

the flame

the newsletter of epilepsy queensland inc

Issue 2 – 2018



MY EPILEPSY STORY
GATEWAY TO AN ADVENTUROUS
NEW LIFE

NDIS
Helpful Hints

Purple Day

**Elders Cattle Muster drives
support for epilepsy in the bush**

EPILEPSY QUEENSLAND'S REGIONAL VISITS



As part of Epilepsy Queensland's endeavour to improve awareness, reduce stigma and educate the wider community, we travel to regional destinations throughout Queensland to deliver Understanding Epilepsy workshops and Administration of Midazolam training.

Across February and March 2018, our team members have visited the Hervey Bay, Bundaberg, Mackay and Townsville communities.

Not only was this a great opportunity to deliver training to the community, it also provided a valuable opportunity to meet with people with epilepsy and their families, as well as engage with the National Disability Insurance Agency in the regions – providing additional information and support in relation to people with epilepsy accessing the National Disability Insurance Scheme.

We are planning on travelling to Ayr, Townsville and Rockhampton in the near future, and other regions as per identified need.

People with epilepsy, families, teachers, teacher aides, nurses, disability support workers, child care providers, and people with a general interest in epilepsy are welcome to attend the sessions. Previous training has been a great success with very positive feedback from attendees with a request from several people and agencies for Epilepsy Queensland to return soon to deliver more training to the area.

We are also happy to come to your school or disability organisation if you require training. If you would like training in your area, please call Epilepsy Queensland on 3435 5000 or 1300 852 853 and express your interest.

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EDITORIAL DISCRETION

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NDIS UPDATE

HELPFUL TIPS

If you are living in the areas of Townsville, Mackay, Toowoomba, Ipswich, Bundaberg, Rockhampton – then the NDIS is already live in your regions. If eligible for the NDIS, we hope you have received your NDIS plan and it is providing you and your loved ones with the necessary support to live your life well.

Other regions, as identified by the NDIA, are yet to transition to the NDIS – these are Beenleigh, Cairns, Brisbane, Maryborough, Caboolture/Strathpine, Maroochydore and Robina regions. These regions will transition between July 2018 and June 2019. Most people who have received services from the Department of Communities in the past, have been sent a letter from the NDIA advising that they will soon receive a phone call to organize their NDIS meetings. Some people have already had a phone call and have their planning meetings scheduled for coming days/weeks.

Don't forget that you have the right to a face to face meeting, so when the NDIS representative calls you, if this is what you are seeking (and my suggestion would be that is a preferred option), then please ensure you advise the representative that you request a face to face meeting.

So, now is the time to ensure that you are getting your documentation in order, and working through the pre-planning. Our experiences have shown that the more preplanning a person has done, the more prepared and confident they are, which can lead to better outcomes.

Remember Epilepsy Queensland is here to help you at every step of your NDIS journey.

NDIS – Helpful Hints...

As the National Disability Insurance Scheme (NDIS) continues to roll out across the state, Epilepsy Queensland (EQI) want to ensure that eligible people living with epilepsy and their families/carers receive the necessary supports and services to meet their needs and enhance their quality of life.

To assist, we will be sharing regular hints and tips to help people navigate the NDIS.

Access and Eligibility Stage:

- If you have been receiving funded services in the past, it is a good idea to contact the National Disability Insurance Agency (NDIA) on 1800 800 110 to clarify what supporting evidence you may need to submit. This phone call may just save you a

lot of time and appointments, if the NDIA have the information they need for your access and eligibility.

- If you have been sent the Access Request Form for Health Professionals to complete – please ensure that they complete this with a focus on the IMPACT that epilepsy / (other conditions) have on your life; rather than purely confirming diagnosis. This is important evidence for the NDIA to consider your application. EQI have a Checklist document to support the health professionals to complete this form – contact us for a copy.

Preparing for your NDIS Meeting:

- The supports you will receive from the NDIS, are driven by your goals. Generally this is two goals for the 12 months (length of your first NDIS plan), and a few longer term goals. It is important to keep these goals quite broad – so you have greater flexibility in how you achieve your goal and you can seek to identify various elements of support required to meet that goal. For example, rather than 'to continue with horse riding' – the goal may be something like 'to be more active in my community, explore interests, become involved in social activities and make long term friends.'
- You can bring in anybody to the NDIS planning meeting – so think about who is a good support/advocate of your/ your loved ones needs.

Implementing your plan:

- Some people may find it helpful to have a separate bank account for any NDIS funding they receive as part of their funding arrangements. This enables greater management and transparency of the funding. Check with different banks, who may be able to offer no-fee accounts.

Epilepsy Queensland is here to help you every step of your NDIS journey. We have many targeted resources available to assist you, and can help you prepare for your NDIS meeting. We are happy to work alongside any other providers you may have in your life, so that this is a coordinated and seamless process for you/your loved ones.

If you have any tips and hints to share with others, please contact Leonie Hogarth on 3435 5000 or lhogarth@epilepsyqueensland.com.au and these can be included in the next edition.



Gateway to an adventurous new life

Colin Furphy's epilepsy story By Kayla Zonneveld

At the age of seventeen, many people would be daunted by the prospect of brain surgery. For Colin Furphy, who had been living with epilepsy since the age of six, surgery was a "Gateway to a new life". Colin as a teenager had begun goal setting and after the surgery he wanted to be able to drink, have a girlfriend and to drive. Colin's determination and mind set is what has helped him greatly in achieving his goals and led him to climb one of the world's highest mountains, Mount Kilimanjaro.

Colin was first diagnosed with epilepsy at six years old. A diagnosis was made after journeying through a world of migraines. At the time, his parents were not convinced and believed there was something else happening. After he started to experience tonic clonic seizures, his doctor diagnosed Colin with epilepsy. With this outcome, Colin was put onto medication and at one stage was taking up to thirty-two tablets twice a day.

Colin's childhood did raise some challenges but overall he says he didn't really notice a difference growing up with epilepsy until he was much older. The people around him were extremely supportive and the school he attended was very encouraging. Colin says "They didn't make a big deal about it. I was never ostracised for the condition or made to feel awkward."

It was when Colin was an older teenager that epilepsy began to effect his lifestyle. It was at this time that the option of surgery was first discussed and Colin had his first surgery at seventeen. It was a long process to get the tests and final approval from the doctors, however, Colin and his parents were persistent.

When Colin had finished recovering he had many experiences that he wanted to tick off his bucket list. He had a passion for hotel management and wanted to study it. As well as his drive for hotel management his desire to travel and explore was a massive goal. His aim between the ages of eighteen and thirty years of age was to live and work in every state in Australia. He travelled to New South Wales and worked for a season, went to

the Whitsundays and lived on the islands for another season and went to Northbrook Island in the South Pacific for a year. He then moved to central Queensland where he worked in the mines for a year and a half, which he found pretty lonely at times.

Unfortunately Colin's seizures returned after five years, while he was working in the mines. At the time, he had been working a long shift with minimal hours sleep. At about 2am one morning, Colin had one of the biggest seizures he had ever experienced. He was at the time working on his own, but luckily a worker came back, as he had forgotten an item of his and he saw Colin. Immediately emergency services were called and he was air lifted to hospital. The seizure was so extreme that Colin had smashed a hole through the concrete wall, however, he didn't suffer any head related injuries. It was the support from his fellow work colleagues that helped get him through this tough point in his life. The workers drove a two hour trip to the hospital, after their shift to keep him company and make sure he was okay.

He said "It was really touching and it helped with the recovery." After six months the seizures were returning approximately sixty times a week. This was extremely challenging for Colin, as he was not able to work or drive and lived with the effects of epilepsy for another three years before having the second surgery.



Colin had his second surgery in 2009 at the age of twenty-five. He remained persistent about getting the second surgery despite doctors concerns. He says "Doctors thought I was a bit mad because there was only a small chance that it would change anything." However, Colin wanted to achieve so many more life goals. The surgery process was different to the first as Colin was under general anaesthetic and then was placed under local anaesthetic and had to talk during surgery.

The recovery period for the first and second surgery remained the same however, Colin says the "environment was different". He had to move back in with his parents and although now he is extremely grateful for the help his parents provided, Colin at the time felt a loss of independence. At the time, Colin was suffering from depression, however, expressed his feelings through drawings, while also keeping a record of how he was feeling each day.

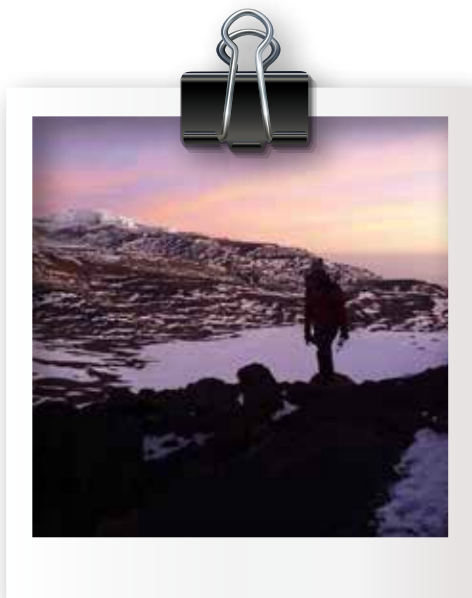
Depression is often common after surgery, however it is important to seek help. Our team at Epilepsy Queensland can offer counselling during our office hours in person or via phone on (07) 3435 5000. Support is also available through Beyond Blue ph. 1300 22 4636 and Lifeline ph. 13 11 14.

After the recovery, Colin wanted to continue his passion for traveling and moved to Alice Springs and became a travel guide. Colin says "Moving to Alice Springs was the best decision I had ever made".

While in Alice Springs Colin wanted to achieve more goals and set up a goal chart. They included, climbing Mount Kilimanjaro, to be medication free, to travel the world making friends, and to lose forty-six kilos.

Colin wanted to challenge himself and do something extraordinary. At the time of his second surgery he told the doctors that he would climb Mount Kilimanjaro. The doctor "killed himself laughing and thought it was cute".

People around him would tell him he couldn't do it but this only made Colin more determined "I'm going to prove you wrong". After six months of training Colin was able to run ten kilometres a day. After a year with continual training, Colin lost the forty-six kilos and finally achieved his ultimate goal of climbing Mount Kilimanjaro.



There was media coverage of the climb, with Colin and his team raising thirty-two thousand dollars through community sponsorships for the Alice Springs Hospital. The money was going towards buying a new anaesthetic machine for the children's ward. Colin says the most challenging part of climbing the mountain is the barriers that you put up in your own mind and having the confidence in yourself.

Colin's experience with epilepsy is an inspiration, as he rose to every challenge that was thrown at him, as well as having the amazing support from so many. He had set himself goals to achieve at his own pace. With each challenge he has conquered, he has learnt a lot along the way and wants to share his story with others that are also going through hard times associated with epilepsy. He says "Learn how to listen, focus on beating your own goals, learn to learn and never give up." Most importantly he explains that "it's getting through those tough times that's important. If you can get through epilepsy, you can get through anything."

To read more of Colin's story visit:
www.epilepsyqueensland.com.au/colinfurphy
For more information on surgery options for epilepsy visit www.epilepsyqueensland.com.au/surgery or call the Epilepsy Queensland Helpline on 1300 852 853. We can connect you to others who have been through surgery and are happy to share their experience.

30 minutes with...

Helen

McCullagh



What is the exact title of your role?

Clinical Nurse Consultant with the State Schools Nursing Service of Queensland Government's Department of Education.

Where do you currently work & how long have you been working there?

The Department of Education first employed me in 2008 as a State Schools Registered Nurse based at Mackay District Special School. I became a Clinical Nurse Consultant in 2013 and I'm currently based Mackay Regional Office supporting schools and supervising a small but fabulous team of nurses based in various locations across Central, North and Far North Queensland. The State School Nursing Service's purpose is supporting students with specialised health needs to access and participate fully in their education alongside their peers. I am committed to improving epilepsy awareness, its impacts on learning and the safe management of seizures as a core part of the service role.

I am sure you have seen a great deal of change in epilepsy in the education sector.

What do you think is the most exciting/important change and why?

I have been thrilled to see many school staff now embracing the opportunity to learn more about epilepsy and developing a positive culture across schools and school communities. School staff are accessing training not just about the essentials of managing a seizure event, but also to better understand and address the implications of epilepsy on learning. Teachers seek strategies to make adjustments that enhance learning opportunities and maximize student inclusion. Many teaching staff are active in learning seizure management and the administration of rescue medications. We have varied the delivery of training to include face-to-face sessions and webinars to more remote areas to ensure support for all staff and students. Epilepsy Queensland Inc is an important component of this training delivery and has traveled to regional areas to provide valuable support for educators in epilepsy and to share evidence based practice advice.

I am proud of the State Schools Nursing Service who deliver training to schools staff statewide, and are always very professional and enthusiastic in their delivery. In the last 6 months, over 1500 school staff have attended epilepsy awareness sessions delivered by State Schools Registered Nurses in just my regions alone. A teacher calmly and respectfully managing a student having a seizure is a great role model for the students and the school community as this has a ripple effect for society and builds a better understanding and culture for bringing epilepsy out of the shadows now and into the future.

What do you feel the main challenges are for a person living with epilepsy in a regional area?

In the regions I support, it has to be local or improved access to medical specialists. Telehealth technology supports improved access to have appointments remotely, but I would like to see this platform used to provide professional learning for many health and professional staff that support the students and families more broadly. Telehealth offers a great advantage to reducing the costs and impacts on families who would previously have to travel for appointments to visit with paediatric neurology teams and other specialist support services.

Tell us about what you do for Purple Day and why you are so passionate about raising awareness and funds for epilepsy.

Since it started in 2008, Purple Day has always been a real thing in my family as two of my four children have a genetic epilepsy disorder. Working with children and their families and school communities has only increased my passion to raise awareness and funding. Funding is essential to maintain support and enable research. There are many equally passionate people in Mackay who have raised funds through a variety of activities including some great purple balls a few years ago, and school based activities such as encouraging school students and staff to wear purple, produce purple crafts, and eat purple food for a gold coin donation. Social media is filled with purple, and with epilepsy information and stories. One of my daughters was a governess on a remote property near Birdsville and celebrated purple day with the two children and their poddy calves. We have been lucky that Mackay Regional Council turns the city's fountain purple. In Mackay Regional Office, staff certainly know when it's Purple Day with a very purple morning tea with best-dressed prizes. Life experiences are discussed and latest research and information is shared. Last year 30 purple bears, lambs and mammoths from the Epilepsy Queensland team found new homes with staff in our office. All this activity is key to starting ongoing conversations about epilepsy.

Where else have you worked in your life?

My first nursing job, while I was still at school in Townsville, was in a residential home for children with disabilities. When I left school I completed my nursing training in Brisbane, lived, worked there for eight years, and loved it. However, regional and remote areas is where my heart is. I have continued to work mainly in Central and North Queensland.

MEMBERSHIP

Your subscription to "the flame" is just one of the benefits of Epilepsy Queensland membership.

To continue receiving your complimentary quarterly copy, we ask you to renew your member by 30 June. You can also opt for an electronic copy of "the flame" if that is your preference.

To join or renew return the enclosed form, contact us on 1300 852 853 or visit: www.epilepsyqueensland.com.au/membership.

What do you love about your job?

Supporting children with health conditions to safely attend and be fully included at school is my purpose and this makes working for the State Schools Nursing Service one of the best nursing jobs ever. While I am no longer directly working with children and their families, I still know that the job I do contributes to this and makes a difference. It is great to see a child with a significant health issue or disability go to school camp for the first time. It is so rewarding to hear about a child go back to school safely and supported after their diagnosis (e.g. diabetes, epilepsy). It is good to hear a parent report that their child had a seizure at school and the staff managed it really well. It is wonderful to have feedback from a school principal saying that the staff knew what to do in a medical emergency because my team had been involved in developing this competence. Illness impacts on learning, and good management at school enables children to engage to the best of their ability. I love hearing that the impact of our service has improved attendance or learning outcomes as well as the quality of life for a student.

The people that I work with are amazing and I love this about my job. My role includes collaboration in the health and education sectors and I have met so many caring dedicated people. I travel across several Department facilities including Central Office, Regional Offices, schools and camp settings. I meet people in varied roles who all have a common goal of every child in every school succeeding. Staff may work in non-student related areas such as HR, ICT, finance or facilities but still all have this goal.

Where would you most like to travel?

I am so lucky that my job has taken me all over Queensland but I would love to spend more time travelling all around Australia. For overseas travel-Italy. I have been once already and hardly touched the surface of such a diverse, wonderful country.

What is your favourite food?

Oh the list is endless! The only food I do not like is watermelon.

Describe your most embarrassing moment?

I was riding my bike home from work at the Mater Mackay hospital around school pick up time and was stopped at a busy corner. While getting back on the bike, I somehow managed to insert the bike seat into my pocket and fell over spectacularly, but without injury, in front of many cars stopped at the lights.

What/who is your favourite book/author?

The Happy Prisoner by Monica Dickens

Who would you like to meet?

Kurt Fearnley –what a fabulous athlete, spokesperson and human being. His comments after the Commonwealth Games were positive, humble and inspiring. I have just returned from eight absolutely wonderful days attending sporting and festival events. What a brilliant few weeks. I love the way para-sports were integrated. Accessibility is the issue-not disability, and this was well displayed by the organization of transport, volunteers, spectators as well as the more visual para-events. An example of this is the text I received on the day prior to each event to check if I needed a wheelchair accessible bus to get to the venue from my booked parking spot.

What genres of music do you like listening to/ favourite song?

Every single type of music for different times and moods from classical to jazz to country and rap. I have recently been to the Big Red Bash -rocking the desert and the Wintermoon Festival- folk music in a tropical rainforest setting and have had a fabulous time. I am trying to learn the "floss" dance to be part of a flashmob at an 18th birthday party. I am appalling at it! I have no musical talent at all but great enthusiasm.

Do you have any interesting hobbies you would like to tell us about?

I love sleeping under the stars-especially on the roof rack of our car.

What do you feel would greatly improve epilepsy care currently in regional Queensland?

It would be great to have more professional development about epilepsy for health professionals in regional areas. The sessions delivered throughout the state by QPEN in the past were really beneficial. Improving the epilepsy knowledge of health professionals at every level from student doctors and nurses onwards and how to diagnose and treat it would be great for all patients and families.

The Thinking Outside the Box Epilepsy Symposium is always excellent. Listening to Dr Sasha Dionisio last year talk about Stereo EEG and how it can allow patients with focal epilepsy and normal imaging to have epilepsy surgery done was inspiring. It would be great if regional areas could perhaps access sessions such as this remotely via videoconference in the future. Innovations, improved medications and treatment, as well as the awareness of epilepsy by all of society will continue to improve the quality of life of people living with epilepsy.



Purple Day for epilepsy QLD



The theme for Purple Day 2018 was #MyWhy. Purple Day is an important day for people living with epilepsy and their family and friends, but it means different things to different people. During the month of March we asked people to share the reason why they go purple. For many people it is to show support for someone they love, to fight epilepsy or to help build understanding.

Thank you to everyone who helped to raise funds and bring epilepsy out of the shadows. We are extremely grateful to everyone who went purple, held morning teas, sold merchandise and/or helped to bring awareness via social media or sharing their story.





Purple Celebration

Epilepsy Queensland's Purple Day Celebration had an amazing turn out, with 133 people dressed in purple and ready to celebrate. There was plenty of entertainment throughout the night with face painting, best dressed competition, as well as a visit from Little Poss. Thank you to MC Emily Prain from the Channel 9 Brisbane news team and our special guests Racheal Johnson and Liam Warriner who shared their epilepsy stories.

The Hon. Jackie Trad MP, Deputy Premier, Treasurer, Minister for Aboriginal and Torres Strait Islander Partnerships, and Member for South Brisbane showed her support by speaking on the night of the work of Epilepsy Queensland. She said, "I first became aware of Epilepsy Queensland many years ago, when the young son of a close friend was diagnosed with epilepsy. I know how important your help and support was to her. I want to commend you for the incredible work that Epilepsy Queensland has been doing as a quiet achiever in the local area, providing services state wide for people wanting advice and support about epilepsy. Tonight is about publically acknowledging the work that you do, raising much needed funds, and for others in the community, helping them understand epilepsy, so have a very special Purple Day".

A number of celebration attendees were also part of a live sports broadcast with Epilepsy Queensland Patron, Wally Lewis, overlooking the Story Bridge lit purple for epilepsy awareness. We are sincerely grateful of the time Wally spends listening to the stories of our members and his ongoing support to bring epilepsy out of the shadows. Thanks also to the news team in the studio, Melissa Downes, Andrew Lofthouse and Garry Youngberry for dressing in purple to help raise awareness.

Throughout the night people were also able to visit all of the many purple illuminations happening across the city. There was a total of seventeen landmarks lit up captivating the city and regional cities across Queensland.

Our wonderful supporters held over 80 events across the state for Purple Day. We were thrilled to see schools, hospitals, businesses and pharmacies hosting purple free dress days, morning teas and other events to help raise awareness and funds for epilepsy.

The incredible support from the Purple Day Heroes, friends and family shows that everyone together raises above the challenges that epilepsy can bring.



The Cairns Hospital Neurology Department went purple with a scrumptious morning tea during Epilepsy Clinic day



The Redcliffe Hospital Pharmacy Department held a fantastic Purple Day bake sale



Epi Ape kicked off celebrations in Gayndah raising awareness and funds at St Josephs Primary School

Purple Bridge Climb

One of the highlights of the night was the Purple Bridge Climb of Brisbane's Story Bridge. This was an extraordinary experience for a group of our supporters to climb the bridge whilst illuminated purple to raise funds and awareness for people living with epilepsy – they raised over \$23,000!

Jade Whitlock and her Daughter Charlotte were two of the bridge climbers on the night. Charlotte is 13 years old and has had epilepsy since she was six years of age, although that has not stopped her. Jade says "Charlotte loves theme parks, water, motorbikes and will dare you to attempt it all with her!!" Although Charlotte is living life to the fullest, she has started asking questions

in relation to epilepsy. Jade says "she is now asking questions, like, why am I different? What do I tell my friends?"

Jade says, "I would love to do this with her and continue to nurture her adventurous spirit, raise vital funds for such a supportive organisation, and see her cheeky smiling face at the top of bridge on Purple Day!!!" Jade and Charlotte have done an incredible job raising a combined total of \$3721. It was important to both of them that everyone has access to the important services and resources that Epilepsy Queensland provides. "We are doing our bit on Purple Day because we want to help ensure that other families don't have to go it alone."



Deni Knuth

Every year on Purple Day, people come together to support members within the community living with epilepsy. It is the amazing support from family, friends and the community that help dispel the myths and misconceptions associated with epilepsy. It is a day where people acknowledge the challenges and show how people have risen above and accomplished so much. These people are inspirational as they have not been beaten by epilepsy however, they continue to fight.

Deni Knuth's beautiful daughter Teddy was battling with epilepsy and she sadly passed away in 2015. Deni explains, "living without her is not easy and remembering the good times is what gets us through the tough days." She mentions that, "We wish to honour her life by raising awareness for epilepsy in these ways". On 26 March, Deni was in full support of Purple Day, wearing purple, changing their business logo to purple as well as continuing to post via social media. Deni did an amazing job of raising over \$2,000 in recent years. In addition to this Deni continues to fundraise and raise awareness throughout the year with several events and invitations. She says, "For Teddy's 17th birthday (1 June, which is also my birthday!) Instead of presents, flowers, cards and stuff, I will be sending out envelopes and invitations for donation to Epilepsy Queensland".

Deni explains, "I'm making a difference and quitting something important to me to raise money for a cause that's close to my heart". It is Deni's amazing strength, passion and support that makes her an extraordinary Purple Day Hero. Deni has fought against the many challenges, to continue to make a positive difference to so many people.



Queensland Politicians supporting Purple Day

Small things make a big impact to raise awareness for epilepsy, like an MP wearing a Purple ribbon and going public on Facebook or Twitter. We appreciate all of the support and good wishes that we received from our MPs, Senators and Councillors from across Queensland.



Queensland's Purple Pharmacy of the Year

Congratulations to Scott Street Pharmacy - Toowoomba for winning the 2018 Purple Pharmacy! We thank you and all the Pharmacies across Queensland that participated in Purple Day. The funds raised through the sale of our purple merchandise is vital and will help us continue to provide services to Queenslanders living

with epilepsy and their families across the State. We loved seeing the pictures of staff dressed in purple and pharmacies decorated purple. Every conversation you had throughout the month helps to raise awareness and let people living with epilepsy know that they are not alone.

THE GREAT ELDERS CATTLE MUSTER

Kicking epilepsy out of the bush

FRIDAY 18 MAY 2018
CQLX | GRACEMERE

Elders are proud to present The Great Elders Cattle Muster raising awareness and funds for those in the bush affected by epilepsy.

Funds raised from this event will help Epilepsy Queensland establish a service on the ground in regional Queensland.

Please support this worthy cause by donating a beast to The Great Elders Cattle Muster for auction.



All net proceeds donated
to Epilepsy Queensland

Donate a beast today and go in the draw to win 'Smoko' with Wally Lewis or a Great Keppel Island getaway.

For more information and to make donations contact:

Virgil Kenny
0427 334 100

Claver Kenny
0409 724 486

Maria Harms
0419 782 767



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**QUEENSLAND
Country Life**



THE GREAT ELDERS CATTLE MUSTER DRIVES SUPPORT FOR EPILEPSY IN THE BUSH

By Paula Heelan



In July 2016, at the age of just 14, Charlie Harms undertook brain surgery for epilepsy at the Royal Children's Hospital in Melbourne.

At the time, Charlie, from Yeppoon, was the youngest Australian to stay awake during brain surgery.

This allowed the very brave teenager to guide his neurosurgeon through the complex process of cutting deep into his brain.

More than 100,000 Queenslanders (1 in 50) will be diagnosed with epilepsy during their lives.

A seizure is caused by disruption of the normal electrochemical activity of the brain.

With many different forms of epilepsies and people's experiences differing greatly, surgery isn't an option for everyone.

While 70 percent of people with epilepsy can control seizures with medication, others experience severe, disabling consequences.

Up to the time of Charlie's surgery, he had been experiencing numerous seizures a day.

Diagnosed with focal seizures at the age of two, Charlie's seizures were severe causing stiffening of limbs, collapsing and violent jerking.

Now 16, he has been seizure free for the past 18 months. His life has changed dramatically.

Charlie's eight-year-old sister, Milli, grew up worrying about her brother's wellbeing.

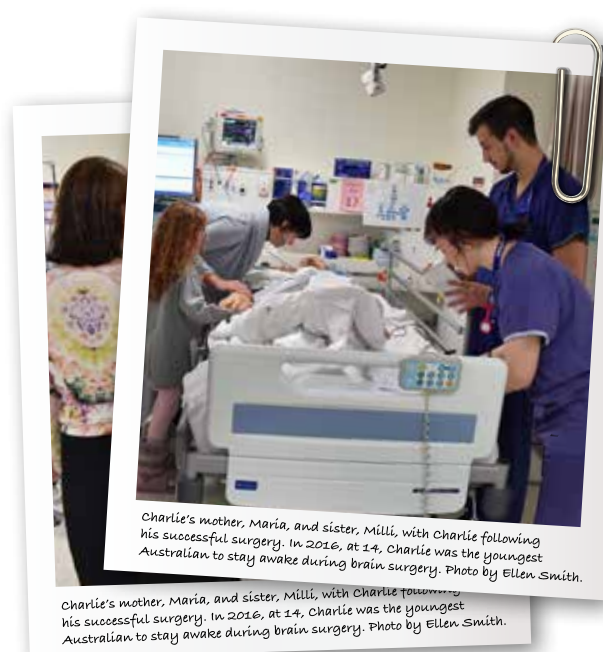
At the sound of a crash, she'd run through the house looking for Charlie.

Milli decided to organise a Purple Day fundraiser for Epilepsy Queensland, and with the support of her primary school, she raised \$800.

This success led to the family's idea of a bigger fundraiser. Charlie's father, Rod, suggested a cattle auction.

Now, with the support of Elders' Rural Services Rockhampton and cattle producers, Clay and Corina Kenny of Llanarth Station, south of Charters Towers, the group is organising The Great Elders Cattle Muster with the sale of more than 100 donated cattle.

Clay and Corina, whose 19-year-old daughter, Tayler, has battled with epilepsy since she was a baby, will manage the northern cattle in-take.



Charlie's mother, Maria, and sister, Milli, with Charlie following his successful surgery. In 2016, at 14, Charlie was the youngest Australian to stay awake during brain surgery. Photo by Ellen Smith.

Charlie's mother, Maria, and sister, Milli, with Charlie following his successful surgery. In 2016, at 14, Charlie was the youngest Australian to stay awake during brain surgery. Photo by Ellen Smith.





Charlie pictured with his parents, Rod and Maria Harms, and sister, Milli, soon after his surgery in 2016.

They'll hold the donated cattle at their feedlot before transporting them to the Central Queensland Livestock Exchange (CQLX) at Gracemere for the May 18 sale.

Elders will manage the southern cattle intake, the sale and the proceeds, which will be donated to Epilepsy Queensland. A prize draw will take place for cattle donors.

Charlie's mother, Maria, said the funds raised would see the establishment of a vital service to ensure people in the bush received current epilepsy information and support.

The Epilepsy Queensland program would also help young people in rural and remote areas with epilepsy take greater charge of their lives.

Elders Rockhampton launched the Great Elders Muster on Purple Day for Epilepsy. Charlie, front row, and his family joined the team, including high school student Georgia Sherry, who also has epilepsy.

"Young people in the bush are disadvantaged by distance," Maria said.

"Adolescence is challenging even without epilepsy. Teens with epilepsy suffer from the effect of seizures and medication, of being stigmatised, social isolation, anxiety and limitations of leisure activities and vocational opportunities."

Throughout his primary years, Charlie missed a lot of school and Maria homeschooled him in Year Seven.

He then attended St Brendans' College, but having daily seizures meant he spent a lot of time in the school health centre or had to return home.

"Since his surgery, he has been able to attend school full time," Maria explains.

"It was like watching a person walk out of the shadows. He loves being able to go to school for the full day, every day. He has some wonderful teachers who help him and the Ronald McDonald program has helped with tutoring."



To donate cattle and organise collection contact:

Clay Kenny, Charters Towers: 0409 724 486 (northern cattle)
Virgil Kenny, Elders Rockhampton: 0427 334 100 (southern cattle)

Great Elders Cattle Muster: 18 May 2018 at the CQLX fat and store sale, Gracemere

For information or to make a donation:

Maria Harms: 0419 782 767.

The story Great Elders Cattle Muster drives Epilepsy funding first appeared on Queensland Country Life.



In Memory

'You left ground and sky weeping, mind and soul full of grief. No one can take your place in existence, or in absence. Both mourn, the angels, the prophets, and this sadness I feel has taken from me the taste of language, so that I cannot say the flavour of my being apart'. Rumi

The Epilepsy Queensland Bi-Annual Memorial Service is an opportunity for us all to remember those who we have lost to epilepsy. It is a time where we come together to share a sacred space. In that space, we use music, personal reflections, prayer

and poetry as a way of acknowledging our loss and the grief of a wider community. In addition, that space is different for us all, however it is the same grief, the same sadness and at the same time, there are the memories. It is those memories that we share with each other that are sacred.

Later in the year we will be holding a special afternoon tea in memory of loved ones. Now we would like to remember those who have died and celebrate their lives amongst us.

We remember especially

Glenda Bradey	Darren Elms	Brendan Krause	Samuel Milne	Denis Wright
Nathan Britton	Shavanne Fourmile	Andrew Ladyko	Bronwyn McInnis	Katrina White
David Patrick Connors	Tegan Richelle Ham	Daniel Landrigan	Jane Robinson	
Polly Cummins	John Heston	Amanda Martin	Nicholas Stapleton	
Cameron Scott Dallinger	Stephen Jory	Catherine McCallum	Kelly Louise Thompson	
Nikki Jayne Dalziel	Teddy Knuth	Taya Michelle McErlane	Jessie Towner	

While we remember these very special people, we also celebrate their memorable contribution to our lives. We are thankful for our family and friends and grateful for the memories we have of those who have died because of epilepsy. We reflect now on that gratitude, and the commitment we continue to draw on as parents and families, as support people and as professionals.

Therefore, as parents, caregivers and family members, we have hopes and dreams for our children and siblings. We are grateful for the love that is given and returned and we strive to continue to be the role model and advocate they deserve. May we continue to love, remember and celebrate the people who have died because of epilepsy. May we continue to provide guidance, good practice and support to all those entrusted in our care, especially those with epilepsy and other disabilities.

We all face things that are difficult in our lives and many of the most difficult, are often those we are unable to talk about. We, at Epilepsy Queensland, are grateful that the community

entrusts us with the continuing care of their family members with epilepsy. We will continue to do our very best to optimise quality of life through our leadership, services and research.

We are grateful for the medical communities who provide compassionate care for family members and those with difficult epilepsies. May they continue to work successfully in the field of epilepsy research so that deaths from epilepsy diminish even further as medication and treatments are improved and made more accessible

'Say not in grief that she is more but say in thankfulness that she was. A death is not extinguishing of a light, but putting out of a lamp because the dawn has come.' R.Tagore

We would like to invite anyone who has experienced loss through epilepsy or those looking to show support to join us for an afternoon tea later in the year, where we can gather, salute and celebrate those who have left us. We will let you know when a gathering date has been confirmed.



ASK THE EDUCATOR

Q: I have heard people in my support group talk about Sodium Valproate (Epilim) used in the treatment of epilepsy and there was a query for women and girls. Can you provide some information?

A: What is it?

Sodium Valproate is a medicine used for the treatment of epilepsy in adults and children. It belongs to a group of medicines called anticonvulsants. It is sold under several brand names including: Epilim, Sandoz, Sodium Valproate and Valpro. It was released onto the market almost 50 years ago.

Why is it used?

These medicines are thought to work by controlling chemicals in the brain which send signals to nerves so seizures do not happen. The medication aims to decrease or stop seizures in people living with epilepsy. It may be used by itself or combined with other medications.

It may also be prescribed to treat migraines and bipolar disorder.

Some background

There have been warnings about the use of Sodium Valproate for some years for specific groups including female children, female adolescents and women of childbearing age (or childbearing potential).

Teratogenic risks (drugs, chemicals or infections which can cause abnormal foetal development) have been associated with Sodium Valproate and other medicines of that kind, if taken in the first trimester of pregnancy.

In 2015 a joint taskforce of the International League Against Epilepsy (ILEA) on Valproate in the treatment of epilepsy in women and girls made a number of recommendations including consideration in each individual circumstance of the likely effectiveness of Sodium Valproate compared to alternatives for the seizure type being experienced. There should also be discussion on risk to the foetus of uncontrolled seizures as a result of medication changes and diminished or delayed seizure control.

The Epilepsy Society of Australia (ESA) recognises the Sodium Valproate is associated with a greater risk to an unborn child when taken by pregnant women than other anti-epileptic drugs, however according to the ESA the risk is highly dependent on the dose.

Data from the Australian Pregnancy Register shows a decline in the last decade in the dose and number of prescriptions to women enrolled on the Australian Pregnancy Register. There has been a fall in the mean Sodium Valproate dose of 1061 mg per day (1999-2005) to a dose of 748 mg per day (2006-2012).

According to the 2018 Position Statement issued by the ESA Sodium Valproate remains a valuable treatment option in many patients with epilepsy, including a carefully selected group of women.

Things to consider

As with all medical treatments, the benefits of a treatment need to be balanced against the potential risks.

Treatment choices should consider the types of seizures being experienced, whether the woman is considering/planning a pregnancy and the medication dosage.

The choice of treatment for women of childbearing age should be based on a shared decision between clinician and patient.

References

www.dictionary.com/browse/teratogenic

<https://www.ilae.org/files/dmfile/ValproateCommentILAE-0315.pdf>

Position statement: The use of Sodium Valproate in women of childbearing age 2018: Professor Frank Vajda (Australian Pregnancy Register); Dr Michelle Kiley (President, ESA)

<https://www.ebs.tga.gov.au/ebs/picmi/picmirepository.nsf/pdf?OpenAgent&id=CP-2015-CMI-02631-1&d=2018022116114622483>

Want to talk?
Contact Epilepsy Queensland on
(07) 3435 500 or 1300 852 853
Email:
epilepsy@epilepsyqueensland.com.au

2018

DIARY DATES

23 June	LITTLE POSS' BIRTHDAY PARTY Save the date for Little Poss' Party. Each year Epilepsy Queensland's mascot Little Poss celebrates his birthday with members of the Little Poss Club. If you have a child living with epilepsy, Little Poss would love for them and their brothers and sisters to join his club. For more information contact services@epilepsyqueensland.com.au or 07 3435 5000.
30 October	QUEENSLAND EPILEPSY SYMPOSIUM SAVE THE DATE! Epilepsy Queensland has proudly presented Queensland's Epilepsy Symposium since 2010. The Symposium has presentations that will be of interest to anyone with a connection to epilepsy whether you are a person with epilepsy, a family member, a health professional or care worker. More information on speakers and topics coming soon. Register your interest today by contacting Epilepsy Queensland on 07 3435 5000 or services@epilepsyqueensland.com.au .
26 August	Bridge to Brisbane Join our Purple Power team and walk or run to raise awareness and funds for epilepsy.
17 May, 14 June (9:30am and 6pm), 19 July, 16 August, 13 September, 18 October (9:30am and 6pm), 15 November	Understanding Epilepsy Workshops (Woolloongabba) For Disability Support Workers, Child Care Workers, Nurses, Allied Health Professionals, Volunteers, People with Epilepsy and their Families
16 May, 25 July, 5 September, 14 November	Understanding Epilepsy Workshops (Gold Coast) For Families, People with Epilepsy, Carers, Child Care Workers, Teachers, Nurses and Allied Health Professionals
1 May, 15 May, 29 May	MyTime Social and Support Group (Woolloongabba)
Informally First Saturday of the Month Formally –2 June, 1 September, 3 November	Brisbane Adult Support Group Meeting
30 May, 27 June, 25 July, 29 August, 26 September, 24 October, 28 November, 19 December	Adult Social Group Ipswich

Please call 07 3435 5000 for further information on any of the above events

Ninth Annual

Queensland Epilepsy Symposium

Thinking
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the box !

Save the date
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Bookings essential!