

# the cornflower

MOTOR NEURONE DISEASE ASSOCIATION OF QUEENSLAND NEWSLETTER



## HIGHLIGHTS

- Wolters End Their Year-Long Ride
- MND Research News
- NDIS Planning
- Honda Foundation Grant
- Gold Coast MND/Cannabis Trial

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## MND AWARENESS WEEK - 5-11 MAY 2019

**MND Awareness Week falls between 5 and 11 May in 2019 with Blue Cornflower Day falling on Friday 10 May.**

Look out for MND Queensland's street collections around Brisbane. They will be collecting donations and selling our merchandise too. We're also hopefully going to also have Brisbane lit up in blue for at least one of the nights during awareness week.

As a supporter of our efforts, you can get involved and help increase awareness about Motor Neurone Disease in the wider community and also help fundraise so that MND Queensland can continue to provide support and services to Queensland families affected by MND.

You might want to hold an event during MND Awareness Week like a 'Drink Tea for MND' party, or come up with your own unique event idea.

Thinking of participating in the Brisbane Walk to D-Feet MND on 26 May? You might want to use awareness week as an opportunity to approach potential sponsors and talk about why MND is important to you and help increase awareness during this week.

Perhaps your school community could put on an MND fundraiser and increase awareness. A dress in blue day (for Cornflower Blue Day), or even an Ice Bucket Challenge!

If you have a shop or business you also might want to collect donations on our behalf for that week or sell our fundraising merchandise.

You could even just look out for our social media posts and share them through your networks to help us boost awareness. It doesn't take much to help out.

There are all sorts of ways that you can get involved and help us to increase community awareness on Motor Neurone Disease and also fundraise to support the work of MND Queensland. If you would like to discuss your idea further, please contact our Fundraising and Communications Manager Jason Russo by calling 07 3372 9004 or emailing [fundraising@mndaq.org.au](mailto:fundraising@mndaq.org.au).

# Never Give Up!

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## CONTACT US

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### SOCIAL MEDIA

**Facebook:** [www.facebook.com/MNDAQ](http://www.facebook.com/MNDAQ)

**Walk to D-Feet MND:** [www.facebook.com/Walk2DFeetMNDQld](http://www.facebook.com/Walk2DFeetMNDQld)

**Twitter:** [twitter.com/MNDQueensland](https://twitter.com/MNDQueensland)

**Instagram:** @mndqld

### FEEDBACK AND CONTRIBUTIONS

Please send your feedback or story ideas to [fundraising@mndaq.org.au](mailto:fundraising@mndaq.org.au).

### DONATIONS

You can make a donation by credit card by calling 07 3372 9004 or at [www.givenow.com.au/mndaq](http://www.givenow.com.au/mndaq). You can also post a cheque or money order (made out to MND Queensland) to the postal address above. Donations \$2 and over are tax deductible.

Cover Image - The Wolters family visit the MND Queensland office in Inala on their One Year on Our Bike journey.





## MESSAGE FROM PRESIDENT PETER DENHAM



### IT'S LIKE CHASING A RABBIT AROUND THE PADDOCK

**Motor Neurone Disease is described in many ways but to one carer it was simply described as, *"It's like chasing a rabbit around the paddock - one minute you head off in a particular direction and then suddenly you are going somewhere completely different."* It is a difficult disease to understand and to cope with.**

Our researchers around Australia and the world are often puzzled by the complexity of the disease. This year the research is heading in several directions and we are hopeful of success.

A recent visit to meet Professor Perry Bartlett at the Queensland Brain Institute revealed that he has a drug called 'mEph4-Fc' that is close to Phase One of a clinical trial to examine whether the drug can slow the disease. This is wonderful news and we wish him and his teams of researchers every success. Our National MND Research Institute along with other funding bodies funds this trial. There are many other trials and research projects that are all detailed on our website so please spend time reading about them.

MND Australia is our national voice and this year we will be raising awareness around Australia during MND Awareness week from the 5<sup>th</sup> to the 11<sup>th</sup> of May so please join us so we can spread the word around Queensland and our local communities.

The NDIS is supporting many people with MND under the age of 65 years and the help they are receiving under this national scheme is a great improvement. Please contact us if you need assistance with the NDIS as not everyone may fully understand the planning and support available. Our loan equipment service is operating throughout the State for all families regardless of whether they are

supported by the NDIS or the My Aged Care scheme. Our main items continue to include wheelchairs, hoists, and adjustable beds. We also have a limited supply of respiratory and specialised eye-gaze computers.

Your membership to our Association is due now (calendar year) so I encourage you to rejoin and enjoy our research updates, newsletters and the friendship of all our members. We welcome new members and hope that you enjoy the friendship, sense of belonging, and community of the MND family.

A huge thank-you to the Wolters Family for their amazing fundraising venture around Australia. They completed 18,000 kilometers (including Tasmania) riding their bikes, pushing their bikes, and spreading awareness of MND to thousands of people. Their enthusiasm, vitality, and courage inspired everyone who met with them.

In July the city of Mackay will conduct their annual ChillFactor Challenge and MND Blue Tie Ball to raise awareness and proceeds for our Association so look out on Facebook for the event. In August we launch our 'Ice Bucket Challenge' month to raise funds for research and services. For further information on any topic please Freecall us on 1800 777 175 or call 07 3372 9004 or go to the website [www.mndaq.org.au](http://www.mndaq.org.au).

Finally we thank you for your wonderful support and dedication to our Association that enables us to continue the good work and I look forward to meeting you at a Walk to D-Feet MND or at our support and social group gatherings. Please remember to 'Never Give Up'.

Kind Regards  
Peter Denham  
President



Pictured - MND Queensland Board Members touring the Queensland Brain Institute with Professor Perry Bartlett. Photo courtesy of Zoe McDonald/QBI .

CAUSE CARE CURE

## FAMILY COMPLETE ONE YEAR ON THEIR BIKES FOR MND

The Wolters family, Dad Jozef, Mum Diana, Cloe (14) and Jack (13) recently completed a one year ride around Australia for MND Queensland. Over the course of one year they visited every State and Territory in Australia and managed to raise almost \$60,000 in the process to assist MND Queensland. We recently interviewed them for The Cornflower.

**Q: How many kilometers did you ride in total?**

*Diana:* 18,000 kilometers in exactly 365 days.

**Q: What was the highlight of your ride?**

*Jozef:* There were many highlights of the ride. Every location had its special uniqueness about it.

**Q: Winds, rain, heat, floods... What was the biggest challenge thrown at you by Mother Nature?**

*Diana:* The biggest challenges were the winds and the heat. When it was very windy it meant that we had to ride for 2 hours longer during the day. On one particular stretch it was so windy that it actually took us 3.5 hours to travel just 36km.

**Q: What were some of the other biggest challenges you faced?**

*Diana:* Water was the biggest challenge of all throughout the trip. Many towns had bore water that tasted terrible. It was hard to get water in some towns and service stations as they just refused to give us any.

*Cloe:* Cloe's biggest challenge was to get up at 4:30am and pack up her bed, tent and put it all back onto her bike.



**Q: Do you know how many punctures you all had?**

*Diana:* We ended up having 80 punctures throughout the trip. We had the majority of them up until Darwin. In Darwin we bought Schwalbe Marathon Plus tyres as this particular tyre was stronger and more durable when there was rubbish on the road.

**Q: What advice would you give our readers who are thinking of doing their own fundraiser for MND Queensland?**

*Diana:* The best way to make the most amount of money when thinking about doing a fundraiser would be to ask your local market if you can shake the tin and get a few of your friends and family to help you. Many people give generously and have small change on them as they are purchasing things from the market.

Sausage sizzles are a great idea but don't raise a lot of money and end up being a lot of work. Just getting a few friends together and having a BBQ is still a wonderful way to raise money as any amount of money raised goes a long way.

*Thinking back at the year just gone, the biggest thing I learnt is that no matter what situation you are in, in life, you can always change it. Nothing is ever set in concrete... never give up. I learnt that anything is possible you just need to believe in yourself. - Diana Wolters*

**Q: How did it feel when you reached your fundraising goal of \$50,000?**

*Diana:* I was super proud that we achieved what we intended to.

**Q: The kids continued school over the course of your journey. Was this easy? Were there challenges?**

*Diana:* The challenges faced with school were; lack of internet reception, and time was another factor as we found that we did not have as much time as we wanted during the day as the majority of the day was spent riding.

**Q: Which part of Australia did you fall in love with during your ride? Will you revisit any sites?**

*Diana:* Tasmania was very beautiful and scenic. The Pilbara was spectacular in its landscape especially Adelaide River.

**Q: What do you think you learned about yourself over your one year ride?**

*Diana:* Thinking back at the year just gone, the biggest thing I learnt is that no matter what situation you are in, in life you can always change it. Nothing is ever set in concrete... never give up. I learnt that anything is possible you just need to believe in yourself.

*Jozef:* I am fitter than I thought I was and I am more capable of things than I thought I was. Living on the road brings much more challenges than living in a house and it is much more exciting to be on the road.

**Q: Did you get into any dangerous situations?**

*Diana:* The only time I ever felt scared was when it was blowing 60km/h and we were trying to climb up to Marion's lookout at Cradle Mountain.





Pictured: (Top) The Wolters celebrating arriving in Canberra and Sydney. (Bottom) Greenbank community event and meeting some of the MND team and Board at our office.

**Q: How heavy were your trailers and what did you carry in them?**

*Diana:* My trailer was 40kg filled up. Contents of the trailer consisted of enough food to last 10 days. Jozef's trailer had 40L of water and spare parts in case we had any breakdowns and weighed 60kg.

**Q: When you think about all of the people that you met over your journey, does anyone stick out? Or did anyone leave a lasting impression?**

*Diana:* Many people stick out. It was such an incredible experience to meet so many wonderful people. Everyone we met has left me with a little bit of something special. They were all helpful, full of advice, there to lend an ear, helped fix our bikes and taught us how to give to others and how to help others in the future.

**Q: You had quite a bit of media attention around the country for your effort. How was this for your family? Did you need to adjust or learn anything after being thrust into the media spotlight?**

*Diana:* Being thrust into the media spotlight was a bit daunting at first. I was worried about what other people thought however, I soon realised that what others think is none of my business. We all just became more comfortable and stayed the same as we were. We learnt to just be who we are and to be honest.

**Q: Being a part of a family that has been touched by Motor Neurone Disease, what advice would you give others going through a similar situation?**

*Diana:* MND has to be the worst disease known to mankind! It is debilitating and horrible! I suggest you make the most of the time you have left. I would recommend the sufferer stay active, be positive, find peace and enjoy life to the max. Go on that holiday and get those things on your bucket list done. Go out with a bang.

For the family left behind and who are watching your loved one suffering; breath in breath out, its going to be a bumpy ride and there is no right or wrong way of dealing with how your loved one is coping, or you. Make sure you surround yourself with positive people, get counselling, associate with other sufferers. The biggest thing is don't be afraid to ask for help.

**MND Queensland would like to congratulate the Wolters family on their amazing ride around the country for MND and also thank them for their fantastic fundraising effort which is still climbing as we write this article. We are so grateful for your wonderful support and for increasing awareness about Motor Neurone Disease around the country. Well done!**

## CAR RALLY RAISES FUNDS FOR MND QUEENSLAND

**The Holden/Ford rivalry has been around for many years in Australia, but there is at least one day a year where all of this is put aside for a good cause.**

The XR6 and XR8 Club of Brisbane, along with the Commodore Owners Club of Queensland recently held their annual rally and raised over \$11,000 for MND Queensland!

The one-day rally in February had 27 cars participating with around 47 people involved. There were stops at The Pitstop Café (who generously donated vouchers for fundraising), and the rally also took in Morayfield, Mary Cairns Cross Reserve and then a scenic route from Mount Mee to Mount Pleasant.

MND Queensland would like to express our sincere thanks to both car clubs and members for your wonderful support of our work to help families affected by MND.

If you have a fundraising idea please contact our Fundraising and Communications Manager, Jason Russo by email [fundraising@mndaq.org.au](mailto:fundraising@mndaq.org.au) or by calling 07 3372 9004.



Pictured - XR6 & XR8 Club of QLD and Commodore Owners Club of QLD members present a cheque to President Peter Denham.

## HONDA FOUNDATION GRANT FOR COUGH ASSIST MACHINES

**MND Queensland was the lucky recipient of a grant of almost \$18,000 from the Honda Foundation which allowed us to purchase two new cough assist machines to add to our Equipment Service.**

We were very grateful to the Honda Foundation and Westpoint Honda Indooroopilly for supporting our application and recognising the needs of people with MND.

The first recipient of a new cough assist was Kevin from Brisbane. We were welcomed into Kevin and his wife Jean's home and learned a little more about them.

Kevin was diagnosed with MND in September 2017. "I was in Winton digging up dinosaur bones. When I woke up in the morning I couldn't do my buttons up! So when I came back I went to my GP." That was in June 2017. Jean added "Our son had already noticed how much his

father's hands had deteriorated.

Kevin isn't letting MND get the better of him just yet though. He proudly passed his driving assessment a little while ago. He volunteers one day per week at the Telstra museum and still participates in the Lapidary Club. Although Jean does admit that "things have gone downhill in the last few months."

We asked how they came to get in touch with MND Queensland they said that their physiotherapist advised they should register with us to get a cough assist machine.

When asked what they would say to our supporters Kevin responded "Thank you!" and Jean added "It's just incredible! It's just making a world of difference."



Pictured (L-R) - MND Equipment Officer Ricardo shows a cough assist to Westpoint Honda Manager



Pictured (L-R) - MND Equipment Officer Ricardo delivering Kevin's new cough assist machine



## GOLD COAST HOSPITAL MEDICINAL CANNABIS FOR MND TRIAL

The Gold Coast Hospital recently released news of a trial into medicinal cannabis for MND. The trial is designed to test if medicinal cannabis can slow the progression of MND. We recently interviewed Berzenn Urbi who is working on the trial.

**Q: If you have any, what are your expected or anticipated outcomes of this cannabis trial?**

BU: The trial is primarily evaluating if cannabis can slow the progression of MND. It will also assess if cannabis can be helpful in managing MND symptoms such as pain, muscle stiffness, and weight loss.

**Q: There has been some discussion around people not being able to drive if they take part in this trial. This is quite a disadvantage for people who are already losing their mobility and independence. Is this a major hurdle in recruiting participants?**

BU: This is one of the identified hurdles in recruiting patients. As of today, five eligible patients decided not to join the trial because they have to give up driving. We would want to have discussions with the Department of Transport and ask for a waiver to drive for enrolled trial patients. We hope that we can convince the Department. We are investigating this option at the moment to address this hurdle.

**Q: We are aware of clients who have already accessed medicinal cannabis legally in Queensland and they report that it has helped with relieving muscle pain. There was a recent overseas study that showed that an oral spray containing cannabinoids is effective in reducing muscle spasticity in MND patients. Are you aware of any other cannabis trials associated with MND or any other benefits related to using medicinal cannabis?**

BU: We are aware of the CANALS study in Italy (cannabis in muscle stiffness in MND), now in Phase 3



trial to confirm Phase 2 results. We are unaware of any other cannabis trials for MND. Although I've heard from an ALS expert that there are cannabis trials on MND in Europe currently going, I have not read their protocols, and there is no information in clinicaltrials.gov or other trial registries about these trials.

**Q: We've already highlighted one of the legal issues with using medicinal cannabis in Queensland (not driving if using medicinal cannabis). Do you believe there are other health or legal issues related to the use of medicinal cannabis?**

BU: We still do not understand how each cannabinoid (constituents in the cannabis plant) works. Some of the safety parameters we put in place in our trial are:

1. Minimum age of 25. There are convincing studies how cannabis can affect the developing brain.
2. Patients with history or immediate history of any mental disorder other than depression related to MND.
3. Patients if enrolled to the trial have to avoid heavy alcohol consumption.

*Interview continued on the next page...*

## Walk to D-Feet MND Gold Coast 2019

9AM, Sunday 31 March, Hollindale Park, Main Beach  
Register, get sponsored and help people with Motor Neurone Disease



**Never Give Up!**

[www.mycase.com.au/events/walk2dfeetmndgc](http://www.mycase.com.au/events/walk2dfeetmndgc)



**Q: Have either of you worked on any other MND research projects in the past? If so, please let us know a little about your previous MND-related research and outcomes.**

BU: Dr Arman Sabet has been involved in MND research studies in the US. He was involved in the Veterans Affairs ALS registry before moving to Australia. It led to a vast knowledge and understanding of ALS incidence, diagnosis, prognosis, risk factors etc.

**Q: Are you still recruiting candidates for your trial?**

BU: Yes. We expect to complete our trial in 18 months (June 2020).

**For more information about getting involved in this medicinal cannabis trial contact Dr Arman Sabet or Mr Berzenn Urbi by calling 07 5687 4551 or email [DEMSResearch@health.qld.gov.au](mailto:DEMSResearch@health.qld.gov.au).**

## RESEARCH NEWS - COPPER-ATSM TRIAL UPDATE

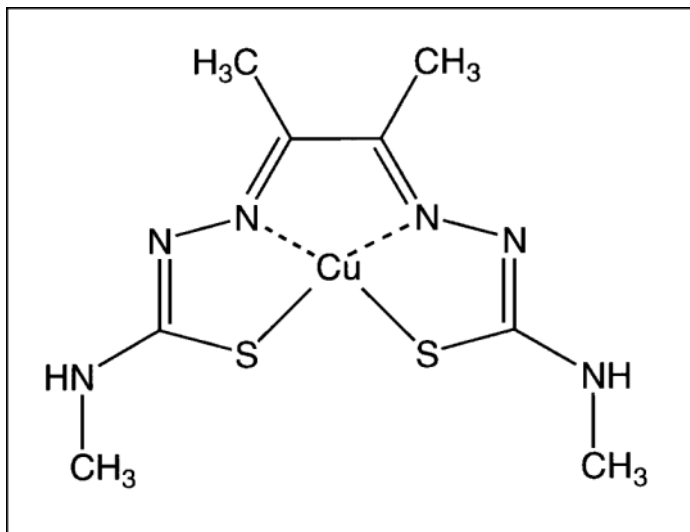
An MND research breakthrough was widely reported in the Australian media in mid-January. The reports stemmed from a research trial announcement at the International ALS/MND Symposium in Glasgow. Unfortunately the media reports mostly told of the successful efficacy of the copper-ATSM Phase 1 trial, but that is yet to be proven.

Phase 1 of the copper-ATSM trial as a treatment for MND began in 2016 in two sites in Australia. The trial had a small number of participants and its purpose was to test if copper-ATSM was safe to administer to humans and to identify the best dosage. The Phase 1 trial was successful in proving these steps which is great news as many drug trials don't get past Phase 1.

The next step is to prove the drug's efficacy on reducing symptoms of MND, and Phase 2 is expected to begin in late 2019. Phase 2 is expected to include 80 trial participants, some of whom will receive a placebo, while others will receive the copper-ATSM drug.

The development of copper-ATSM as a treatment for MND began about 15 years ago when it was first tested on animal models of neurodegenerative disease.

MND Queensland is proud to be associated with the Motor Neurone Disease Research Institute of Australia (MNDRIA). The MNDRIA has invested over \$1.2million into trials of copper-ATSM. These trials have been funded through the Betty Laidlaw MND Research Grant (copper malfunction in Motor Neurone Disease: a therapeutic tar-



get for sporadic MND) and Zo-ee MND Research Grant (Proteomic investigation of functional copper deficiency in MND) as well as the Jenny Barr Smith MND Collaboration Grant (Drug-specific biomarkers to facilitate clinical translation of Cull (ATSM) as a potential therapeutic for MND).

While we live in hope, we know that a possible treatment from these trials is years away, however MND Queensland looks forward to Phase 2 of the copper-ATSM trial. No locations for the trial are currently known, but as we learn more, we will share the news with you. We strongly encourage you to follow our Facebook page for more up-to-date news on issues such as drug trials.

[www.facebook.com/MNDAQ](https://www.facebook.com/MNDAQ).





## BEING AN MND MEMBER VS BEING A REGISTERED CLIENT

Being diagnosed with MND usually comes as a shock and the news can raise a lot of questions. This is where MND Queensland comes in, with help, advice, information, support and referrals. We know that sometimes the journey is difficult and confusing, and we are somewhat responsible for some of the confusion and hope that this article helps clear up the difference of being an MND member versus being a registered client.

MND Queensland, or as we are formally known as the Motor Neurone Disease Association of Queensland Incorporated, is an Incorporated Association. We are owned and managed by our members. Becoming a financial member allows you to vote at our Annual General Meeting and help inform the direction that MND Queensland takes. It makes you eligible to be voted in as a Board member. It gives you access to information such as The Cornflower newsletter.

If you have MND and live in Queensland or receive direct services from us, membership is just \$5 per annum. If you don't have MND but want to support the association you can join by paying an annual membership fee of \$25. MND Queensland membership is annual and becomes due at the beginning of each new calendar year.

If you have MND you are also encouraged to register with MND Queensland to access our services (e.g. MND Advisory Service (information, support and referrals) or the low-cost Equipment Service). There is no fee to become a registered client of MND Queensland. If you are interested in accessing our services and becoming a registered client, please contact us to be sent out a client registration pack and return the completed forms to us to become a registered client.

That said, we strongly encourage all of our registered clients to also sign up to become members of the Association

so that you have a vested interest in how the organisation that you benefit from is being run.

The more members we have, the stronger we are as an organisation. We use our membership numbers when speaking to governments and philanthropic bodies about the work we do and the people we represent, so you are helping us to develop our organisation and the services we provide just by being a financial member!

You can find out more information about becoming a financial member on our website [www.mndaq.org.au/Find-help/Membership](http://www.mndaq.org.au/Find-help/Membership). If you are after further information, or would like to register as a client, please call us on 07 3372 9004 or email [info@mndaq.org.au](mailto:info@mndaq.org.au).




### MND QUEENSLAND AGM DATE

We want to let our valued members know that the Annual General Meeting of the Motor Neurone Disease Association of Queensland Incorporated will be on Saturday 29 June 2019.

The time and venue are yet to be finalised, but if you are a current member of MND Queensland we will officially inform you prior to the meeting.


Not yet a member? Join today and have your say. [www.mndaq.org.au/Find-help/Membership](http://www.mndaq.org.au/Find-help/Membership).



**Save thousands of dollars while supporting people with MND!**

Get your 2019-2020 Entertainment Book and you'll be supporting MND Queensland's work to help people with MND. The books are filled with hundreds of fantastic discounts that can save you thousands of dollars! The books are only available online at [www.entertainmentbook.com.au/orderbooks/2221j21](http://www.entertainmentbook.com.au/orderbooks/2221j21)

There are books available for Brisbane, Sunshine Coast & Surrounds, Gold Coast & Northern NSW, Cairns, Palm Cove & Port Douglas, as well as Townsville. Plus you can access books for other parts of Australia too. They make fantastic gifts! So order yours now!



## NDIS PLANNING - HOW MND QUEENSLAND SUPPORTS CLIENTS

The NDIS has now been implemented throughout Queensland and if you are under 65 and have a diagnosis of Motor Neurone Disease you are eligible.

What does this mean? What do I need to do? How do I plan for my NDIS planning meeting? Get in touch and we can help you and your support network to prepare and go in to your planning meeting with more confidence.

We've helped many people to prepare and implement their NDIS plans and attended many NDIS Planning meetings. Quality time with your loved ones is important and being able to focus more on those relationships than unravelling at times because of complex systems is naturally your priority. While NDIS supports are directed at your goals and support needs they can also help to alleviate some of the stresses of those around you.

Our Senior MND Advisor was able to work with Peter (pictured) late last year to get ready for the NDIS and he has shared his experience with our readers...

### PETER'S STORY ON NDIS PLANNING ASSISTANCE

It was a Wednesday back in August and it still feels like a moment ago. I was about to go home after a Toastmasters meeting and a couple of members approached and asked if I was ok. One of them was a nurse and other was a head of paediatrics at SSC. I shared that I had been diagnosed with MND earlier that day, the response from the paediatrician shocked me, although it is the common way most medical people respond (*'ah that is really sh!t'*).

At the time my wife was at a conference in USA and was not due home until the following Sunday, therefore I had to keep the news from her until she was back home and able to be supported by her family.

As the weeks unfolded the maze and quagmire expanded with the medical vortex strengthening by the day. We felt totally lost and helpless trying to figure out what to do

and where to get help.

Fortunately, it did not take long to discover MND Queensland existed. Towards the end of 2018 I had my NDIS application approved, however without the guidance from Kylie at MND Queensland my file would still be sitting in an in-tray at NDIA today (that is another story). Kylie's wealth of experience in the pre-planning meeting, attending the NDIS planning meeting with us and quick attention to detail identifying the need for amendments to my NDIS plan and liaising with the planner made the madness evaporate.

Yes it is a difficult road, but without the wonderful knowledge and support of Kylie (and MND Queensland) we would still be feeling immensely overwhelmed, by frustration and despair.

Also, thanks to Kylie's introductions and guidance I now have support and the provider networks in place and feeling that we are in very good hands from here on.

Sure the progression of MND has been unexpectedly rapid, but the support situation is now resolved by the maze and complexities being transformed into a set of steps to follow. That has enabled us to have a sense of calm and move forward while having quality time together while we still can.



Pictured - Peter appreciates the NDIS planning support from MND QLD

**THE CHILLFACTOR 2019 & CHALLENGE**

**MND Blue Tie Ball**

Saturday 27 July 2019 at Magpies Sports Club, Mackay

To sponsor someone or register as a challenger go to [www.mycause.com.au/events/chillfactor](http://www.mycause.com.au/events/chillfactor)

Ball tickets available from [www.magpiesmackay.com.au/whats-on/events](http://www.magpiesmackay.com.au/whats-on/events)

Sponsor a challenger and watch them take the icy slide!

Then dance the night away at the MND Blue Tie Ball that evening!

Supporting

**mnd**   
Queensland



## NATIONAL 'MAKE AGED CARE FAIR' CAMPAIGN CONTINUES

For almost a year, MND Australia and its state bodies (including MND Queensland) and our supporters have been advocating to the Federal Government to 'Make Aged Care Fair' for people over the age of 65 who can't access the benefits of the NDIS.

With the Federal election looming, MND Australia, along with all of the State bodies, has been working on some resources to share with politicians and candidates to highlight the issues that people with MND experience and how Aged Care Packages are lacking compared to the NDIS.

Two brochures have been developed, one to educate and inform politicians about MND, and the other to call on them to 'Make Aged Care Fair' for people over the age of 65 with MND. As well, a door hanger has been developed to talk on your behalf if anyone comes door-knocking and you're not home, or even if you are, you can use it to highlight what's important to you.

We encourage you to lend your voice to the campaign and share the information with your local MP and any running candidates.

You can download the brochures here [www.mndaction.org.au/Resources](http://www.mndaction.org.au/Resources). MND Queensland will also have a supply of brochures and door hangers. If you would like any of these sent out, please call our office on 07 3372 9004 or email [info@mndaq.org.au](mailto:info@mndaq.org.au) to have them sent to you.



## PLEASE DONATE TO THE MND QUEENSLAND EASTER APPEAL

Without the support of people like you, MND Queensland's work would not be possible. We recently launched our Easter Appeal and ask you to please make a donation so that we can continue to provide quality services and support to families affected by Motor Neurone Disease.

You can donate online and become a monthly regular donor at [www.givenow.com.au/mndaq](http://www.givenow.com.au/mndaq) or if you're using a Visa or MasterCard you can call us on 07 3372 9004. Alternatively you can send a cheque or money order (made out to MND Queensland) to: MND Queensland, PO Box 470, INALA QLD 4077. Donations \$2 and over are tax deductible.

**MND ICE BUCKET CHALLENGE 2019**

Since 2014 the Ice Bucket Challenge has been an important way to increase awareness about Motor Neurone Disease as well as raise vital funds. We'll soon be launching the website for this year's challenge so check [www.mndaq.org.au](http://www.mndaq.org.au) for more information. Register, get sponsored (or make a donation to your own page) film yourself drenching yourself with a bucket of icy water, share it on social media (with the hashtags #MND, #everyaugustuntilthereisacure and #IceBucketChallenge2019) and nominate others to do the same!

**#everyaugustuntilthereisacure**

## WHAT'S ON

- 31 Mar** - Walk to D-Feet MND Gold Coast, 9AM Hollindale Park. Register at [www.myclause.com.au/events/walk2dfeetmndgc](http://www.myclause.com.au/events/walk2dfeetmndgc)
- 5-11 May** - MND Awareness Week
- 10 May** - Blue Cornflower Day (a great opportunity for you to host a Drink Tea for MND or dress in blue event)
- 26 May** - Walk to D-Feet MND Brisbane, 9AM, Roma Street Parklands. Register at [www.myclause.com.au/events/walk2dfeetmndbris2019](http://www.myclause.com.au/events/walk2dfeetmndbris2019)
- 29 Jun** - MND Queensland Annual General Meeting. More information coming soon.
- 27 Jul** - Chillfactor Challenge and MND Blue Tie Ball, Magpies Sporting Club, Mackay. See [www.mndaq.org.au](http://www.mndaq.org.au) for more info.
- 1 Aug** - Start of Ice Bucket Challenge Month. Registration/fundraising website coming soon. Check [www.mndaq.org.au](http://www.mndaq.org.au) for more info.

## MND SUPPORT GROUPS

Do you have MND, or are you a carer, family member or close friend of someone with MND? MND Support Groups are there for you!

Groups can vary in format and type of venue and are tailored to the needs of clients and families. They are a great chance to connect with others going through the same experience, a chance to share ideas and experiences, ask questions and learn what to expect.



### CAIRNS

**Location:** TBC

**Frequency:** TBC

**Time:** TBC

**RSVP:** Register interest by contacting [info@mndaq.org.au](mailto:info@mndaq.org.au) or call 07 3372 9004.

### TOWNSVILLE

**Location:** Kirwan Health Campus, 138 Thuringowa Dr, Kirwan

**Frequency:** 10 April, 22 May, 3 July, 14 Aug

**Time:** 10:45AM to 12:45PM

**RSVP:** Sharon Edwards, [sharon@mndaq.org.au](mailto:sharon@mndaq.org.au), 0424 408 657

### BUNDABERG

**Location:** TBC

**Frequency:** TBC

**Time:** TBC

**RSVP:** Register interest by contacting [info@mndaq.org.au](mailto:info@mndaq.org.au) or call 07 3372 9004.

### MARYBOROUGH

**Location:** TBC

**Frequency:** TBC

**Time:** TBC

**RSVP:** Register interest by contacting [info@mndaq.org.au](mailto:info@mndaq.org.au) or call 07 3372 9004.

### HERVEY BAY

**Location:** TBC

**Frequency:** TBC

**Time:** TBC

**RSVP:** Register interest by contacting [info@mndaq.org.au](mailto:info@mndaq.org.au) or call 07 3372 9004.

### SUNSHINE COAST (in partnership with MND & Me)

**Location:** Coolum Civic Centre, 2-4 Park Street, Coolum Beach

**Frequency:** 9 April, 11 June, 13 Aug

**Time:** 10.00 AM to 12.00 PM

**RSVP:** Email [info@mndaq.org.au](mailto:info@mndaq.org.au) or call 07 3372 9004.

### BRISBANE NORTH & CABOOLTURE (carer support & fundraising)

**Location:** Pine Rivers Health Centre, 568 Gympie Road, Strathpine

**Frequency:** Normally held on the 4<sup>th</sup> Saturday of every month (except Dec). 23 Mar, 27 Apr, 25 May, 22 Jun.

**Time:** 9:30AM to 11:30AM

**RSVP:** Graeme & Liz Holyer 0458 021 783

### NORTH BRISBANE (in partnership with MND & Me)

**Location:** Chermside Library, 375 Hamilton Road, Chermside

**Frequency:** 12 March, 14 May, 9 Jul,

**Time:** 1.00PM to 3.00PM

**RSVP:** Email [info@mndaq.org.au](mailto:info@mndaq.org.au) or call 07 3372 9004.

### SOUTH BRISBANE (in partnership with MND & Me)

**Location:** 5/28 Cavendish Rd, Coorparoo

**Frequency:** 7 March, 4 April, 2 May, 6 June, 4 July, 1 Aug

**Time:** 10:00AM to 12:00PM

**RSVP:** Email [info@mndaq.org.au](mailto:info@mndaq.org.au) or call 07 3372 9004.

### IPSWICH & WEST BRISBANE (in partnership with MND & Me)

**Location:** Wolston Park Golf Club, Ellerton Dr, Wacol

**Frequency:** 18 April, 20 June, 15 Aug

**Time:** 10:00AM to 12:00PM

**RSVP:** Email [info@mndaq.org.au](mailto:info@mndaq.org.au) or call 07 3372 9004.

### GOLD COAST (sponsored by Maylake Pty Ltd)

**Location:** Gold Coast Business Hub, Level 2 "Kay House", 35-39 Scarborough Street, Southport

**Frequency:** Bi-monthly, 13 April, 8 June, 10 Aug

**Time:** 1:00PM to 3:00PM

**RSVP:** Dianne Brauer 0411 742 265 or Lorraine Lovatt 0408 661 212

## MND QUEENSLAND DONATION FORM - AUTUMN NEWSLETTER

I would like to donate: \$.....(write amount) ☐ I'd like to give this amount monthly via my credit card

I am paying by: ☐ Visa ☐ MasterCard ☐ Cash ☐ Cheque/Money Order (made out to MND Queensland)

**For direct deposit donation details, please call 07 3372 9004**

### My Details:

Name:.....

Address:.....

Suburb:.....

State:.....Postcode:.....

Phone:.....

Email:.....

### Card Number:

**Card Expiry:**  **CSC:**  (3-digit CSC on back of card)

**Cardholder's Name:**.....

**Cardholder's Signature:**.....

**Send to: MND Queensland, PO Box 470, INALA QLD 4077** ☐ Please send me information about leaving a gift in my Will

**Or, if you are using a credit card you can call us on 07 3372 9004 or donate online at [www.givenow.com.au/mndaq](http://www.givenow.com.au/mndaq)**