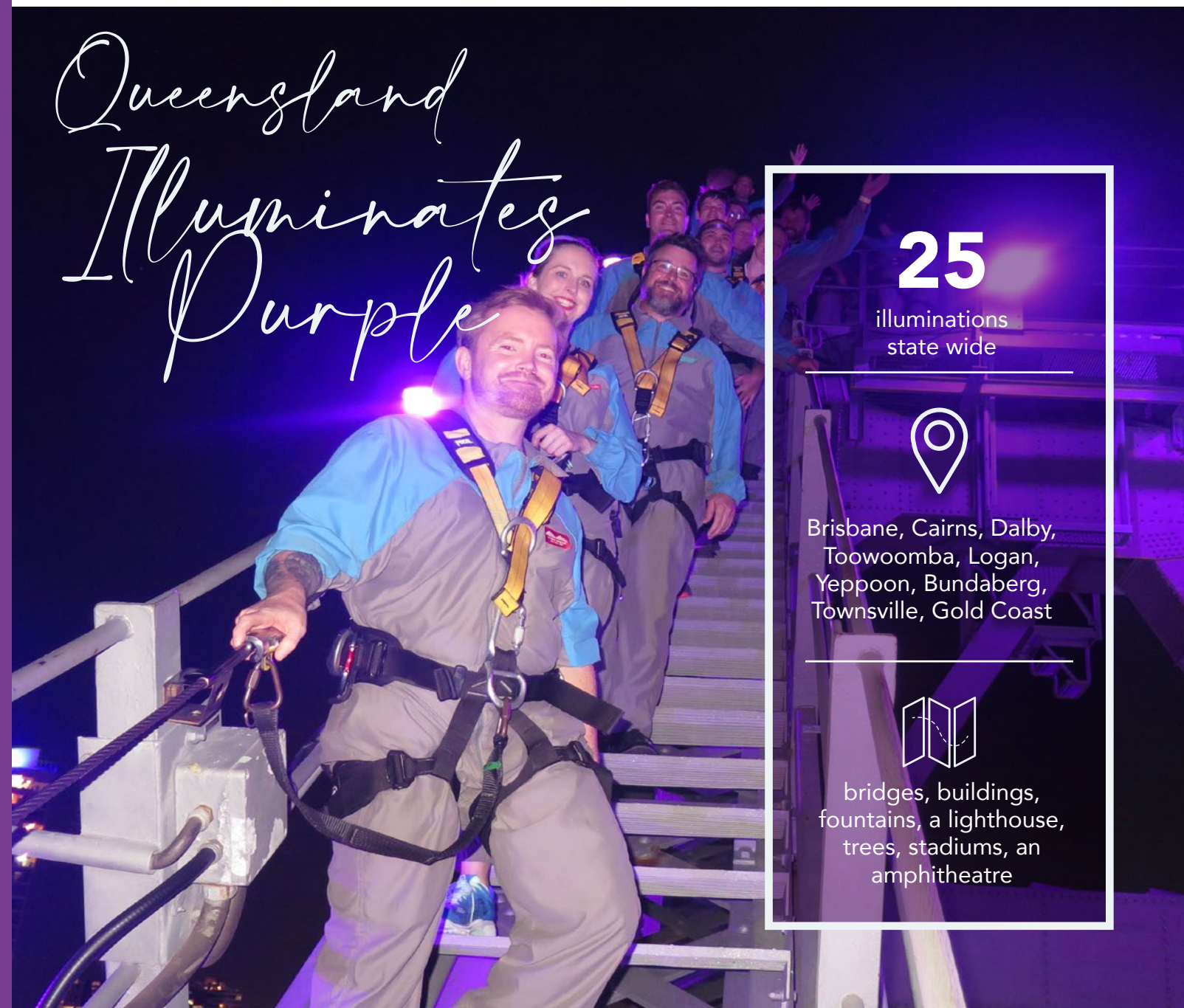
illuminations
state wide



Brisbane, Cairns, Dalby,
Toowoomba, Logan,
Yeppoon, Bundaberg,
Townsville, Gold Coast



bridges, buildings,
fountains, a lighthouse,
trees, stadiums, an
amphitheatre



Purple Muck Challenge



Watch the video



Our Partners

THANK YOU TO OUR PARTNERS

Partnerships with the corporate sector are essential for Epilepsy Queensland. This is an area we aim to develop significantly in the year ahead.



ACMENA GROUP \$5,000

Total raised

Each year, this Australian owned and operated engineering and management services provider generously donates to a number of charities supported by their team members.

We were nominated by Ricky Clayton, whose wife was recently diagnosed with epilepsy.

"In January this year my wife had a seizure, which was frightening and definitely unexpected," said Ricky. "When we tried to find out why this happened to her, the doctors couldn't give us definitive answers and we realised how little we knew about the subject. That's why this year I decided to support Epilepsy Queensland, which helps to raise awareness and support people living with the condition."

This support will help ensure more Queenslanders impacted by epilepsy will have access to our vital services such as the Epilepsy Helpline, training, information and support during these tough times.

TOWNSVILLE SUPPORT

\$8,500

Raised to date

When Natalie Griffiths' teenage son Chad was rushed to the Intensive Care Unit at Townsville University Hospital, she felt like she was living a parent's worst nightmare.

The 17-year-old was diagnosed with absence seizures at age 14, which involve brief, sudden lapses of consciousness. But on Christmas night, Chad, who seemed fine during the day, was rushed to the emergency department after experiencing a tonic-clonic seizure.

To celebrate International Epilepsy Awareness Day in February, a fundraiser was held by the family's business City Cheer and Dance Townsville, as well as other local Townsville businesses, including Chad's employer Procut Meats.

If you'd like to help with a donation supporting a vision of hope, visit: <http://bit.ly/EpilepsyAwareTownsville>

NATHAN & BRENORRS

\$5

Donated for each shirt sold



It affects everyone differently, and also affects those close to the person with epilepsy.



Nathan Garvie, of Brenorrs, Roma launched his Epicool work shirts at Beef Week 2021, donating five dollars from the sale of every shirt to Epilepsy Queensland.

It's a project close to the heart of Nathan, who himself lives with epilepsy.

Brenorrs, which has been making workwear for 20 years, has recently become a corporate partner with Epilepsy Queensland.

Nathan says he's taken on an ambitious goal in designing and selling the work shirts with hopes to generate support for people with epilepsy. "We hope to keep on track to sell 400 a month," he says.

The 100 percent Australian - made shirts are available for men and women, each with special design features. The cotton blend offers UPF 50+ sun protection and are available for \$69.50.

The ultra-cool mesh underneath the armpit is a distinct lavender while the internal side of the cuffs is the same colour and features the Epilepsy Queensland logo.



Fundraising Highlights

Despite the ongoing challenges of fundraising during a pandemic, Epilepsy Queensland ended the financial year in a strong position.

\$437,000
raised in 2020-21

YOUR IMPACT

Epilepsy Queensland have invested in fundraising in FY21 to ensure we have the technology and human resources to enable a financially strong organisation.

The cornerstone of our fundraising efforts are our community and corporate supporters, many of whom have a personal epilepsy experience.

Our new community platform Funraisin allows the creation of a personal website – called “my impact” and is an opportunity for individuals to share their reasons for fundraising. Just as epilepsy can impact anyone at any time, we see a diverse range of fundraising activities from head shaves to high teas.

183

fundraising
pages created

\$3,500

average
raised

25

average
donations

75%

donated to
yourself!

REGULAR GIVING

Planned and regular income is the backbone of Epilepsy Queensland, it allows us to consistently deliver the most vital services – support at diagnosis and during a crisis. We are grateful to the valued donors who have been supporting Epilepsy Queensland for years.

Regular giving is when you chose to make a regular donation of any amount. This can be made monthly, annually or anything in between. If you would like to know more about contributing to regular giving, please email fundraising@epilepsyqueensland.com.au

40

families making
regular donations

16yrs

our longest
regular supporter

MAJOR APPEALS

Each year Epilepsy Queensland relies on two major fundraising appeals: the Christmas Appeal and the Tax Appeal. Thanks to the Quabba family for sharing their

epilepsy story with us this Christmas. In June 19-year-old Keeley Sorensen shared her story for the Tax Appeal, raising funds for research into the cause of epilepsy.

CHRISTMAS APPEAL

86 **\$12,540**

people
donated

total
raised

TAX APPEAL

206 **\$33,891**

people
donated

total
raised

IFLY

COVID could not keep our fundraising team down, the iFLY event was postponed from March 2020 until September. Newly diagnosed, nine-year-old Bonnie Fairbanks, was a superhero flyer. Her family drove from Toowoomba for her to participate and helped to raise \$6,822.

10

people
soared

\$11,644

total
raised

Thank you

Community fundraising



\$5,000

Raised by
Barrels 4 A Cause
Aramac, January 2021

The Barrels 4 A Cause is a fitting tribute to local Aramac identity and horsewoman, Jenny Schmidt, who passed away two years ago following a seizure. The event is an important day to raise epilepsy awareness in Central West Queensland and fundraise for Epilepsy Queensland.





JAZARAH'S HELPING HAND

\$3,505



When Jazarah told me she wanted to shave her head to raise money, I knew she had thought this through. It was after speaking with a dear friend with epilepsy, that Jazarah decided that Epilepsy Queensland was the organisation she wanted to support.



The courageous and effervescent nine-year-old planned to shave her head for epilepsy awareness setting her fundraising target at \$2,000.

Her mum Kylie shares: "For anyone fortunate to know our baby girl, you know that she has a heart of gold; she has a personality that is larger-than-life and since the day she was born has done life on her terms."

Jazarah told us that she thinks epilepsy is not as well understood with not as many people raising money for epilepsy as other conditions.

Jazarah exceeded her fundraising target by over \$1,500. Suncorp, where Kylie works, generously matched donations up to \$1,000 through the Brighter Futures matched giving program.

Jazarah plays AFL and adding to the excitement was Emily Bates from the Brisbane Lions Premiership winning team who kickstarted the shave. Jazarah's efforts were supported by Yeronga Devils Juniors Football Club where the shave took place.

Thank you to Jazarah, her family and supporters for making a difference in the lives of Queenslanders impacted by epilepsy.

Governance

Epilepsy Queensland strives for good governance throughout the organisation. Key features of our governance framework include a skills-based Board, supported by a fit-for-purpose Board Charter, our Quality Management Systems and a highly skilled and qualified leadership team who are committed to #transparent stewardship of the organisation on behalf of our membership and stakeholders.



**FIND OUT MORE
ABOUT OUR BOARD
AND LEADERSHIP
TEAM HERE**

GOVERNANCE MODEL

On behalf of members, the EQ Board will embark on a Board effectiveness and governance review in the coming year which will ensure our governance model is fit-for-purpose for our organisation into the future.

Epilepsy Queensland Inc is a profit-for-purpose incorporated association, registered under the Associations Incorporation Act (1981) in Queensland.

We were incorporated in 1985 and are a registered charity in Queensland and with the Australian Charities and Not-for-profits Commission (ACNC), Australia's national regulator of charities. You can find our information here:



ATO CLASSIFICATION

The Australian Tax Office has classified us as a Public Benevolent Institution and granted us Deductible Gift Recipient and Income Tax Exempt Charity status. Our Australian Business Number is (ABN) 42 025 269 961

QUALITY MANAGEMENT SYSTEM

We are committed to the highest possible standards of customer experience and outcomes for our community delivered through our services. Our Quality Management System (QMS) supports and empowers this commitment throughout the organisation and provides for an effective mechanism to monitor our overall performance and achievement of our Vision & Impact.

Our fit-for-purpose QMS is not only designed to empower our work but also to meet the requirements for certification under the Human Services Quality Standards and the National Disability Insurance Scheme Practice Standards. We continue to enjoy a strong reputation of excellence in quality externally validated by our auditor HDAA Australia Pty Ltd.





**Donate
now**



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queensland

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