

the cornflower

MOTOR NEURONE DISEASE ASSOCIATION OF QUEENSLAND NEWSLETTER



HIGHLIGHTS

- ◇ Innisfail, Toowoomba and Redcliffe Walk to D-Feet MND events
- ◇ MND Connect Conference
- ◇ MNDRIA Research Grants
- ◇ National MND Conference 2018

ICE BUCKET CHALLENGE - EVERY AUGUST UNTIL THERE IS A CURE

This year we reinvigorated the Ice Bucket Challenge which was a worldwide phenomenon in 2014.

Founded by Pete Frates, a Boston College captain with Motor Neurone Disease (or ALS as it is known in the US) the Ice Bucket Challenge quickly went viral. Ice Bucket Challengers included celebrities such as Bill Gates, Oprah Winfrey, Mark Zuckerberg, Justin Timberlake and many more.

Pete Frates set August as the Ice Bucket Challenge month until a cure for MND is found. This August we had 19 people register and together they raised a total of \$7,145.

MND Queensland's CEO Lisa Rayner took on the chilly challenge. A star this year was Ethan Power who managed to get his school (Toowoomba East State School) behind the event and he even managed to drench his principal and vice-principal in ice-cold water! Ethan and his friends raised almost \$1,300 - a fantastic effort.

We would like to thank everyone who participated or donated to the 2018 challenge and let you know that we'll be doing it all over again in August 2019! Watch out for more news in coming months.



Top/left - MND CEO Lisa Rayner and her granddaughters taking the challenge. Top/right - Volunteer Innisfail walk coordinator Robyn Cataldo took on the challenge after the walk (photo by Maria Girgenti). Bottom - Ethan Power gets drenched by his younger brother at their school Ice Bucket Challenge.

CONTACT US

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SOCIAL MEDIA

Facebook: www.facebook.com/MNDAQ

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Twitter: twitter.com/MNDQueensland

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FEEDBACK AND CONTRIBUTIONS

Please send your feedback or story ideas to 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. 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 - Walk to D-Feet MND Toowoomba participants



CHRISTMAS CLOSURE

Please note that the MND Queensland office will be closed from Friday 21 December for the Christmas break. We will reopen on Monday 7 January.

Equipment requests must be received by 13 December. Equipment loan agreements and payments must be received by 19 December for a delivery before the office closes.

For any emergencies during our closure please call Kylie on 0424 408 657 and she will do her best to assist you.



GRATITUDE, AND LOOKING AHEAD WITH YOU IN MIND



In this newsletter for the summer season I reflect on the past year, what we have achieved, and what is really important. Our team has worked extremely hard this year as it has been a year of rebuilding (with more to come). It has been tough but very well worth it as we always have our clients and their families first and foremost in our minds. This is what keeps us going.

I welcome our new clients, new members and their families, while being conscious of the fact that the “club” of MND is not something anyone wants to be part of in the first place. I can only say to clients and their families that I hope we are making the challenges of MND a little easier.

We certainly want to do more to ease the burden, particularly in terms of the number of staff hours to meet the needs of clients and their carers. Very soon we will be sending out our Client Satisfaction Survey and we hope that clients and carers will fill this in and return it so we can assess your priorities. This will help us set the most appropriate goals for the next year, and the combined results of the survey will also be useful in demonstrating the need when we apply for grants.

We have had some staff changes this year, where we have said goodbye to valuable staff members. Mal Farrow our part-time Equipment Officer left to take on a fulltime role. Thank you Mal for your dedication in the work you did to upgrade our Equipment Service. Mal has been replaced by Ricardo Brule who has taken on the role with dedication, and continues to improve the service. Eirlys Pijpers our Senior MND Advisor unfortunately had to return to the Netherlands. This was unexpected and we were disappointed to see her go as Eirlys’ strong knowledge of MND was extremely helpful in providing guidance to clients. We welcomed Kylie Kellalea to our team as the new Senior Advisor and her caring nature and experience in client support is already coming to the fore. Recently our Office Coordinator Telisa Sekona left to take up a wonderful

opportunity for a step up in her career. Telisa gave six years of dedicated service and I am sure clients, members and donors will miss her caring and helpful approach on the phone and at some of our events. We are currently recruiting for a new Office Coordinator and they are big shoes to fill!

During especially busy periods this year there have been times where I have taken quite a few calls from the carers or family members of clients. I have to say these conversations are very valuable for me as CEO, as I learn more and more about the challenges for carers and loved ones in dealing with the diagnosis, and the demanding caring duties. The insight I have gained will help me develop plans for the support we provide next year and beyond.

Of course we can’t achieve our goals without community support – individual donors, event organisers, Walk to D-Feet participants and sponsors, grant providers and bequestors. Thank you so much. Fundraising events and campaigns are very labour-intensive, so donations and contributions from events you have organised are crucial for us to keep supporting very deserving families living with MND. Every little bit helps, but major gifts are always very welcome!

I would like to take this opportunity to wish you all a very Merry Christmas and a safe and Happy New Year. I hope that you are surrounded by love and the people you care about this festive season.

Warm regards
Lisa Rayner
Chief Executive Officer
MND Queensland



mnd Action

It's time for the Government to
#makeAgedCareFair

Join the campaign and help make sure people living with MND Aged 65 and over receive the care and support they need and deserve

Visit www.mndaction.org.au to find out more

NATIONAL MND CONFERENCE 2018

I attended the National MND Australia Conference, hosted by MND South Australia, in Adelaide in August. The conference *MND Care: Informing, Influencing, Innovating* attracted hundreds of delegates with diverse health, allied health and community support backgrounds from Australia and New Zealand. Over 60 staff from MND Australia and the six State based MND Associations also came together for a national support staff meeting the day before the conference.

This excellent conference began with personal perspectives from two people, one under the age of 65 and one over, highlighting the positive impact on quality of life, timely access to diagnosis, support from MND Associations, multidisciplinary health care, assistive technology and at home supports, and the negative impact of waiting lists and lack of understanding particularly for older Australians.

The program covered topics as diverse as adapting to the introduction of the National Disability Insurance Scheme (NDIS), carer support and wellbeing, research updates, the impact of assistive technology and equipment on quality of life, and pain management for the MND patient.

CONFERENCE HIGHLIGHTS

Professor Samar Aoun is doing valuable work in social research. She is a palliative care researcher with a public health approach and a focus on under-served population groups such as people with MND, dementia, terminally ill people who live alone and caregivers before and after bereavement. Samar advocates strongly for person-centred health and social care with a strong focus on supporting family caregivers. Professor Aoun will be conducting research in 2019 involving surveying bereaved family carers of people with MND, and we are looking forward to working with her when her focus is on Queensland. Look out for more information next year.

Our own MND Queensland Advisor from Bundaberg Mark Whitley, an accredited mental health social worker, spoke on *End of Life Care - having the difficult conversations*. His caring approach, devotion to people with MND and expertise in applying appropriate models for end of life care came together in his presentation. The benefit to MND Advisors and health professionals was evidenced by the high ranking his talk was given in the collated evaluation responses. We are very proud of Mark and it is wonderful to know that his expertise has now been shared with so many people, for the benefit of families living with MND.

A trial of Suprascapular Nerve Block for shoulder pain in MND was presented by Peter Allcroft, Physician, South-



MND Australia CEO Carol Birks opening the National MND Conference 2018.

ern Adelaide Local Health Network, Flinders Medical Centre. Dr Allcroft pointed out that while the pain experience for people with MND is not consistent in severity across the board, there are a significant number experiencing shoulder pain. I was heartened to hear of his extremely successful trial results, with an injection having lasting effects for patients for up to three months, and patients coming back for more.

For more on the pain trial, or any of the other conference presentations the list of presentations on the program is here www.mndaust.asn.au/Get-informed/For-health-professionals-and-service-providers/Get-informed-For-health-professionals-and-service/

MND_ConferenceProgram-2018 and then videos of all of the presentations, grouped in 4 sessions, can be found here www.youtube.com/playlist?list=PLpLXU2QzUiV5kHZTJYMtWDMHmnx1Rd2cN

INSPIRING IN-SERVICE DAY

The meetings and in-service programs on the previous day included a face-to-face National Board meeting, a face-to-face CEO meeting which included CEO's of State MND Associations and New Zealand, plus an all-day program for client service teams of MND State bodies. The first part of this day was open to Board members and CEO's, and presentations from key service staff in each State were given about their programs and services and the wonderful outcomes they are achieving for people with MND.

This inspiring and motivating day, meeting so many brilliant and dedicated support staff, and hearing about their successful initiatives left me very proud to be a part of this national group, and full of ideas and insights which I will consider in our future planning.

Lisa Rayner
CEO

MND AUSTRALIA RESEARCH CONFERENCE & MND CONNECT

The 14th MND Australia Research Conference was held in Melbourne on Friday the 9th of November. There were many great minds discussing where their current research has brought them and looking at the road ahead.

Conference presenters were able to share their expertise and findings which led to much dialogue between presenters and attendees about the latest developments in MND research.

The following day the 4th MND Connect conference was held (also in Melbourne).

People living with MND, their friends and family, community health professionals and researchers all came together. The interesting presenters that discussed cognition and behaviour, managing bulbar symptoms, advances in communication technology, genes and the environment, and, the importance of multidisciplinary care and palliative care. There was also a clinical trials update and a valuable contribution from a carers perspective.

MND Queensland was represented at both conferences by our President Peter Denham, and our Senior MND Advisor, Kylie Kellalea.

NDIS AND MND

If you are under the age of 65 and have a diagnosis of MND then you are eligible to register for the National Disability Insurance Scheme (NDIS). Given the progressive nature of MND, planning for your support needs should include both your current and future support needs. With assistance from NDIS your needs can be supported in the following ways.

Capacity building supports are available such as your allied health team including (but not limited to) occupational therapist, physiotherapist, speech therapists, psychologist and dieticians. It does not extend to your medical supports though.

Support Coordination is available to help you to navigate and coordinate your supports and to implement your NDIS plan. MND Queensland is currently in the registration process to provide this service.

Assistance with daily activities to enable you to remain independent in your home and within the community for as long as possible. This assistance could be with tasks such as personal care, preparing meals, domestic supports, home maintenance, overnight care, two person transfers and accessing the community.



John Laidlaw (left) and the Betty Laidlaw MND Research Prize winner, Dr Marco Morsch from Macquarie University at the 14th MND Australia Research Conference.

During the research conference the recipients of MNDRIA Research Grants were announced – details overleaf. You can also check out details of the MNDRIA Research Strategy here www.mndresearch.org.au/News-and-media/MND-Australia-announces-Research-Strategy-2018-2.

Assistive technology such as mobility and communication equipment can be included in your plan. This could be in the form of equipment that you hire or purchase (if the item needs to be customised) or home or vehicle modifications (with supporting documents including an assessment and report from an occupational therapist and a quote). MND Queensland's Equipment Service will soon be operating under the NDIS.

Participants with MND must be streamed as 'super intensive' to ensure they are appropriately supported through NDIS processes. Whether you are yet to register or already registered and waiting for your planning meeting it is really important to call and confirm that you are streamed appropriately to avoid unnecessary delays and so that you are allocated an NDIS Planner to complete your planning meetings and reviews.

Further information is available on the NDIS website www.ndis.gov.au or by calling 1800 800 110.

Not sure where to start or would like assistance with pre-planning prior to your NDIS meeting? Give our MND Advisory Service a call on 07 3372 9004.

NATIONAL MNDRIA RESEARCH GRANTS ANNOUNCED

MND Australia's research arm – the MND Research Institute of Australia (MNDRIA) - has awarded almost \$4 million for new research projects commencing in 2019.

The MNDRIA Research Committee awarded 28 new research grants across the country for 2019, along with funds previously committed to support an innovative, national NHMRC partnership grant (2019-2023) and the Australian MND Registry. The grants included 6 for projects to be conducted in Queensland. A summary of the grants awarded follows:

PROJECTS COMMENCING IN 2019

GRANT	RECIPIENT	PROJECT
Betty Laidlaw MND Research Prize awarded to an outstanding mid-career researcher	Dr Marco Morsch, Macquarie University, NSW	Targeting the nucleo-cytoplasmic transport machinery in sporadic and familial ALS
Bill Gole MND Postdoctoral Fellowship 2019 – 2021	Dr Rosemary Clark, University of Tasmania, TAS	Clinical heterogeneity in ALS: insights from interneurons
Beryl Bayley MND Postdoctoral Fellowship 2019 – 2021	Dr James Hilton, University of Melbourne, VIC	Ferroxidase dysfunction drives glial ferroptotic stress and motor neurone death via neurotoxic A1 astrocyte conversion
Charcot Grant - Awarded to the highest ranking innovator grant application	Professor Julian Gold, The Albion Centre, Prince of Wales Hospital, NSW Health	Phase 3 placebo controlled group sequential trial of Triumeq in patients with Motor Neurone Disease
Neil and Norma Hill Foundation MND Research Grant	Dr Rebekah Ahmed, University of Sydney, NSW	Physiological changes along the frontotemporal dementia/amyotrophic lateral sclerosis spectrum – The hypothalamus where eating, metabolism and neurophysiology meet
MS WA MND Research Grant	Professor Samar Aoun, La Trobe University, VIC	Best practice in end-of-life care and bereavement support: A national survey of bereaved family carers of people with MND
Gross Foundation MND Research Grant	Dr Catherine Blizzard, University of Tasmania, TAS	Can oestrogen protect against synaptic disturbances in ALS?
MNDRIA Innovator Grant	Professor Roger Chung, Macquarie University, NSW	Revealing the role of protein clearance pathways in sporadic ALS
Janette Hamilton MND Research Grant	Dr Anthony Cook, University of Tasmania, TAS	Proteomic analysis of exosomes from iPS cell-derived neurons with mislocalised TDP-43
Jenny Barr Smith MND Research Grant	Associate Professor Peter Crouch University of Melbourne, VIC	The neurotoxic consequences of glial iron accumulation in MND
Lady (Mary) Fairfax MND Research Grant	Associate Professor Kay Double University of Sydney, NSW	Validating molecular pathways of SOD1 toxicity in human ALS
MNDRIA Innovator Grant	Dr Michelle Farrar, University of New South Wales, NSW	Assessing preference heterogeneity with respect to MND treatment. A discrete choice experiment
Peter Stearne Familial MND Research Grant	Dr Jennifer Fifita, Macquarie University, NSW	Investigating the role of large structural variation in MND by analysis of whole-genome sequencing data
Jenny Simko MND Research Grant	Associate Professor Nimeshan Geevasinga, Western Sydney Local Health District, NSW	Utilising novel MRI connectomic analysis to explore pathophysiological changes in ALS
Col Bambrick MND Research Grant	Dr John Lee, University of Queensland, QLD	Investigating the beneficial effects of complement C3aR on immune cell glucose metabolism in MND
Superball XI MND Research Grant	Associate Professor Seth Masters The Walter and Eliza Hall Institute of Medical Research, VIC	Targeting cGAS/Sting to block neuroinflammation in MND
Jenny Simko MND Research Grant	Professor Pamela McCombe University of Queensland, QLD	Immunogenetics of motor neurone disease - a pilot study
MonSTaR MND Research Grant	Dr Fiona McKay, University of Sydney, NSW	Anti-inflammatory and metabolic effects of dimethyl fumarate in amyotrophic lateral sclerosis
MNDRIA Innovator Grant	Dr Parvathi Menon, Western Sydney Local Health District, NSW	ALS progression: multimodal approach to assessing cortical dysfunction which may underlie pathogenesis

PROJECTS COMMENCING IN 2019 CONTINUED

GRANT	RECIPIENT	PROJECT
Fat Rabbit MND Research Grant	Dr Sean Millard, University of Queensland, QLD	Identifying molecular pathways affected by the sporadic ALS risk factor, GGNBP2
MS WA MND Research Grant	Dr Sarah Rea, The University of Western Australia, WA	Defining the interaction between p62 and TDP-43 as a potential therapeutic target for Amyotrophic Lateral Sclerosis and Frontotemporal Dementia
Andrew Butcher MND Research Grant	Dr Mary--Louise Rogers, Flinders University of South Australia, SA	How does Triumeq work as an MND treatment? A study to determine the relationship between endogenous retrovirus, TDP43 pathology and inflammatory signals in MND
Benalla Act to d'feet MND Research Grant	Dr Rachel Tan, University of Sydney, NSW	Prions, RNA binding proteins with prion-like domains and motor neuron degeneration
Mavis Gallienne and Graham Lang MND Victoria Research Grant	Professor Julian Trollor, University of New South Wales, NSW	Using big data to understand the health status and service use of people with motor neurone disease
MNDRIA Innovator Grant	Dr Mehdi van den Bos, Western Sydney Local Health District, NSW	Cortigofugal dysfunction and cortical hyperexcitability in ALS – a window into ALS onset and progression utilising TMS EEG
MonSTaR MND Research Grant	Professor Mark Wilson, University of Wollongong, NSW	Rapid screening of small molecule libraries to identify new drug leads to treat Motor Neurone Disease
NTI MND Research Grant	Associate Professor Trent Woodruff, University of Queensland, QLD	Manipulation of free fatty acid receptors to tame the immune response in MND
Dr Paul Brock MND NSW Research Grant	Associate Professor Justin Yerbury, University of Wollongong, NSW	Is UBA1 a therapeutic target in AL

OTHER GRANTS COMMENCING IN 2019

NHMRC Partnership Grant	Professor Matthew Kiernan, Brain and Mind Centre, University of Sydney,	MND: Patient-centred care for a progressive neurological disease - evidence driving policy
Lord Mayor's Charitable Foundation - Eldon & Anne Foote Trust	Associate Professor Paul Talman Deakin University, VIC	Australian Motor Neurone Disease Registry

MULTI-YEAR GRANTS FROM PREVIOUS YEARS CONTINUING IN 2019

SALSA - SGC (2016 – 2020)	Professor Naomi Wray, University of Queensland, QLD	Sporadic ALS Australian Systems Genomics Consortium (SALSA-SGC)
Bill Gole MND Postdoctoral Fellowship 2018 – 2020	Dr Nirma Perera, Florey Institute of Neuroscience and Mental Health, VIC	Targeting autophagy protein homeostasis pathway to improve motor neurone health in MND
Beryl Bayley MND Postdoctoral Fellowship 2018 – 2020	Dr William Huynh, Brain and Mind Centre, University of Sydney, NSW	A multimodal approach combining novel electrophysiological and neuroimaging techniques to explore the pathophysiological mechanisms and patterns of disease spread in MND
Bill Gole MND Postdoctoral Fellowship 2017 – 2019	Dr Jennifer Fifita, Macquarie University, NSW	Investigating the molecular and pathological origins of amyotrophic lateral sclerosis
Beryl Bayley MND Postdoctoral Fellowship 2017 – 2019	Dr Emma Devenney, Brain and Mind Centre, University of Sydney, NSW	Behaviour, cognition, eye-movements and psychiatric disease in C9orf72 MND and FTD; a cross modal-approach to facilitate early and accurate diagnosis

MNDRIA PhD SCHOLARSHIP TOP-UP GRANT

MNDRIA PhD Scholarship Top-Up Grant 2018 - 2020	Camille Paynter, University of Melbourne, VIC	A longitudinal study of involvement in health care decision-making in motor neurone disease: Patient and caregiver perceptions, impact of communication and swallowing difficulties, and quality of life
MNDRIA PhD Scholarship Top-Up Grant 2018 - 2020	Britt Berning, Queensland Brain Institute, QLD	Sub-cellular dysfunctions associated with pathological TDP-43 in MND: disease mechanisms and therapeutic relevance
MNDRIA PhD Scholarship Top-Up Grant 2017 - 2019	Timothy Tracey, The University of Queensland, QLD	Using in vitro human cortical neurons as a model to study neurometabolic defects in motor neuron disease

NHMRC/MNDRIA POSTGRADUATE SCHOLARSHIP (2017 – 2019)

NHMRC/MNDRIA Postgraduate Scholarship	Camille Paynter, University of Melbourne, VIC	Communication, quality of life and advance care planning for people with MND and their caregiver
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WALK TO D-FEET MND - INNISFAIL, TOOWOOMBA AND REDCLIFFE

Walk to D-Feet MND events are important ways of increasing community awareness on Motor Neurone Disease and they are also important fundraisers so that MND Queensland can continue to provide services and support. In the last few months we have once again held the Toowoomba walk, and two new walks in Innisfail and Redcliffe have been introduced into our fundraising calendar

On 12 August, Innisfail saw the region's very first Walk to D-Feet MND event take place at Callendar Park. The event came about due to the actions of Robyn Cataldo who sadly lost her father to MND. She formed a volunteer committee and with the support of our head office, went about putting together a very successful event. The day had close to 150 people attend with people travelling from all over Far North Queensland to participate. The event raised close to \$9,000. The local Mayor John Kremastos attended and even participated in the Ice Bucket Challenge which took place after the walk!

Next up was Toowoomba's turn. The Toowoomba walk is a well-established event and we once again held the walk in the Queens Park Botanic Gardens. This year the event was held the week before the Carnival of Flowers so the gardens were looking spectacular! Almost 180 people attended the Toowoomba walk on the brisk morning of Sunday 16 September and the event raised around \$7,500. The crowd was entertained by the very talented Singer/DJ/Karaoke Kerryanne who volunteered her time and talent. Participants also filled up on hot drinks provided

by Vanochino (who also donated part proceeds from their sales on the day) and enjoyed a BBQ breakfast put on by the Lions Club of Toowoomba West (who also donated proceeds from the day). It was great to see such wonderful media coverage of the day too which helps us increase community awareness about MND.

The final walk for 2018 was the Redcliffe walk. While we've previously hosted walks nearby in Sandgate and North Lakes, this was the very first Redcliffe walk. Our Board members Liz and Graeme Holyer took the reigns on the event and had their amazing volunteers from the Brisbane North and Caboolture MND Support Group helping out. Despite it being a rainy day at Suttons Beach, the event was a great success raising around \$5,500. In attendance were Federal MP Luke Howarth and Moreton Bay Regional Council Mayor Allan Sutherland.

We want to thank all of the amazing volunteers, participants, special guests, donors and everyone else involved for your support of our walks.

With two of our recent walks being run by volunteers (with the support of head office) we think that the Walk to D-Feet MND events are replicable in other parts of the state too and we'll soon be working on a manual to help anyone that is thinking of putting on a walk. This will hopefully be ready by the end of January, so if you're thinking of hosting your own walk in your town, start talking to family and friends who might want to help out and get in touch with our office in the new year.

INNISFAIL (Photos courtesy of Maria Girgenti)



TOOWOOMBA



REDCLIFFE



MARISKA & BILL'S BRISBANE VALLEY RAIL TRAIL RIDE FOR MND

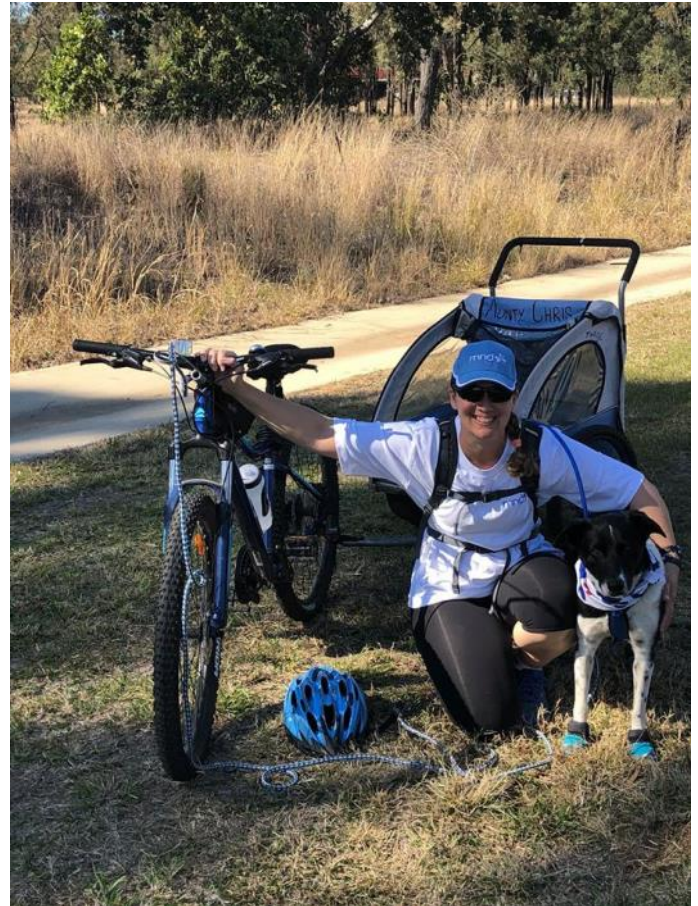
Mariska's family have been touched by familial MND. Sadly seven of her family members have had MND and now her Auntie Chris is battling this devastating, incurable disease that will cut her life short. After witnessing firsthand how cruel MND is, Mariska was inspired to make a positive difference in the lives of people affected by MND.

Mariska and her amazing search and rescue dog Bill (who was rescued/adopted by Mariska) rode the Brisbane Valley Rail Trail to help raise awareness on MND as well as much-needed funds for MND Queensland.

At 161km in length, the Brisbane Valley Rail Trail is the longest rail trail in Australia. Mariska pedalled and Bill joined her for the journey, running some of the way with his special dog shoes, and occasionally resting in his carriage being towed by Mariska. As far as we know, Bill was the first dog to undertake the entire length of the Brisbane Valley Rail Trail!

Mariska's partner Wade also joined the ride that occurred on the weekend of 25 and 26 August.

Mariska has raised almost \$5,000 from her efforts. We appreciate her energy and enthusiasm to make a difference in the lives of people affected by MND. If you have a fundraising idea that you'd like to discuss, please call our Fundraising & Communications Manager Jason Russo on 07 3372 9004 or email fundraising@mndaq.org.au. There are all sorts of ways we can support you to make your effort a success.



Pictured: Mariska with her search and rescue dog Bill along with her bike and Bill's carriage.

TOOWOOMBA FUNDRAISING ART EXTRAVAGANZA

Creevey Russell Lawyers in Toowoomba hosted a fundraising exhibition for MND Queensland in October at their office featuring works by artist Allan Cooney.

A large crowd of art lovers gathered to enjoy great art, fine wines and tasty gourmet treats. The night raised around \$7,000 through an auction of several pieces by Allan as well as work by his mother, Faye Cooney and work by Suzie Killen, plus a raffle, and this will help MND Queensland continue to provide crucial support to people affected by MND.

MND Queensland CEO Lisa Rayner spoke about our work and paid tribute to supporters, artists and attendees, some of whom had lost a family member to MND.

Many thanks to Dan Creevey and staff, Allan Cooney, the other artists involved and all who attended and bid on the art. The evening capped off an incredible year of support from the generous people of the Downs.



Artist Allan Cooney with one of his paintings being auctioned for MND Queensland.

MEET OUR FUNDRAISING & COMMUNICATIONS MANAGER

Jason Russo commenced with MND Queensland as Fundraising & Communications Manager in January this year. In this issue we get to know him a little more.

Tell us a little about your background and the skills you bring to MND Queensland?

I've been working in charity fundraising and marketing for almost 20 years now. I have had a lot of varied experiences having worked for three other not-for-profits previously. I also have a degree in graphic design which comes in handy and gave me a basis in advertising and marketing which has helped in my fundraising career.

Can you tell our readers a little about what you do at MND Queensland?

My role is quite varied and I'm always busy as I work just four days per week. I get to help people put on their own fundraisers for MND Queensland and it's really great to see people go from being a bit scared of the unknown to confident fundraisers ready to take on more challenges.

I coordinate all aspects of fundraising for MND Queensland along with communications. For example I look after our social media accounts, I put together our newsletters, I coordinate events like our walks, I put together our fundraising appeals, write grants and much, much more. I also work with media to try to raise awareness on MND and the work that we do at MND Queensland.

What is it that you like about working for MND Queensland?

As with the other charities I've worked for, the most rewarding aspect of my work with MND Queensland is knowing that my work is helping people. I like knowing that I'm helping to make a positive difference in the world and not just making someone richer. As I mentioned before, I also like helping people with their own fundraising ideas too and helping them be successful.



What have you learned about MND since working at MND Queensland.

That a lot of people have no idea what MND even is! The lack of community awareness on MND definitely makes my job more challenging.

Any final words that you'd like to share with our readers?

Thanks for your support! I know it sounds corny, but I'm always very grateful for every donation, or fundraiser or volunteer. I think that MND Queensland's supporters are amazing people who have often been through the darkest times. It seems for some, helping others can be a way to heal and cope with the grief of losing a loved one.

"the most rewarding aspect of my work with MND Queensland is knowing that my work is helping people"

PLEASE DONATE TO THE MND QUEENSLAND CHRISTMAS APPEAL

Without the support of people like you, MND Queensland's work would not be possible. We recently launched our Christmas 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. Donations are welcome into the new year.

You can donate online at 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. Thanks for your support.

MND Queensland Christmas Appeal

Please give generously to help families affected by MND like Amanda's and Nathaniel's

donate online at www.givenow.com.au/mndaq

or call us on 07 3372 9004

mnd 
Queensland

To read Nathaniel's and Amanda's stories visit:
www.mndaq.org.au/Donate/Christmas-Appeal-2018



Amanda (middle) with her sisters and their late Dad David



Nathaniel, Sarah & daughter Emily - still doing the things they love

WHAT'S ON

31 Mar - Walk to D-Feet MND Gold Coast, 9AM Hollindale Park. Registration details on our website soon.

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. Registration details on our website soon.

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 with Kylie Kellalea, seniormndadvisor@mndaq.org.au, 07 3372 9004

TOWNSVILLE

Location: Kirwan Health Campus, 138 Thuringowa Dr, Kirwan

Frequency: 16 January, 27 February, 10 April

Time: 10:45AM to 12:45PM

RSVP: Sharon Edwards, sharon@mndaq.org.au, 0424 408 657

BUNDABERG

Location: TBC

Frequency: TBC

Time: TBC

RSVP: Register interest with Kylie Kellalea, 07 3372 9004, seniormndadvisor@mndaq.org.au,

MARYBOROUGH

Location: TBC

Frequency: TBC

Time: TBC

RSVP: Register interest with Kylie Kellalea, 07 3372 9004, seniormndadvisor@mndaq.org.au,

HERVEY BAY

Location: TBC

Frequency: TBC

Time: TBC

RSVP: Register interest with Kylie Kellalea, 07 3372 9004, seniormndadvisor@mndaq.org.au,

SUNSHINE COAST (in partnership with MND & Me)

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

Frequency: 12 February, 9 April

Time: 10.00 AM to 12.00 PM

RSVP: Kylie Kellalea, 07 3372 9004, seniormndadvisor@mndaq.org.au,

BRISBANE NORTH & CABOOLTURE (carer support & fundraising)

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

Frequency: Normally held on the 4th Saturday of every month (except Dec). The first for 2019 will be on Sat 19 Jan due to the Australia Day long weekend)

Time: 9:30AM to 11:30AM

RSVP: Graeme & Liz Holyer 0458 021 783

NORTH BRISBANE (in partnership with MND & Me)

Location: Chermide Library, 375 Hamilton Road, Chermide

Frequency: 12 March, 14 May

Time: 1.00PM to 3.00PM

RSVP: Kylie Kellalea, 07 3372 9004, seniormndadvisor@mndaq.org.au,

SOUTH BRISBANE (in partnership with MND & Me)

Location: 5/28 Cavendish Rd, Coorparoo

Frequency: 7 February, 7 March, 4 April

Time: 10:00AM to 12:00PM

RSVP: Kylie Kellalea, 07 3372 9004, seniormndadvisor@mndaq.org.au,

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

Location: Wolston Park Golf Club, Ellerton Dr, Wacol

Frequency: 21 February, 18 April

Time: 10:00AM to 12:00PM

RSVP: Kylie Kellalea, 07 3372 9004, seniormndadvisor@mndaq.org.au,

GOLD COAST (sponsored by Maylake Pty Ltd)

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

Frequency: Bi-monthly, 9 February, 13 April

Time: 1:00PM to 3:00PM

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

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Send to: MND Queensland, PO Box 470, INALA QLD 4077

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