

A woman with dark hair pulled back, wearing a maroon sleeveless dress and a pearl necklace, stands next to a man with a mustache wearing a grey suit and a red patterned tie. They are both smiling and holding a dark, flame-shaped plaque together. The background is a wood-paneled wall with a brass door handle and a framed picture on the right.

the flame

the newsletter of epilepsy queensland inc

Issue 1 – 2019

**Are you ready for
Purple Day?**

MY EPILEPSY STORY
CELEBRATING 50 YEARS OF
MAKING A DIFFERENCE

**30 minutes with
Dr Linda Blomster**

Celebrating our community



Epilepsy at school

One in every 200 students are living with epilepsy, so all school communities will be impacted. Epilepsy Queensland can provide your school community with amazing resources including information sheets, templates of management plans, seizure first aid posters, and much more.

Epilepsy Queensland offers training in a variety of formats – face to face, zoom, and online training – for teachers whether they be independent, Catholic, or state school based. We collaborate closely with the Department of

Education, which has a strong commitment to providing a supportive environment for students with epilepsy.

A big shout out to all the education centres and schools supporting students with epilepsy in Queensland and thanks to the many who are showing their support through our Purple Day Awareness and Fundraising activities!

For more information about helping your students with epilepsy, phone our services team on 1300 852 853.

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EDITORIAL DISCRETION

Epilepsy Queensland welcomes you to share your stories for inclusion in Flame. However, the Editor is responsible for the content of Flame and for ensuring the integrity of all work that is published in it. The Editor is responsible for ensuring an appropriate balance of stories published and for taking reasonable care to ensure that no work is published that contains material that is unlawful, or otherwise objectionable, or that infringes any other person's copyright, right of privacy, or other rights.

The Editor reserves the right to edit or exclude stories from inclusion in Flame at his/her discretion.

The Flame is published quarterly by Epilepsy Queensland – www.epilepsyqueensland.com.au



Trent Erik Carlson Long will always be fondly remembered as a long-time volunteer and supporter of Epilepsy Queensland, a committed friend, son, brother, uncle and colleague. Trent had lived with epilepsy for many years, but sadly passed away just before Christmas in 2018.

As a long serving volunteer at Epilepsy Queensland, Trent took charge of the Wednesday volunteer crew, who helped him organise our mail outs including Flame, Little Poss Club newsletters and Livewires. Trent was a supportive and calm leader. He was able to take the stress of looming deadlines and technical problems out of the room with his good nature and through leading by example. His sense of humour and dry wit is missed.

His natural technical prowess was a big hand with office equipment. He had a knack with our ancient folding machine that no-one else had. Trent had a generosity of spirit and a genuine concern for his colleagues. He always spoke fondly of the volunteers he shared his time with and was the first to check up on anyone who was struggling with any aspect of their epilepsy, or anything else in their life. He supported his team with friendship and a listening ear.

Trent was reliable and a man of action, rather than words. If a job was not done, then he would volunteer to come back the next day to finish it off. He was modest about his achievements and preferred to take a back seat, especially in photos.

Trent showed a lot of patience and concentration coordinating the packing and counting of thousands of stuffed toys, badges, pens and all things purple, as they were prepared for distribution across the State for each Purple Day and Little Poss Appeal.

Any merchandise that came back unsold, would then have to be counted again and packed away.

Trent's pride shone through on our Purple day walks held at Southbank. Without fail he was there to lend a hand and proudly held the banner and led the awareness walk.

Trent's dedication as a volunteer was recognised in 2011 when he won the Pam Wellings Memorial Award. Pam Wellings was the wife of John Wellings, a past President of Epilepsy Queensland. This award is dedicated each year to a volunteer or supporter of Epilepsy Queensland.

On a personal note Trent loved to cruise in his dad's boat and when mechanical things went wrong, he was able to fix the issue. He was a gentle soul who loved his family and children. He always treated everyone with respect and kindness. The loss leaves a large hole in the hearts of all who know our tender Trent.



Epilepsy Queensland Annual Celebration

years: then, now and future

MARELLA JENKINS EPILEPSY STORY - CELEBRATING 50 YEARS OF MAKING A DIFFERENCE





When Marella Jenkins met Wally Lewis at Epilepsy Queensland's annual celebration in late 2018, she didn't want to let go of him. Marella was one of the people who attended Epilepsy Queensland's first meeting on 19 February 1969, after she answered a letter to the editor by our Founder Doris Kemp in the Courier Mail.

Marella shared: "Doris had often said, if only someone who was notable would say they had epilepsy, it would make such a difference."

Marella firmly believes that we have found that person in Epilepsy Queensland's Patron Wally Lewis. One of the original aims of the Association was to break down the stigma of epilepsy and to end discrimination that left many people with epilepsy socially isolated and struggling to keep stable employment.

50 years on, Marella believes Epilepsy Queensland has come along in leaps and bounds, but the organisation must continue to be there for people with epilepsy when they need support. She also believes that while the community view of epilepsy has improved, we still need to continue to educate.

"There will always be people that are prejudiced and who judge without knowing what is wrong. The more we all talk about it, the more we can change attitudes. When I was younger, I was told by my Doctor not to broadcast the fact that I have epilepsy. That was a common attitude back then."

Marella was diagnosed with epilepsy at the age of eight. She was at work with her mother who worked in a hotel. Marella describes the feeling when she had her first seizure as going "round and round like a merry-go-round". Her mother took her to the doctor and Marella was diagnosed immediately with epilepsy. She continued to have regular seizures until she was 10, when her seizures were controlled by medication.

Marella considers herself lucky that she has remained seizure free for so many years. She did have one incident when she was 15 and decided to go off her medication. She was working in an office at the time and had a seizure at work. That was enough for Marella to go straight back on her medication. "I learnt my lesson" Marella said.

Her experience as a committee member and volunteer for Epilepsy Queensland meant that she met many people who had uncontrolled seizures. Epilepsy had such a big impact on their lives, so Marella was pleased she was able to help. "The hardest memories were of those people lost through accidents

when having a seizure." Marella shared.

For many years Marella's role as a committee member was Assistant Secretary, but Marella was also an eager helper when it came to fundraising. She remembers the first stall they ever held. "Everyone made something, jams, cakes, pickles and other handcrafted items and we were so proud that we were able to earn \$27. We held regular stalls outside Woolworths Ashgrove and Fay and Don Kranz were always there to lend a hand. Fay would organise all sorts of events including theatre parties at the Arts Theatre. I always felt we brought the fun into fundraising."

One of the things Marella thought hadn't changed was how difficult it is to get enough funds to be able to achieve all that is necessary for Queenslanders living with epilepsy.

"The money that has been raised over our history has been hard won, raised from a variety of methods. Most ways of fundraising were tried in the early years, with varying degrees of success."

When asked about the enormous contribution she made over so many years, Marella in her ever modest way deferred to the contributions of Founder Doris Kemp. "Doris was the association. When she told her son Robert's Doctor about the Association she had formed, he initially looked at her as if to say "You poor thing". Later on, after he had seen what the Association was achieving he acknowledged what a good thing she was doing."

Epilepsy Queensland CEO Helen Whitehead said "The staff and volunteers are honored to carry on the work of Doris, Marella and all of the founding members who worked voluntarily and tirelessly to improve the lives of people living with epilepsy in Queensland. Their vision and commitment is an inspiration."

Marella's hope for the next 50 years is for there to be more treatments so everyone with epilepsy won't have seizures. In the meantime, Epilepsy Queensland is there to support people living with epilepsy and their families. As well as work to build awareness and understanding of epilepsy.

At our recent celebration we returned to the tradition of lighting a candle at the beginning of the night. Marella and Fay Kranz lit the candle and said these words.

"The candle which is our symbol has been lit – it is up to all members to see that it is not extinguished until the darkness of ignorance and prejudice are completely overcome."

SUPPORTING QUEENSLANDERS FOR 50 YEARS

Doris Kemp OAM,
Founder, with Jan Taylor,
previous Chairman



In 2019 Epilepsy Queensland will celebrate 50 years of supporting Queenslanders living with epilepsy, their families and support networks. The Epileptic Welfare Association in Queensland has evolved from humble beginnings as a volunteer organisation operated out of the Kemp family home. The organisation was formed to address discrimination and stigma of Queenslanders living with epilepsy.

Robert Kemp was employed in a number of jobs since leaving school, but was unfairly terminated repeatedly when his employers found out he had epilepsy. His mother Doris, with the support her husband Arthur were the driving force behind the forming and running of the organisation for many years.

During 2019 Epilepsy Queensland invites the community to celebrate and acknowledge the many volunteers, staff and supporters who have contributed and fought for a more inclusive environment for the epilepsy community. We also ask you to contribute your stories of living with epilepsy and share your vision and hopes for the future. As part of our celebrations we hope to share 50 stories.

Excerpt from Doris Kemp's farewell speech: "Looking back over the past 15 years I realise the job of having made many friends and the sadness of not always being able to solve all the problems associated with epilepsy. I would like to stress that it is important we all work together to bring about a better understanding of epilepsy. When one realises this condition does not respect any person, surely it is time to take stock and ask "what can I do to help make the association one to be reckoned with?"".

Excerpt from Marella's farewell speech: "Much still remains to be done, and there is a need for members to support the association, not merely financially, but by personal effort and input at meetings. Time and tide awaits for no man but time changes all things. Each person can only achieve a limited amount – even the longest life is short – then, as in a relay race, the baton must be passed on.

The candle which is our symbol has been lit – it is up to all members to see that it is not extinguished until the darkness of ignorance and prejudice are completely overcome."

Epilepsy Queensland timeline

- 19 February 1969 ○ Inaugural public meeting of The Epileptic Welfare Association in Queensland driven by Mrs Doris Kemp OAM in response to the challenges her son, Robert, who had epilepsy was facing with employment issues and discrimination
- 1969 ○ First fundraiser organised by Mervyn and Allison Welsby at the Jacaranda Butter Factory, Ipswich \$1,000 raised
- 9 September 1969 ○ The Association has its first public education event with neurologist Dr George Burden speaking at the University of Queensland on the social aspects of epilepsy
- Early 1970s - 1982 ○ Weekend trips to "the House of Happiness", Bribie Island commenced as a social activity
- 1972 ○ Name changed to "Epilepsy Association of Queensland"
- 1974 ○ First office space rented by the Association on fifth Floor Penneys Building, Brisbane. All work and meetings were previously held at the Kemp Home, Wavell Heights
- 1975 ○ The first street collection certificate was organised by Marella Jenkins - \$244.70 was raised
- 1984 ○ Foundation Members Doris Kemp and Marella Jenkins relinquished their positions on the committee
- 1992 – 2008 ○ Jan Taylor served as President/Chair. Jan has a significant influence on the organisation and is instrumental in securing government funding. She is a fearless advocate for people with epilepsy
- 1993 ○ A children's awareness program commenced with the publication of two books "And Down Went Poss" and "Poss's School Days" written by Anne Little
- 1994 ○ World of Trivia commences as fundraising and awareness program in schools
- 1995 ○ Annual Badge Appeal commences with Little Poss badges sold through Westpac, newsagents and the Pharmacy Guild of Australia (Queensland Branch)
- 1995 ○ The organisation changes its name to Epilepsy Queensland Inc and rebrands
- 1998 ○ Incoming Premier launches Epilepsy Week and signs Epilepsy Queensland manifesto
- 2000 ○ Won Cable and Wireless Award for best not for profit website for children in the world
- 2009 ○ Wally Lewis becomes Patron
- 2009 ○ Epilepsy Queensland brings Purple Day to Australia
- 2012 ○ First Purple Procession held at Southbank on 26 March
- 2017 ○ NDIS – first Epilepsy Queensland client



GET READY FOR PURPLE DAY FOR EPILEPSY!

Purple Day (26 March) each year is an opportunity for anyone living with epilepsy and the people who support them, to help bring epilepsy out of the shadows. People from around the globe wear purple, help build understanding of epilepsy and break down the myths and misconceptions.

In 2008 a nine year old from Canada, Cassidy Megan created Purple Day to get people talking about epilepsy and to let people who are living with epilepsy know that they are not alone. Epilepsy Queensland proudly introduced Purple Day to Australia a year later. In 2019 the lack of public awareness and stigma associated with epilepsy is still unfortunately very real. Now in its exciting 10th year in Australia, we hope to make Purple Day the biggest ever, but we can't do it without your help.

This year our National theme for Purple Day is 'I can'. Throughout March we will be focussing on the amazing things people living with epilepsy CAN do. We will also be highlighting what you CAN do to get involved with Purple Day and show your support for Queenslanders living with epilepsy.

Your support will assist the 100,000 Queensland children and adults with epilepsy to live without fear and prejudice, while you spread awareness of one of the world's most common serious brain disorders.

How Can I get involved?

Whether it is at home or work, with your local school, pharmacy, club or in your community, there are so many ways you can raise funds and awareness for Purple Day. We've included a small sample to get you started below.

1. Wear purple on 26 March and share your pictures on Facebook, Instagram or Twitter with #PurpleDay.
2. Host a Purple event or activity and go in the draw for great prizes! This can be as simple as a morning tea at work, BBQ with friends. There is so much you can do to raise awareness, funds and have fun at the same time.
3. Become a Purple Day Hero with your very own online Purple Day fundraising page. Simply share your epilepsy story or take on a challenge. Get your friends to sponsor you for a walk, run or colouring your hair purple!

4. Buy or sell Purple Day Merchandise – including our cute new purple dinosaur and purple charm bracelet! Order using the enclosed flyer or purchase online.
5. Share your story or our posts on social media – change your cover photo to let others know why you Go Purple, add one of our frames to your profile picture, snap a selfie with a Purple Illumination or share our Purple Day Facebook, Instagram and Twitter posts.

Contact Us Now!

Contact our team on 07 3435 5000, 1300 852 853 or email purple@epilepsyqueensland.com.au, visit www.epilepsyqueensland.com.au/purple-day or www.facebook.com/EpilepsyQueensland, www.instagram.com/epilepsyqld for more information, to register today and GO PURPLE!

Join our Purple Climb or Purple Day Celebration

This year we have options for everyone, whether you are a thrill seeker looking to climb the Story Bridge as it goes purple, attend our Purple Day celebration in Brisbane or take the free City Hopper to see Brisbane light up purple. We have great incentives for Purple Heroes willing to join the Adventure Climb on Purple Day and fundraise for our essential services and programs. To find out more about the Purple Climb or Celebration visit www.epilepsyqueensland.com.au/purple-climb-celebration or phone 07 3435 5000.

Purple Illuminations

On Purple Day 2019 we will have more purple illuminations and fountains across the State than ever before. Confirmed sites include Story Bridge, Brisbane City Hall, QPAC, Gasworks ULA group gasometer, Parliament House, Suncorp Stadium, Treasury Casino, Sir Leo Hielscher Bridges, Victoria Bridge and Kurilpa Bridge (Brisbane), Victoria Street Bridge (Toowoomba), Civic Centre (Ipswich), Logan Water Towers (Underwood, Shailer Park and Hillcrest - Logan), Gladstone Yacht Club fountain (Gladstone), Town Hall (Maryborough), trees (Hervey Bay) and Oxley Street fountain (Townsville). We will continue to keep you updated and post events where you can meet-up with other members of the epilepsy community via our Facebook page www.facebook.com/EpilepsyQueensland with more sites.



I can...

Host a
workplace
morning tea.



ARE YOUR EPILEPSY TRAINING AND MANAGEMENT PLANS UP TO DATE?

Epilepsy Queensland is the place where you can access opportunities for everyone to receive current epilepsy and medication administration training. We also can assist you, your school or your support organisation with management plan reviews, which are required to be reviewed annually.

As a family caring for a child with epilepsy, have you thought about the following?

- Do you have an Epilepsy Management Plan? Epilepsy Queensland can help you with a template or help complete the plan with you, making it easier for you to update at any time or obtain a new copy.
- Midazolam Management Plans need to be written by the doctor who has prescribed the emergency medication. We can support you to understand all about emergency medication and its administration.

• Check Your Midazolam Kit:

- ✓ Check the expiry date of the Midazolam
- ✓ Is the Midazolam wrapped in the original foil packaging or aluminum foil?
- ✓ Is the foil packaging labelled with the date the packaging was opened? (Midazolam expires within 8 months of opening the foil packaging)
- ✓ Does the kit have your child's name clearly marked for easy identification?

• Does Your Midazolam Kit Contain?

- ✓ Plastic Midazolam vials 5mg in 1ml solution
- ✓ Syringes if required
- ✓ An atomiser for intranasal administration if required
- ✓ Disposable plastic gloves
- ✓ Pencil and paper for documentation

✓ The updated Midazolam Management Plan

• Have You Considered the Following?

- ✓ Are the contents of the kit stored in a container? (a small plastic lunchbox is suitable)
- ✓ Is the container kept out of reach of children, both at home and school?
- ✓ Is the kit kept below 25 degrees Celsius, and out of direct sunlight, both at home and at school? (Midazolam is not to be stored in the fridge or freezer)
- ✓ Have you provided an ice brick and cooler for the kit to be stored in during the hotter months when taking the kit outside?
- ✓ Do you have a separate kit for home and school?

As a carer of someone with epilepsy, whether a child in school or a person being cared for in a support organisation, the following options can assist you:

Option 1 - Face-to-face training delivered by an experienced epilepsy educator.

Available on a regular basis at our Woolloongabba Brisbane office and on the Gold Coast. Training can also be delivered in your workplace, however, travel costs apply. We also offer this option via live Zoom training.

WEBINAR

Option 2 - Self paced webinars

Webinars are pre-recorded with each session running from 45 minutes to 1 hour in duration. You can purchase all of the modules or just one.

Option 3 - Online training

Epilepsy Australia's on-line courses include Understanding and Managing Epilepsy, Understanding the Epilepsy Management Plan and Administration of Emergency Medication.

Find out more: www.epilepsyqueensland.com.au/our-training

Option 4 - Learn Epilepsy

Online awareness for Understanding Epilepsy and Seizure First Aid learnepilepsy.com

Epilepsy Queensland looks forward to assisting more families, schools and organisations to be current, supportive and confident in providing a safe environment for all our people with epilepsy. The services team can be contacted on (07) 3435 5000 or services@epilepsyqueensland.com.au.

Training request forms can also be accessed on our website. Find out more: www.epilepsyqueensland.com.au

Is your membership due for renewal?

Your subscription to "the flame" is just one of the benefits of Epilepsy Queensland membership. To continue receiving your complementary quarterly copy, we ask you to renew your membership by 30 June 2019.

As a valued member you will receive:

- Free (daytime in-house) workshops in Brisbane and the Gold Coast for members who have epilepsy and their immediate families
- Discounts on publications, regional workshops, seminars and special events
- An invitation to attend special events including the Annual General Meeting and Awards Ceremony
- Opportunity to contribute to research and awareness initiatives.

To join or renew your membership today return the enclosed form or contact us on:

Phone: 07 3435 5000 or 1300 852 853 (outside Brisbane)

Email: member@epilepsyqueensland.com.au

Your continued support is important to us - Together we CAN make a difference!



30 minutes with...

Dr Linda Blomster



What is the exact title of your role?

Research Officer. It basically means that I am an early career researcher with a PhD who is developing my own research niche whilst still under the mentorship of a professor.

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

I work at the Institute for Molecular Bioscience at The University of Queensland in St Lucia, Brisbane. I started here in early 2017 after my husband, who is originally from Brisbane, and I relocated from Sweden.

How did you end up here? Why did you become a scientist and researcher?

I always liked all the science subjects at school, which slowly developed into a passion for human health and disease. I came to Australia for the first time in 2008 to do my Master thesis and then later a PhD. I like Australia a lot and IMB is a leading research institute so I feel very fortunate to contribute to and be a part of the research activities here.

What exciting changes are you currently seeing in epilepsy research? What do you think is the most exciting change and why?

There are still a large number of people diagnosed with epilepsy where the underlying cause is unknown. However, with the increasing focus on determining individual causes we will hopefully be able to reduce the size of this group in the future. Although this is a more complex way of looking at it, this is also the reality of medical conditions and will hopefully lead to better and more individualised treatment options with minimal side effects in the future. I want to believe that research will one day find a cure to epilepsy.

What are the discoveries that have lead up to your current work?

I used to work for a biotech company where the focus was on finding new drugs. I am very excited about being able to find out more about the underlying biological mechanisms behind epilepsy in my current research, as well as searching for new drugs and treatment options.

Why is your research important? What are the possible real world applications for people living with epilepsy?

I hope that my research will help understand the genetic and molecular mechanisms behind some specific childhood epilepsies involving the gene KCNQ2. The more we can learn about the underlying mechanisms involved the better and more individualised treatments we can develop for, in this case, children with epilepsy.

What do you love about your job?

It is a very creative job where each day is different to the next. I love working with people e.g. clinicians, peers and students, which I get to do a lot. I love solving problems and I feel very accomplished each time we learn something new. The University of Queensland is a wonderful work place with modern thinking and high ethical standards, with a lot of emphasis on gender equality, something that is very important and resonates with me.

How do people respond when they find out you're working in a venom lab?

They think it is cool and interesting that we can actually use molecules derived from venomous animals as a potential treatment. Our lab has a very extensive collection of more than 600 venoms from different creatures (including spiders, scorpions and centipedes) from all over the world. Spider venoms for example contain millions of bioactive molecules



and they use these to target the nervous system of their prey. Evolution has fine-tuned venom molecules towards specific targets without affecting the ones that cause side effects, properties that we can make use of when developing new drugs to treat nervous system disorders in humans.

Is there one particular inspirational woman in science or research that you have met or would love to meet?

There are obviously lots of famous women that have, and are currently doing, amazing things in science that inspire me. However, the women that I look up to the most are the ones that are approachable and that are willing to reach out and support myself and other women. They work across diverse fields and understand that we can achieve more together as a community.

Where would you most like to travel?

I would like to visit South America and Africa simply because I have not yet visited those continents.

What is your favourite food?

The food my husband cooks for me.

Describe your most embarrassing moment?

Oh....where to start! There are quite a few to choose from. I am not entirely comfortable being in the spotlight so being featured in an article like this pushes me right out of my comfort zone.

What is your favourite book/author?

I don't have the kind of personality where I can limit myself to having 1 favourite book/author. There are simply too many good books and authors to choose from. I like practically everything from fiction, biographies and non-fiction. I do prefer literature that differs from my own reality and / or where I will learn something new. I recently finished reading yet another

inspirational novel written by the renowned author Khaled Hosseini. Next I wish to read the autobiography of former rugby league player Wally Lewis who talks about his life with epilepsy.

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

Whatever is currently playing on the radio.

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

I love animals and dogs in particular. I have 2 border collies. So lots of dog related activities such as going for walks, dog training activities including obedience, dog agility, and sheep herding.

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

Getting people to talk about their epilepsy will help to raise awareness about the condition. I don't think most people are quite aware of how common it really is. Increased awareness would lead to more knowledge in the community and potentially also increased funding for research and other services that would help people living with epilepsy. A lot of women in Queensland are working hard towards improving the health for individuals with epilepsy and I do believe that highlighting their work will get them the encouragement that they deserve.

**For more information on the venom lab at the Institute for Molecular Bioscience at UQ visit:
<https://imb.uq.edu.au/venom>**

CELEBRATING

The 2018 Awards Ceremony capped off a wonderful evening on 3 December. Our AGM is always a festive celebration of our accomplishments over the year, and the Awards are a very special part of this annual celebration.

Through the awards, we celebrate the talent and generosity of people who are making a difference for people with epilepsy and Epilepsy Queensland. It is an opportunity we love to take, to acknowledge the achievements and to say thank you to each and every one. We appreciate the support of all award nominees and winners.

Linda McClelland was selected for the Role Model Award 2018. She earned the award through her success as CEO of a community organisation in Ingham. Linda made many lifestyle changes in order to cope with her diagnosis and to excel in not letting epilepsy get in the way of living her life to the full.

Gerrard Gaudiello was also selected for the Role Model Award. Gerrard has been a reliable volunteer at Epilepsy Queensland while completing his nursing degree.

Dr Harry Singh, is a favourite paediatric neurologist to many and is a caring soul. His nomination was heartfelt and said a lot about a dedicated health professional. Congratulations to Dr Harry Singh on the 2018 Health Award.

Annelies Shaw's dedication to volunteering at Epilepsy Queensland for so many years has earned her the Pam Wellings Memorial Award. Always available and consistent, Annelies never frowns, only smiles when she arrives to do whatever is asked of her. Many thanks Annelies, we appreciate you.

The John Wellings Memorial Education Award is awarded to teachers and personnel in schools and educational facilities who provide assistance to people with epilepsy. **Mt Maria College** is a welcoming, caring and inclusive community, very worthy of this nomination. They go out of their way to make sure every new teacher at this school, every year, is trained in understanding and managing epilepsy and its impacts, both socially and physically. Their students are well supported in an environment that is consistent, safe and where students with epilepsy can learn and thrive.

Peter Jamieson from Cox Industries at Acacia Ridge is a boss who give his staff a fair go! His reputation for being a solid and generous character, particularly to staff with different abilities, earns him this "Fair Go" Award for 2018.

Ivy McAllister is 11 years old and an inspiration to others living with epilepsy. Ivy has a trademark wicked sense of humour and focuses on assisting others living with epilepsy by helping to raise awareness and funds. She has recorded an awareness video, called "Still me" and is happy to share her story. She is very deserving of the Youth Award 2018.

Maria Harms and her family are another inspiration. They were instrumental in the coordination of a successful fundraising event, developed earlier in 2018, which raised an incredible \$105,000 to kick epilepsy out of the bush. The Marella Jenkins Award was named in honour of Marella Jenkins who was an integral part of establishing the organisation. She worked tirelessly to build good strong foundations and sustainability. Congratulations to Maria and her family for this Marella Jenkins Award.

Queensland Collective for Inclusive Education is a group of families who promote inclusive lives for children with a disability and work together to make inclusive schools a reality for all. The whole community benefits from having exposure to the true diversity that exists in our society, one that includes disability! Congratulations on receiving the Disability Award for 2018.

Nine News personalities have been a part of many of our highlights and important events over the last few decades. Epilepsy awareness campaigns, appeals, exhibitions, award ceremonies, and Little Poss launches were performed with great professionalism and flair thanks to Melissa Downes. Andrew Lofthouse was central to the success of fundraising events and was the MC for our Purple Balls. In recent years Emily Prain has added her delightful touch and expertise to our Annual Celebrations and 2018 Purple Day function. The Nine News team have been an integral part of our Purple Day activities, supporting our efforts to reach out to Queenslanders via outside broadcasts featuring Wally Lewis and our Purple Day highlights. Such publicity has been of inestimable benefit to raising the profile of epilepsy in Queensland. Congratulations to Nine News Queensland on receiving the Media Award in 2018.

Toby Turner's Mum sent in a video, telling us how deserving her son was, of the Young Carer Award. She quotes "I didn't mention the countless hours Toby sits in emergency and hospitals or how he helps me lift William or how he times the length of his seizures or how much he knows about epilepsy and Lennox Gastaut Syndrome." The Young Carer Award is certainly yours Toby!

Rhondel Scott received the 2018 Carers Award, because she has been caring for her daughter who lives with epilepsy for the last 44 years. She continues to support her daughter no matter what, through surgeries, medication changes, random seizures, driving across town, and simply always being there!

Ashlee Green also received the Carers Award this year for being an outstanding carer and support for her sister Jasmin and her Mum since she was three and a half years old. She has been and continues to be, that brave, supporting and loving big sister. Congratulations on this recognition Ashlee.

We look forward to recognizing and celebrating the fine achievements of our community again this year as part of our 50th Anniversary celebrations.

OUR COMMUNITY



2019

DIARY DATES

26 March

Purple Day

Purple Day is a grassroots effort dedicated to increasing awareness about epilepsy worldwide. On 26 March each year, people from around the globe are asked to wear purple and spread the word about epilepsy. See enclosed flyer for more information on Purple Day activities.

11 April, 9 May, 13 June (9:30am and 6pm), 18 July, 15 August
12 September, 17 October (9:30am and 6pm), 14 November

Understanding Epilepsy Workshops (Woolloongabba)

For Disability Support Workers, Child Care Workers, Nurses, Allied Health Professionals, Volunteers, People with Epilepsy and their Families

15 May

Further dates will be advised closer to the date

Understanding Epilepsy Workshops (Gold Coast)

For Families, People with Epilepsy, Carers, Child Care Workers, Teachers, Nurses and Allied Health Professionals

Informally First Saturday of the Month
Formally – 1 June, 7 September, 2 November

Brisbane Adult Support Group Meeting

20 March, 17 April, 15 May, 19 June, 17 July, 21 August, 18 September, 16 October, 20 November, 18 December

Adult Social Group Ipswich

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

REGIONAL PROGRAM FOR YOUNG PEOPLE WITH EPILEPSY



Do you know someone aged 15 -25 living with epilepsy in regional or remote Queensland? Have your say on how you would like to connect with others in your area and help shape epilepsy supports and awareness campaigns. Register your interest today. Contact Leonie on 1300 852 853 or send us

a message on Facebook or Instagram to register your interest.

This project is made possible by the Harms, Kenny and Sherry families and all of the cattle producers, people and organisations who supported the Great Elders Cattle Muster.