



# 2022 | IMPACT REPORT



## Chief Executive & Chairman Message

It was a challenging year for all Queenslanders as we experienced our first real COVID-19 wave in January / February 2022 followed by another one in 100-year flood event in early March. As a society, we turned our thoughts to the war in Ukraine with its impact felt globally. Despite this unusual operating environment, it was a year of opportunities for our organisation and the Queensland epilepsy community.

In March 2022, the month of epilepsy awareness, we strengthened our brand recognition with the #MakeMarchPurple campaign. The external challenges of the year were reflected in our fundraising results, however, never has our engagement with media, government, and affiliate epilepsy organisations been so successful. Significantly, in March, the Australian Institute of Health and Welfare published 'Epilepsy in Australia' - the first comprehensive national report on epilepsy, which provided us with valuable insights.

In September 2021, Chris was elected to the Western Pacific Region Executive of the International Bureau of Epilepsy (IBE). The IBE, together with the International League Against Epilepsy (ILAE), campaigned to make epilepsy a higher priority for health authorities around the world. Their work was recognised in June 2022 when the World Health Organisation announced epilepsy as a global public health priority for the next 10 years and adopted an Intersectoral Global Action Plan (IGAP).

This is a critical moment in the history of epilepsy care in Australia. We are poised to see a once-in-a-generation change in epilepsy care. First, implementing a bold new vision with strong, embedded values; next evolving our organisational culture, reporting a 40-50% positive increase across all measures of employee experience.

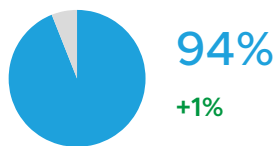
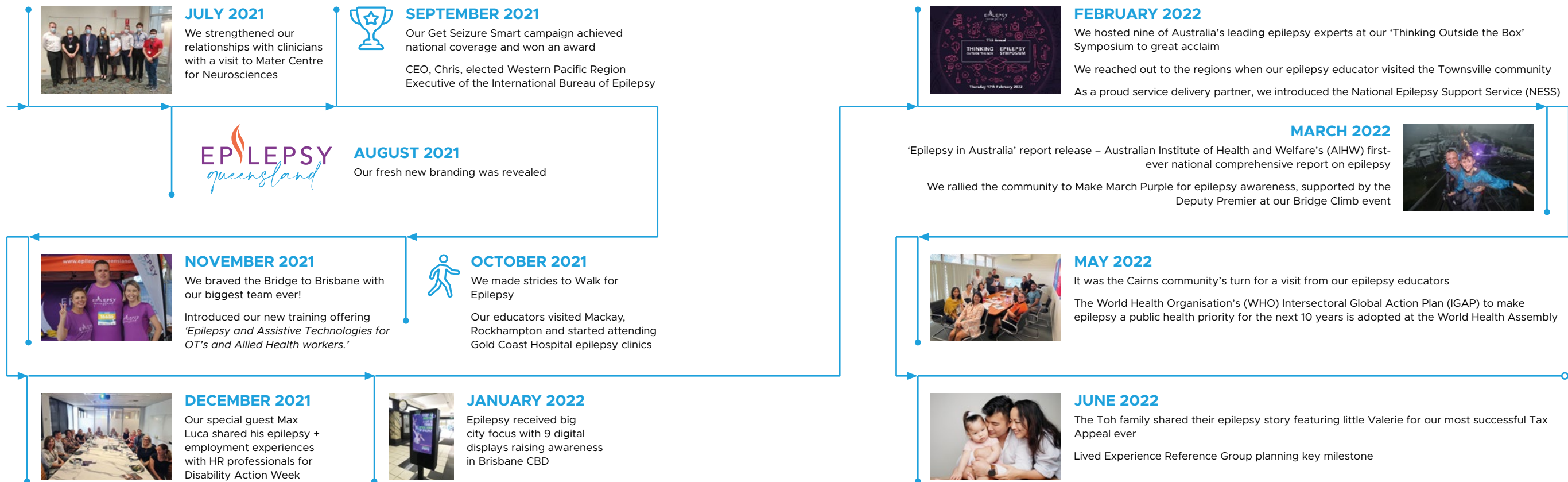
The Epilepsy Smart Australia Project (ESAP) is our response to this critical moment. Together with epilepsy organisations across the country, we are working to change the world for people with epilepsy. Stage one of ESAP was launching the National Epilepsy Support Service this year, the first ever comprehensive national information and referral service for Australians living with epilepsy – no matter where they live.

Our Impact is more about you than us. We are privileged to walk alongside you on your epilepsy journey. We are grateful for the ongoing support of the Queensland Government and the many organisations and individuals that contribute to the impact we have – financially or otherwise. We hope you enjoy reading about the achievements of our community and our progress this year. Thank you for your ongoing support of our work.

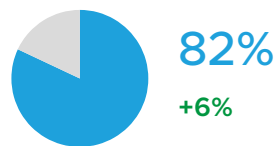
**Photo:**  
Chief Executive, Chris Dougherty  
Chairman, Samuel Bryce  
Patron, Wally Lewis



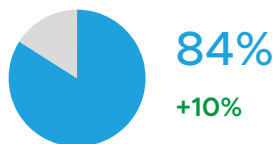




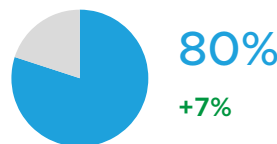
Believe fellow employees are committed to doing quality work



Feel they can do what they do best every day



Responded that there is someone at work that encourages their development



Have had opportunities to learn and grow in the last 12 months

## A United Team

We believe being primed to deliver Impact begins with an engaged and committed team. To foster a strong organisational culture that can deliver change, requires being #brave enough to seek out feedback and being #transparent in sharing the results, both internally and externally. The increase is our employee satisfaction metrics this year compared to 2021 is progress we are proud of. Our team is resilient and feels supported to deliver on our vision.



# Hope for the Future on the Rise

The results of this year’s Customer Survey, an output of our Continuous Improvement Framework, were a powerful indicator that the information, education, and support services we are delivering are meeting the needs of our customers and having an impact on their lives.

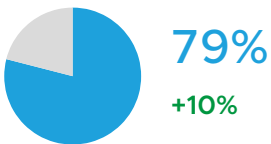
After being diagnosed with epilepsy in September 2021, Emily Dimmick had “never felt so lonely” in her life. When her treating neurologist recommended she reach out to Epilepsy Queensland (EQ), Emily picked up the phone and gave our compassionate team a call.

“I didn’t know what to expect or what assistance I needed as I had no idea what I was doing,” Emily said, “I needed all the information I could get.”

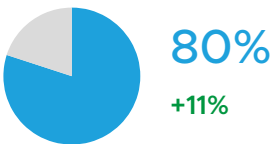
“Not only did Epilepsy Queensland explain what epilepsy actually is and how many different types there were, they helped me with tips on how to manage life now that I was living with epilepsy. They explained what resources were available to me, how to deal with medication side effects and so much more.”

“It felt like, and continues to feel like, they care about me. The support workers are well informed and educated to provide extremely helpful and useful information. My biggest takeaway was that I was not alone, and I will carry that with me always.”

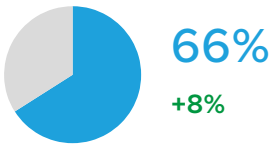
Since that initial phone call, Emily has continued to reach out whenever she needs guidance, knowing that our team is “only a call away”.



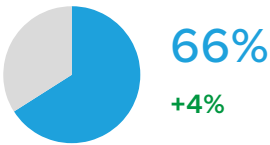
After contacting EQ, I feel more hopeful



The team at EQ understood my unique circumstances



I now feel more confident in managing my condition / diagnosis



Support from EQ has improved my overall well-being

“ Epilepsy Queensland made me feel far more at ease, supported, and confident in living with epilepsy. - Emily ”





# The Path to Independence

Life for the McNamara family was turned upside down in May 2021 when their youngest daughter Ally, 16, unexpectedly experienced two tonic-clonic seizures.

Initially Ally’s tests were all clear and there was speculation that her seizures might have been due to stress. She was sent home with anti-seizure medication to trial for six weeks. Devastatingly, the day she stopped taking this medication, she had another seizure and was diagnosed with epilepsy. Ally continued to experience seizures in the months following her diagnosis and so began the balancing act of trialling different medications.

“Ally’s world spun, it was extremely difficult to come to term with the diagnosis,” explains her loving Mum, Dominica.

“Continuing in Year 11 at school was impossible as the anti-seizure medications made her sleep for long periods. She was also no longer able to continue the driving lessons which she had really enjoyed.”

“Our world revolved around making sure Ally was safe and that her friends knew what to do to help if she ever had a seizure when she was with them.”

For most families, adjusting to a new epilepsy diagnosis is complex and balancing a parent’s instinct to keep their child safe with a teenager’s need for independence is a challenge that is often described.

Ally, who wanted the independence she thought she would have before her diagnosis, moved to Sydney to spend time with her older sister. Initially, Ally managed well and was seizure free for around two months before her tonic-clonic seizures started again. However, in March Ally had a seizure that lasted for 1.5 hours resulting in a three-day induced coma. Her terrified family rushed to her side in Sydney.

“This experience left us extremely fearful of the potential deadly forms of epilepsy,” says Dominica, who is a nurse. When Ally returned to Brisbane with her family, Dominica reached out to us for local support.

“Epilepsy Queensland have been a wonderful support to us. We organised a virtual education session via Zoom on understanding epilepsy and the administration of emergency medication. Ally’s sister and her partner in Sydney also dialled in and we all went through it together.”

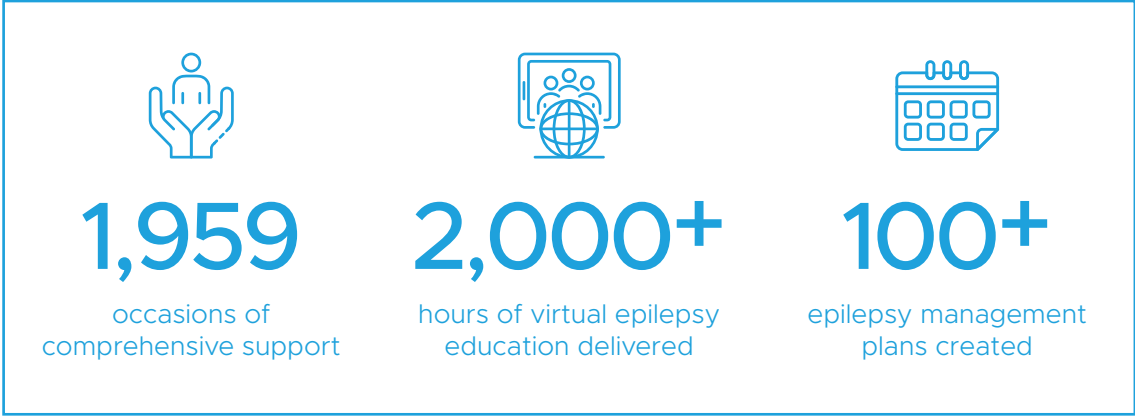
“ I would thoroughly recommend contacting Epilepsy Queensland. The staff are incredibly supportive and caring and are extremely well versed in everything related to epilepsy and epilepsy education. - Dominica , Mum to Ally

”



Building a relationship with our experienced epilepsy educators, Ally’s family were able to support her to manage her condition. “We used the information provided to select the newest Apple Watch and Seizure Alert app. We downloaded and laminated Epilepsy Queensland resources including safety plans, checklists, and Emergency Medicine Management plans.”

Our support team know that everyone’s experience of epilepsy is unique and will tailor services accordingly. “I have also recently made contact once again with Epilepsy Queensland regarding support for family members coming to terms with all of this,” says Dominica.





## Changing Lives Through Advocacy

Helping families navigate and make sense of the complex National Disability Insurance Scheme (NDIS) to access funding can be life changing. With the right information and support, it is possible to live well with epilepsy.

Millie, who is 18 years old and was born with epilepsy, experiences regular absence, focal and tonic-clonic seizures. As her seizures are not able to be controlled by medication, the condition has had a profound impact on her life.

Millie's loving family have always been there, around-the-clock, providing the support she needed. However, like all teenagers, becoming more independent was important for Millie and her family, who began investigating the NDIS to achieve this.

It was decided that Millie's grandfather Tony, who is retired, would take the lead on supporting Millie to achieve her goals which meant navigating the complexity of the NDIS.

“Epilepsy Queensland has been instrumental in helping me navigate through the NDIS applications. Leonie has been pivotal in achieving transformation for Millie and her family.  
- Tony

”

Reaching out to Epilepsy Queensland, Tony connected with Leonie, (Services Development Lead) who guided him in advocating for Millie to gain access to the scheme, by providing information and supporting documentation.

We were pleased to hear that Millie had successfully transitioned from Year 12 into a supportive, community network. Millie now pursues her interests in the creative arts, where she recently made a video about one of her passions – raising epilepsy awareness!

“It's been a journey to reach this point, but ... epilepsy is all about managing the condition so we can unlock her potential. We are committed to allowing Millie to achieve her personal potential whatever that may be,” says Tony.



Watch Millie's  
video



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4,800+

hours training to  
organisations



2,500+

people trained

WHO WE WORK WITH



Health



Disability



Education

# The Gateway to Client Safety

Our objective is to create a world where epilepsy is understood and people living with the condition can participate safely and fully in life, education, and the workplace. Each year, organisations across the state enrol in our training, learning how to remove barriers for people with epilepsy. We are encouraged that around 300 more people participated in training this year than in the previous year.

Gateway Physiotherapy is a Brisbane-based physiotherapy and hydrotherapy practice who specialise in working with clients affected by chronic disease, including epilepsy. Striving to offer best practice service delivery, they require all their therapists to complete our 'Understanding Epilepsy' training.

Practice Principal, Michael Warburton, shares: "We have many clients who have epilepsy, and some have required seizure first aid when completing their therapy session. We have been undertaking training with Epilepsy Queensland for five years and strive to grow our knowledge and understanding to ensure the safety and the welfare of our clients."

Over the years, Michael and his team have participated in several training offerings. Jenny, our Education and Training Coordinator, has built a great relationship with the Gateway team and has delivered training in-person at their practice and has also facilitated virtual sessions online.

"We have even designed custom training to include water-safety and seizure first aid in water, which we have delivered poolside," says Jenny.

"The unpredictable nature of seizures means the pool can be a daunting environment for the client, as well as the families. By having our staff seizure-smart, we can reassure our clients and their families that they are in safe and reliable hands," says Michael.

" The team at Epilepsy Queensland have always been very helpful and knowledgeable when training our staff. They always demonstrate great professionalism whilst being very approachable and kind. - Michael "

Our epilepsy training for organisations takes two - three hours and can be offered for groups of up to 30 people.

We can provide training in person or via a virtual session. We can also customise training for your workplace, educational setting, or individual needs.

Find out more about  
our training



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## Reaching Out to the Regions

This year we travelled throughout the state to deliver education, training and comprehensive support to people living in regional and remote communities.

Access to health and support services can often be challenging outside of metropolitan areas and the need to travel long distances for specialist care can be overwhelming. When we visit these locations, we aim to break down barriers to accessing epilepsy care.

This past year, we have delivered over 1,200 hours of epilepsy education and training to regions outside of Brisbane. Our Living Well team have travelled around Queensland to visit over 600 people in their local communities.

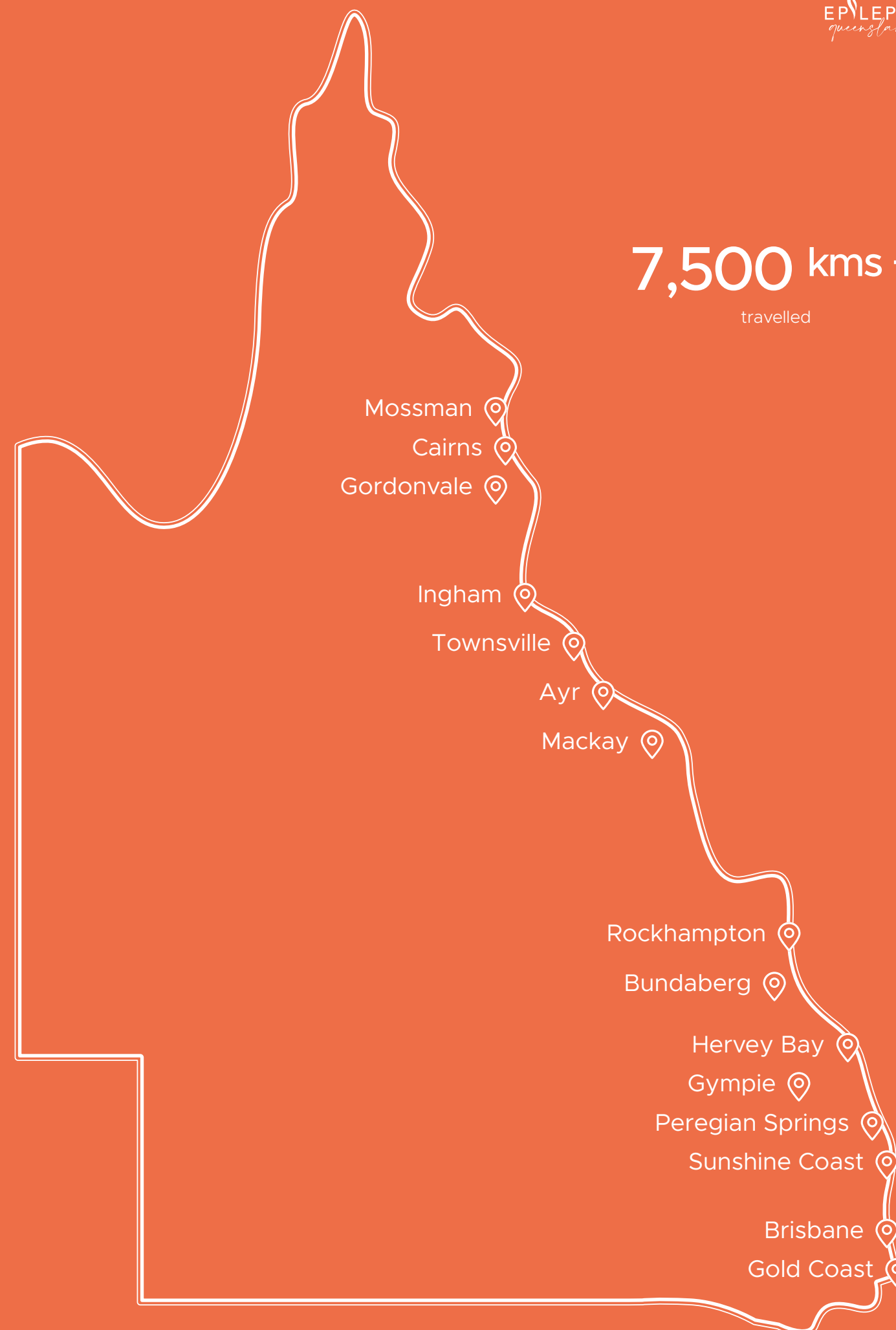
A highlight of our regional visits are the connections we facilitate within communities. Bringing people with epilepsy together over a meal to share their collective lived experience leaves behind a stronger community network.

Building the capacity of local communities to better support people with epilepsy and their families is one of the reasons we visit local hospitals, health, and social service organisations. By establishing relationships and referral pathways in the region, we identify opportunities to work together to improve outcomes for people impacted by epilepsy.

“ I attended the Cairns Regional Meetup in May. It was a great experience to be able to meet other people who know what it's like to live with epilepsy and have faced similar challenges with living in Far North Queensland.  
- Alison ”



7,500 kms +  
travelled





## National Service Goes Live

As a result of our collaborative work with epilepsy organisations across the country, in February 2022 we were proud to introduce our customers to the National Epilepsy Support Service (NESS). The National Epilepsy Support Service is a free, Australia-wide phone line that provides support and information for people living with epilepsy and those who assist them. The NESS supports people of all ages and at all stages of life.

When customers call the NESS, they speak with an epilepsy support worker who understands how epilepsy affects health, wellbeing, and daily life. The NESS provides information on a range of topics, including epilepsy and seizure management, seizure first aid, and strategies to minimise seizure triggers.

The service can provide information tailored for children and young people, older Australians diagnosed with epilepsy, and people with a disability. Queenslanders with epilepsy can also contact the NESS for guidance on how epilepsy could impact pregnancy, diet, education, or employment.

As the state's peak consumer body for epilepsy, we leapt at the opportunity to be leaders in this exciting new initiative, which connects more Queenslanders impacted by epilepsy to our vital services. Assistance with epilepsy education and training sessions, information, guidance, and support for people with epilepsy and their families are just a phone call away.



In Queensland, the 30,000 people living with epilepsy and their families can now access the National Epilepsy Support Service.



National Epilepsy Support Service

**1300 761 487**

Website [epilepsysmart.org.au](http://epilepsysmart.org.au) Email [support@epilepsysmart.org.au](mailto:support@epilepsysmart.org.au)

Hours Monday to Saturday 9.00am – 7.00pm (AEST)

## Innovative Program Delivers

Born out of a partnership with Gold Coast University Hospital Neurologist, Dr Meng Tan, the 'Epilepsy Connected Care Program' launched last October.

Dr Tan saw the benefits of holistic care for people living with epilepsy and invited us to participate in his Gold Coast epilepsy clinics. The new program means people diagnosed with epilepsy can access our comprehensive support, either via telehealth or in person, at the same time as their neurology appointment.

More than 340 people have already accessed the program which also facilitates care in the community. Epilepsy educator, Jenny Ritchie,

says "the program has given us the opportunity to help people manage some of the impacts of epilepsy, for example changes to their driving status and medication side effects. Importantly it also allows us to re-connect with them to see how they are going after they get home".

Following the program's success, Dr Tan has invited Epilepsy Queensland to extend this service to children as they transition from paediatric to adult care.

Together with Dr Tan, we are formally evaluating the outcomes of this program with the view to replicate this model in other clinics.



" All the people and families attending my clinic have supported the educators' presence during their appointments.  
- Dr Meng Tan "



**38** clinics attended



**340** people accessed program



## Expanding Our Services

One positive outcome from the COVID-19 pandemic was people's willingness to access support using technology. Responding to this, our virtual epilepsy education is now a permanent service offering. The monthly sessions see up to 20 people dialling in to better understand their condition.

Organisations including schools, aged care, disability providers, and large employers also began requesting customised training sessions delivered via video conferencing. This shift has allowed us to reach more regional and remote areas of the state and we now have a dedicated 'Zoom Room' for virtual training.

Our commitment to equal access to epilepsy services throughout Queensland saw us introduce a regular '*Understanding Epilepsy and Administration of Midazolam*' program on the Sunshine Coast and Gold Coast. Each month, up to 30 people attend

these face-to-face sessions.

*'Epilepsy and Assistive Technology for Seizure Management'* is a new specialised training offering for Occupational Therapists and the Allied Health sector. The course connects people to assistive technology, by informing health professionals of what is available, and how to help their clients maintain or improve safety, participation, independence, and quality of life. The right equipment can reduce the risk of seizures and potentially be lifesaving.

The pilot project had an overwhelmingly positive response, and we are proud to include '*Epilepsy and Assistive Technology for Seizure Management*' as part of our regular training offerings.

"The strategic expansion of our services allows us to better tailor the training and education sessions that we provide. As everybody's experience of epilepsy is unique, working collaboratively with families and their support networks is both challenging and rewarding. We will continue to work towards reducing the impact of epilepsy on everyone."

Jenny – Coordinator, Education and Training





## Make March Purple!

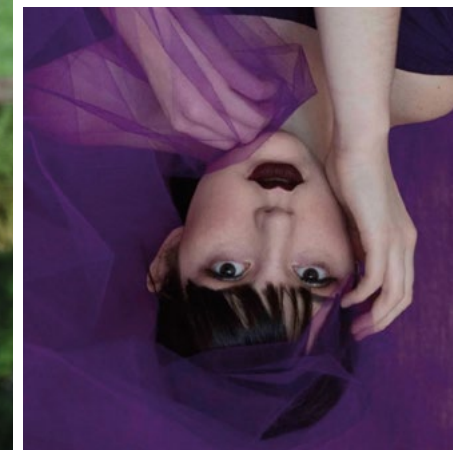
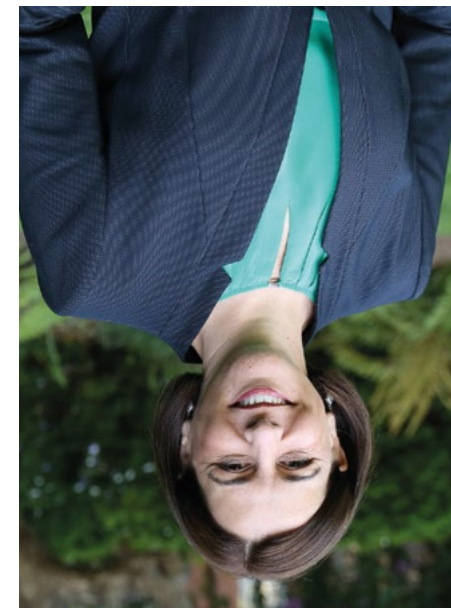
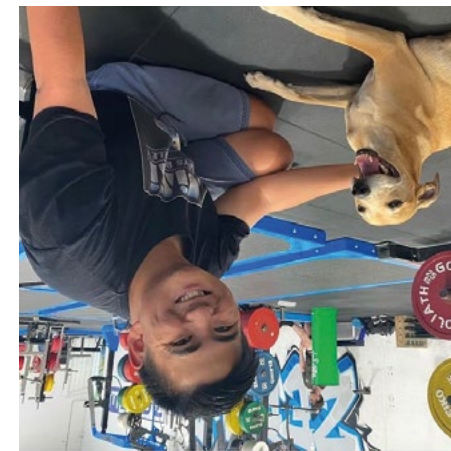
In March the world turns purple! Make March Purple is our Australian campaign that celebrates our community and raises awareness of epilepsy. This year we launched a new message, “Every 33 minutes a life is turned upside down by epilepsy” which we shouted across social media, outdoor advertising, shopping centre displays, print, radio, and TV!

We set the challenge “to turn social media upside down” and people quickly responded by sharing upside-down photos with the hashtag #Every33Minutes. To launch the campaign, we shared a story and photo every 33 minutes for a whole day. Soon, supporters across the globe joined us, as we turned things around for epilepsy. This included Founder of Purple Day, Cassidy Megan and supporters from Canada, Indonesia, Europe, US, and UK.

Community fundraisers, schools, pharmacies, and workplaces took on challenges, hosted events and sold merchandise to raise funds. In a spectacular display, the Brisbane Roar FC swapped their signature orange game day smoke for purple.

Our Chief Executive, Chris, wrote to all 93 Queensland Ministers, Shadow Ministers, and MPs during March, making them aware of the impact epilepsy has on people’s lives.

Encouragingly, many ministers posted upside down to their personal and public social media accounts in support of the campaign. We take this as a positive indication that together we can change the world for people living with epilepsy.







36 M+

views

IN OVER



20

online + print features



381,400

listeners

ACROSS



15

radio outlets



32

news articles



10

radio interviews



1

TV spot



570,761

social media reach



14 M+

digital display views



3.8 M+

radio CSA listeners



58

schools participated



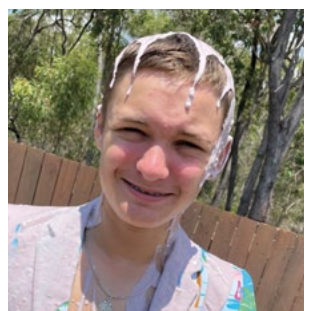
92

pharmacies participated



2000+

purple plush sold





## VIPPs Set Sights High

We had 18 VIPP's (Very Important Purple People) climb to the top of the Story Bridge as it shimmered purple for this year's Purple Bridge Climb Challenge. Not even a mid-climb thunderstorm could dampen the spirits of this crew, as they scaled the bridge at twilight to raise funds and awareness for epilepsy.

Amongst our intrepid climbers was 16-year-old Kiara Osborne who travelled all the way from Stanthorpe to Brisbane with a support crew of family and friends, a.k.a 'The Purple Squad', in tow.

Kiara, along with friend Taylah, set their sights high in more ways than one, smashing their fundraising goal of \$2,500 in the lead up to completing the challenge.

The quest was a personal one for Kiara, who was diagnosed with epilepsy just last year. "In April 2021, I had my first seizure. It came as a real shock to my family. It was extremely out of the blue, we were unsure of what was causing my seizures or what to expect," Kiara recalls.

“ Every time I've spoken to someone at Epilepsy Queensland, they offered help and have been a great support to us. They helped me understand what epilepsy is, as I didn't really know much about it.  
- Kiara ”

After multiple trials of different anti-seizure medications, Kiara has fortunately found one that is working well to control her seizures. Whilst adjusting to the challenges of epilepsy, the determined teen remains positive and focused on helping others.

"Before my seizures, I had no idea how many people are sadly diagnosed with epilepsy each week. Whilst my story has a good outcome, for many people it doesn't. Around half of people diagnosed struggle to find the reason for their seizures. I not only want to raise funds to help those who are struggling but to also raise awareness and how people can help," says Kiara.

True to her word, Kiara shared her story with four newspapers, reaching a potential audience of millions.

Kiara scaled the bridge alongside our special guest Deputy Premier, the Hon Dr Steven Miles. After the Deputy Premier learnt how epilepsy turns lives upside down, he did not hesitate to add his support to our awareness campaign. The Deputy Premier impressed when he turned himself upside down by performing a handstand for the enthusiastic crowd. Scan the QR code to see him helping to turn things around!

Watch as Deputy Premier turns things around



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50+

purple illuminations across QLD





## Raising Community Voices

Our digital community has continued to expand in the last year, and across Facebook, Instagram, and LinkedIn we are now over 15,000 strong.

Our digital platforms have remained a reassuring touchpoint for our community. With COVID-19 continuing to disrupt opportunities for in-person gatherings, our social media channels have provided a safe space for people to connect, find support, and share their experiences.

Our online community are fantastic supporters who engage with our team and our work.

We reached over 1.2 million people in the last 12 months, delivering the latest news and research, evidence-based information, tips for living well with epilepsy, and connecting people with our training, education, events, and vital services.

We had 66 epilepsy warriors bravely share their stories with us on our digital channels this year. We will continue to uplift the voices of those with lived experience, as we know these stories give hope and make others feel less alone.



15,000+

social media  
followers



1.2M

social media  
reach



66

epilepsy stories  
shared

## Get Seizure Smart!

**Get Seizure Smart** (GSS) is our annual community awareness campaign that educates Australians to recognise the signs of a seizure and respond confidently with seizure first aid. This year, we were thrilled to secure national media coverage and reach more than 123,000 people via our social media channels with our potentially life-saving message.

A staggering 1 in 10 people will have a seizure in their lifetime. With 50% of people who experience one seizure going on to have more, being seizure smart is a crucial skill for every Australian.

The campaign focused on the two groups of people most frequently diagnosed with epilepsy: Australians over 60 years of age and children aged five years and under.

Our hope is to create a community that is seizure smart to promote better wellbeing for people that experience seizures.

This year, 400 Australians a week visited an emergency department because of epilepsy. Not all seizures require emergency medical attention and the correct identification and response to a seizure can reduce unnecessary hospitalisations, not to mention reduce the risk of injury.

When people #RecogniseandRespond appropriately to seizures, it goes a long way in preserving a person's dignity and safety. This campaign delivers on our

vision for individuals to be understood and live well with epilepsy.

On World First Aid Day, September 11, we premiered a video featuring 20 amazing Queensland children who bravely spoke our Get Seizure Smart message. We were elated to be recognised as People's Choice Winner in Hancock Creative's Non-Profit Social Media Awards for this piece of work. We won out against other worthy nominees such as Beyond Blue and Guide Dogs WA. However, the real reward was the participation of our wonderful community, casting their vote for Epilepsy Queensland; a true testament to our highly engaged community.



Queensland kids urge  
you to Get Seizure  
Smart!



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"Sharing knowledge, my lived experiences, and support for persons with epilepsy would not be possible without Epilepsy Queensland as this charity works endlessly to reach out, educate, and provide a voice to any person with epilepsy."

Sophie





## Hope Through Research

Until a cure is found, we will continue to support research projects that improve quality of life and offer hope to people impacted by epilepsy. Research plays an important role in ensuring good clinical practice, identifying innovative new diagnostic and treatment pathways, policy development, and evidence-based education and training programs.

Through engagement with researchers and clinicians from The Queensland Brain Institute, University of Queensland, Herston Imaging Research Facility, Mater Health and Mater Research, we have contributed to diverse research projects looking to identify the cause of epilepsy, find new ways to treat seizures, and improve surgical outcomes for epilepsy patients.

We also work proactively with universities and other research institutions to ensure people living with epilepsy have opportunities to access and participate in research.

To share insight into the research process, we went behind the scenes and participated in a University of Queensland research study. The aim of the study was to investigate how MRI can be best used to assess language function in people with epilepsy when planning for surgery.

Go behind the scenes  
of an epilepsy study



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## Thinking Outside the Box

In February, we proudly presented our 11th 'Thinking Outside the Box' Epilepsy Symposium. The symposium is a one-of-a-kind event that tackles big-ticket issues and contemporary clinical subject matter.

We hosted nine of Australia's leading epilepsy experts to present on a range of topics including epilepsy diagnosis and management, SUDEP (Sudden Unexpected Death in Epilepsy), seizure detection and prediction, the impact of epilepsy on employment, the epilepsy surgical pathway, and more.

Understanding the importance of diverse perspectives, those with lived experience of epilepsy were given a platform to share their experiences. This included Deb Tibbotts, who spoke candidly and with courage about losing her beloved daughter Maddie to SUDEP, and Jayden Law who recounted his pathway to epilepsy surgery.

For the first time in its history, the Epilepsy Symposium was a hybrid event with our #agile team adapting to the increased demand for a livestream option. Around 30% of the audience attended virtually in addition to the 70% who gathered in-person at the State Library of Queensland. With support from affiliate organisations across the nation, we were able to extend the invitation to audience members across Australia and the Asia-Pacific region.

Continuing to embed technology into

the event, audience members, both virtual and in person, were able to ask and respond to questions and vote on polls in real time, adding to the interactive nature of the day.

Thanks to our relationships with clinicians and the hard work of those behind the scenes, we are pleased to have presented an event that garnered such positive feedback from the audience. Our attendees particularly appreciated the broad range of topics, quality of speakers and complimented the high level of organisation.

With 96% of surveyed respondents rating the event as "very good" or "excellent" we celebrate the continued success of our Symposium.

“ I learnt something new from each and every speaker. Hearing from two people who have been directly affected by epilepsy seemed to connect everyone in the room. The professional speakers all portrayed a passion for their field, and I am grateful to have heard them speak.  
- attendee ”







Watch Jayden's  
moving  
presentation  
here



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## Surgery Success

In 2018, at the age of 21, Jayden was diagnosed with epilepsy. With almost no warning he began experiencing tonic-clonic and absence seizures – sometimes every day, and at other times, weeks apart.

Being diagnosed in his early twenties, Jayden found it difficult to come to terms with this new normal. “My mental health went down greatly, my social life was essentially destroyed, I had a lot of anxiety and fear doing things people my age should have no problem doing,” he explains.

“After about two years of having epilepsy and many medications not working for me, surgery was suggested as the best option.”

Jayden's pathway to surgery was unexpectedly long, with delays and disruptions due to the COVID-19 pandemic. The most devastating of these delays came on the day Jayden was scheduled for his temporal lobectomy surgery. After months of appointments, testing, and preparation his surgery was postponed at the last minute when the hospital became overwhelmed with COVID-19 patients.

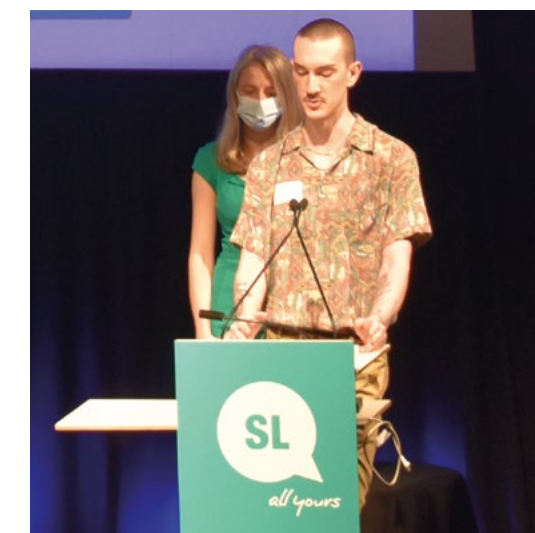
This meant that Jayden was available to speak about his pathway to surgery at the 'Thinking Outside the Box' Epilepsy Symposium. Joined by his neurologist Dr Lisa Gillinder, the pair presented *'The Epilepsy Surgical Pathway: A patient experience and clinical dialogue.'* The popular session explored both sides of epilepsy surgery through Jayden's lived experience and Dr Gillinder's clinical expertise.

The audience resonated with Jayden's story as he shared an open and honest account of living with uncontrolled epilepsy. “The personal experiences of Jayden were especially fascinating, humbling and relevant,” commented one attendee.

The room erupted in applause when Jayden announced that his much anticipated and rescheduled surgery would now be taking place the very next day!

Following his surgery in February, Jayden has recovered well and is focused on enjoying this exciting time in his young life.

We applaud Jayden for his bravery, in sharing the highs and lows of his life with epilepsy in front of a live audience. His engaging, and at times emotional, account of events provided the clinicians and healthcare professionals in attendance with perspective on how impactful surgery can be.





## Team Braves the Bridge

It was “Back to the Bridge” for Brisbane’s biggest fun run – the Bridge to Brisbane. A change of date from August to November 2021 meant the sun was out in force, matched only by the enthusiasm of our racegoers.

After securing a silver charity partnership for the event, we had a record number of 194 people #BraveTheBridge as part of Team Epilepsy Queensland, including Luke Brodie, who was the leading individual fundraiser for the Bridge to Brisbane – until the very last moment.

Luke was diagnosed with epilepsy at age 33, just four short years ago. The 37-year-old featured in The Sunday Mail and shared his reason to run: *“I want to work to improve the lives of people that are affected by this unpredictable and indiscriminate condition”.*

It was also the first opportunity to showcase our new brand and logo. The parade of vibrant purple Team Epilepsy Queensland shirts was impressive. The shirts were easily visible on the course and often appeared in media coverage of the run. After team members crossed the finish line, they were welcomed into our charity tent by our Chief Executive, Chris, Chairman Sam, and our fundraising team. It was a moving display of community spirit and an important opportunity to raise awareness of epilepsy.

**Bolstered by Luke’s spectacular fundraising efforts, we achieved our best fundraising result for the event raising \$34, 275.**



## Going the Extra Mile

In October, we had an incredible 253 people pound the pavement for 25 days straight as we took part in Australia’s biggest epilepsy event – Walk for Epilepsy. Together with epilepsy organisations across the country, the virtual event challenged people to clock up the kilometres from October 1 - 25 in support of the 1 in 25 Australians living with epilepsy.

One determined dad, Rafa Garcia, took the challenge to the extreme, setting an ambitious goal to run a half marathon (21.1km) each day in October – that’s over 650km! In a touching tribute, the elite runner dedicated each of his daily runs to someone impacted by epilepsy.

Rafa joined Walk for Epilepsy after his wife Mel contacted our helpline and had a “really reassuring and helpful conversation” with our Living Well team member, Donna. The Gold Coast couple are loving parents to two-year-old Sofi, who lives with uncontrolled epilepsy. Sofi had her first seizure at eight months old – an hour-long tonic-clonic seizure that Rafa and Mel describe as “the most terrifying moment of their lives”. Epilepsy has had a significant impact on Sofi’s life, with 30 ambulance rides and two intensive care visits this year alone.

Despite the challenges, Rafa and Mel remain positive. Walk for Epilepsy provided the opportunity to share Sofi’s story and raise funds and awareness for the condition that’s changing his daughter’s life.

“Running for me and my family has helped us to cope with lots of hospital visits, stress, anxiety and mental challenges.”

Rafa proudly achieved his fundraising goal of \$5,000. He followed through on his pledge to dye his hair and beard a spectacular purple!

“  
Running for me and my family has helped us to cope with lots of hospital visits, stress, anxiety and mental challenges.  
- Rafa

”



Find out how to Walk for Epilepsy



SCAN ME



## Day for Tayla

A country girl with her whole life ahead of her; no one could have imagined the seizure 21-year-old Tayla Crang experienced whilst feeding her beloved horse would tragically end her life. Tayla passed away from Sudden Unexpected Death in Epilepsy (SUDEP) on November 29, 2020 – a fatal complication of epilepsy that neither Tayla nor her family were aware of before it turned their lives upside down.

Wanting to pay tribute to her daughter and raise awareness for SUDEP, Tayla's devastated Mum, Renee Crang thought "what better way to honour her than with a horse event". So, with the help of the Gympie Horse and Rodeo Association and generous sponsors, Day for Tayla was born.

The Novelties Event, held in November 2021, brought together the community

and their horses to ride, compete and race with proceeds from the day donated to Epilepsy Queensland. Renee created a beautiful legacy for her daughter and raised just over \$6,000. Riders and horses were adorned in purple, trotting around the Noosa Equestrian Centre, with the winning horse and riders presented with hand-crafted purple floral garlands.

The generous support of Tayla's community will give families, just like hers, access to life-saving information and education, helping to reduce the risks of SUDEP.

It was touching to see the community rally in honour of young Tayla, who will forever be remembered as a popular girl, happiest when surrounded by her beloved horses.

"I hope that my story can help someone else through the heartache and pain that SUDEP causes."

Renee



Find out more  
about SUDEP



SCAN ME



## Good 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.

### GOVERNANCE MODEL

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.

Our people



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### 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.

### 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



## A Message of Thanks

The number of people and organisations who have given back to us this year is overwhelming. Thank you to those who bravely shared their story, helping to raise awareness. Thank you to those who reached out for support, allowing us into your life when it had been turned upside down by epilepsy. Thank you to our volunteers, the unsung heroes helping us to succeed. We also thank the organisations who shared our message and encouraged Queenslanders to Get Seizure Smart and to Make March Purple for epilepsy awareness.

It would be impossible to change the world for people with epilepsy without the financial support of our donors, sponsors and partners. Thank you to our generous donors, and our Heroes of Hope who make regular monthly donations. We thank those who remembered us in their will and the families, who in their hardest moments, kindly made donations in memory of their loved ones.

Hundreds of you fundraised for us this year. You ran, shaved, cooked, turned purple and more. We thank each of you. You make a difference.

Thank you to one and all!

## Thank You to our Sponsors & Partners



seer medical





**DONATE NOW**



**EPILEPSY**  
*queensland*

Level 2, Gabba Towers  
411 Vulture St  
Woolloongabba QLD  
1800 852 853  
[epilepsyqueensland.com.au](http://epilepsyqueensland.com.au)