

the cornflower

MOTOR NEURONE DISEASE ASSOCIATION OF QUEENSLAND NEWSLETTER



HIGHLIGHTS

- ♦ Walk to D-Feet MND Brisbane
- ♦ Annual General Meeting
- ♦ Meet Our New Equipment Officer
- ♦ One Year on Our Bike Update
- ♦ Mackay Chill Factor Challenge
- ♦ How a New Idea Article Started MND Queensland

ANNUAL GENERAL MEETING - WELCOME NEW BOARD MEMBERS

MND Queensland's Annual General Meeting was held on Saturday 23 June at the Mt Ommaney Community Hub.

The meeting was well attended and the 2017 Annual Review and Financial Report were adopted by members present.

In exciting news, we had three Board members sworn in at the AGM. Graeme Holyer rejoins the Board and we also welcomed Richard Kilgour and Dean Palmer to the Board.

We look forward to the contributions of our new Board members and appreciate the time and energy they are investing.

Two special guests also attended the AGM, Milton Dick MP, Federal Member for Oxley, and former State Minister Henry Palaszczuk (who officially opened our building in 1993) were in attendance. They took part in cutting our special 35th Anniversary cake to celebrate 35 years



Milton Dick MP cuts the 35th anniversary cake at our AGM.

of support and services, and Milton Dick spoke about his current advocacy for aged care support including his recent parliamentary submission.

You can download the 2017 Annual Review at www.mndaq.org.au/About-us/Annual-Reviews.

MND QUEENSLAND COMMEMORATES 35 YEARS OF SUPPORT IN 2018

CONTACT US

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SOCIAL MEDIA

Facebook: www.facebook.com/MNDAQ

Walk to D-Feet MND: www.facebook.com/Walk2DFeetMNDQld

Twitter: twitter.com/MNDQueensland

Instagram: @mndqld

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.



FROM THE CEO'S DESK



FAKE VS REAL WINDFALLS

I recently attended an NDIS Seminar which focussed on pricing and updates on how the service was working for providers as it continues to roll out. Some of the statistics were startling, such as the fact that 75% of providers at this stage were not making a profit from their NDIS service provision.

In the early days of preparation, most organisations expected to more than cover the costs of many of the services they were providing, and have additional funds to invest in growth and improved service to clients. Government funding to disability organisations is gradually being cut off, deemed unnecessary because of the “windfall” that would come from shrewd NDIS pricing and packaging of services or equipment. This has not been the case so far, with “inadequate prices” and “risk of market failure” sitting in the top three categories of provider concerns.

So where does MND Queensland fit in and what does the future hold? At present we are Registered Providers for Personal Mobility Equipment, we are waiting on approval for other Equipment categories, and we are working on finalising our new NDIS pricing and packaging.

While we are a little behind in our readiness due to staff changes which interrupted our early planning, this could prove beneficial as there has been some great work done to help iron out NDIS problems and improve outcomes for both providers and clients.

National Disability Services (NDS), Australia's peak body for non-government disability service organisations, has worked tirelessly on many issues, as have our own national body, the Motor Neurone Disease Association of Australia (MNDAA). While I alluded to “fake windfalls” in my headline I do believe that the NDIS will get better and better over time.

It is a massive undertaking for any Government or series of Governments to implement such a huge national scheme and a myriad of teething problems are to be expected. We in the sector are doing our part to engage and provide feedback and advocacy. The learnings and

improvements can only assist with the fine-tuning of our NDIS offering, and lead to better outcomes for clients.

We are excited about the future as we are in a growth period that will continue over the next 12 months where we hope to expand our service to clients.

The small amount of State Government funding we have been receiving will end in mid 2019. We still have a lot of hard work to do to prepare for that time and ensure that we continue to improve our NDIS provision and keep in touch with our wonderful clients and their families, as well as our donors and supporters.

This brings me to the many real windfalls we have received recently. Some of those relate to our third party fundraisers who have organised events or taken on challenges such as the big hearted Mackay Chill Factor crew with Mackay Magpies AFL Club and Rio Tinto providing phenomenal support, the amazing Wolters family and the unstoppable Steve Beck, all of whom you can read about in this issue. The Watchman family, Taroom Golf Club and a number of generous private donors in the last couple of months who have made major gifts and organised their bequests have also been an absolute godsend.

There are many more too numerous to name and we value every one. Thank you so much, your generosity really makes an incredible difference. If you would like to discuss how you can provide support through organising a fundraising activity, gift or bequest, please get in touch.

This year is our 35th Anniversary and we hope it will be a milestone year in more ways than one, where we connect with, and provide support for, more families living with MND, knowing we are making their lives a little easier at such a difficult time.

Warm regards



Lisa Rayner
Chief Executive Officer
MND Queensland

P.S. As I complete this report I am currently in Adelaide at the National MND Australia Conference. I am excited about what we are learning by sharing ideas and hearing from inspiring speakers on an incredible range of topics. Look out for brief reports on our website and snippets on Facebook, and a more detailed report in the next edition of the newsletter.

MACKAY CHILL FACTOR CHALLENGE & BLUE TIE BALL 2018

Following on from the success of the Chill Factor Challenge and Blue Tie Ball in 2017, organisers of these Mackay events wanted to make them even bigger and better in 2018... so they did!

Volunteer organisers Kathy and Noel along with the team from the Magpies Sporting Club did an amazing job of increasing the overall fundraising income to around \$40,000 this year! They also managed to get a great deal of sponsors on board including Rio Tinto, WorkPac, Tucker & Cowen Solicitors, Star 101.9 Mackay, Blue River Ice & Water, Let's Jump, Events by Ramona, Magpies Sporting Club and the Magpies Mackay Football Club.

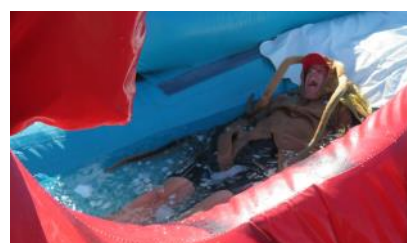
The afternoon of June 8 saw the giant inflatable slide set up for the Chill Factor Challenge at the Magpies Sporting Club. Ten challengers took the icy slide after they had each raised a minimum of \$1,000. The highest fundraiser

was once again Mick Scholer topping his record from last year by raising \$5,340. The Rio Tinto Hail Creek Mine crew also made an incredible contribution.

It was a fun afternoon with all of our challengers dressed up in costume to take the slide. Special guests included football stars Lote Tuqiri and Chris Johnson who posed for lots of photos with the crowd.

In the evening, it was all about dressing up for the Blue Tie Ball at the Magpies Sporting Club where our special guests once again joined us and mingled with the glamorous crowd. There was a fundraising auction with some great donated items and the band Stage Five kept everyone entertained.

Thanks go to the organisers, volunteers, sponsors, competitors and all attendees for your wonderful support.



CAUSE CARE CURE - UPDATE ON MND QUEENSLAND'S SUPPORT

An MND diagnosis can often come after an arduous period of investigations and a process of ruling out other conditions. While it may be a relief to get some answers, MND is not the answer anyone wants to hear.

Suddenly the world changes and a myriad of new questions and challenges emerge. MND Queensland are here to help clients and their loved ones navigate these challenges and learn more about the disease.

One of our most important services is our Advisory Service and we have MND Advisors who can provide you with information, advice and referrals. Our advisors provide support over the phone, via email and in person through home visits and Support Groups.

MND Support Groups continue to be an important way for people to connect with others going through the same situation and share experiences. Our MND Advisors help facilitate MND Support Groups across the State and you can find upcoming dates on the back of this newsletter.

If you have MND you can register with MND Queensland for just \$5 and as a registered client, you can access our low-cost equipment loan service.

Your allied health professionals will recommend the appropriate equipment for your needs as your disease progresses.

We have a range of equipment including wheelchairs, hoists, shower chairs, communication devices, beds and cough assist machines.

We were very fortunate to have recently won a major grant from the Victorian organisation Fight MND which has allowed us to purchase an additional 16 eye-gaze

communication devices to loan to people with MND. We are very grateful for Fight MND's support and this will help meet the high demand for eye-gaze systems and reduce the waiting list for this important equipment.

We also continue to advocate to Government and allied health services to help improve the services available to people with MND. You may have recently seen our national campaign calling for improvements to Aged Care Packages to better meet the needs of people with MND over the age of 65 who cannot access the NDIS. The 'Make Aged Care Fair' campaign continues into a new phase which will be promoted soon, with updated Federal Government contacts and other new information to help keep the pressure up, and a program of local volunteer champions will be rolled out in the next couple of months.

MND Queensland is also proud to support the research efforts of the Motor Neurone Disease Research Institute of Australia so that we can discover the cause of MND, and hopefully a cure, or at least in the meantime, effective treatments to improve peoples' quality of life and increase life-spans.

We speak with people in distress every day and we strive to improve our services to meet the needs of people affected by this cruel disease. Fundraising is critical to our ability to provide the support and services that people living with MND deserve, as we currently only receive 7% of our income from the Government, and this will cease in mid-2019. We are very grateful to our donors, volunteer fundraisers and event supporters who help make our valuable work possible.

If you would like more information on MND Queensland's services, call us on 1800 777 175 (free call within Queensland, otherwise call 07 337 9004) or you can also find more information on our website www.mndaq.org.au.

MND AUSTRALIA ANNOUNCES RESEARCH STRATEGY 2018-2021

Our parent body, MND Australia, along with its research arm the MND Research Institute of Australia, recently announced our new national research strategy. The Strategy's vision is to find effective treatments and ultimately a cure for MND.

People with MND and their families are at the centre of the new strategy, developed following analysis of the current research environment, and extensive consultation with researchers, health professionals, community and MND Australia's State MND Association members.

To read more visit: www.mndresearch.org.au/Documents/Research-documents/MND-Australia-Research-Strategy-2018-2021.aspx



ONE YEAR ON OUR BIKE - UPDATE ON THE WOLTERS' EPIC RIDE

Since the Wolters family (Dad Jozef, Mum Diana and children Jack (12) and Cloe (14)) set off on their year-long journey around Australia in support of MND, they have ridden more than 8,000km across three states!

The family were motivated to raise awareness on MND and funds for MND Queensland after Jozef's father Jack died from MND in 2017.

January 28 saw the family set off on their epic ride from Bundaberg. They travelled to Cairns before heading west and then up to Darwin. The family recently reached Western Australia and have visited Broome and Port Headland and now continue south along the coast.

They've encountered many challenges along their way including; floods, extreme heat, rough roads, broken trailers, bent wheels and quite a few punctures. But they have also encountered lots of generous people who have given them a meal and a place to stay, made a donation, and listened to their story and learnt a little about MND.

They are also enjoying spending time as a family and seeing the sights along the way.

While the family stopped in Darwin for a few weeks for Jozef and the kids to catch up on their studies, it also gave them a chance to improve their branding and they've now all got matching shirts and better signage to show any angry drivers why they are being held up by a family of four cyclists.

The family have also been getting quite a bit of media attention with radio, newspaper and television all giving them coverage along their journey. This has been a great way to raise awareness about MND in the wider public.

Since the Wolters started fundraising in January this year, they have raised over \$20,000 of their \$50,000 goal. You can donate through their fundraising page <https://give.everydayhero.com/au/one-year-on-our-bike>.

We encourage you to follow the family's inspiring ride on their Facebook blog and send them a message of support to help them keep on pedalling. If you are able to billet them on their journey you can get in touch via their Facebook page. www.facebook.com/oneyearonourbike/.



The Wolters Family and some highlights from their amazing journey so far.

NOT ALL HEROES WEAR CAPES

Since August 2017, Steve Beck has raised over \$12,000 for MND Queensland. On top of this great effort he's also raised additional funds for a range of other MND related projects. While he may not wear a cape, he's a hero to us.

We asked Steve why he has been so active in fundraising for MND Queensland.

"MND is a cause that is very close to me as my Dad passed away from this dreadful disease late last year, just four months after he was diagnosed. To see the terrible decline in his health and mobility was awful for our family as Dad was always such a healthy, bright, energetic person. Now, in my own way, I pay tribute to my Dad by doing what I can to help raise awareness about this disease, because like many people, I didn't really know much about it before it touched our lives, and secondly, to raise money for MND Queensland so that they can continue to provide their services such as support, information and equipment and also search for the cause and a cure for MND."

Steve has been very active over the last year helping to raise awareness and funds to help people affected by MND. He told us about some of the great work he's been doing.

"Some of the ways I've been involved in the fight against MND include, attending support group meetings, wearing all forms of MND awareness singlets at park runs (Fight MND, Run MND, MND and Me) running a fundraising boot-camp at Fitness Done Different in Greenslopes (raising over \$500 in 1 hour) doing Walk to D-Feet MND in Adelaide and in Brisbane, attending Neale Daniher's Freeze MND match between Melbourne and Collingwood at the MCG wearing the Big Freeze Beanies and posting all of these on social media."

MND Queensland is extremely grateful to Steve for his enthusiastic support and we applaud his efforts to help make a positive difference in the lives of people affected by MND. We only receive minimal Government funding and this runs out in June 2019, so people like Steve who



Super-fundraiser Steve Beck (right) pictured with his late father Brian (left).

fundraise for us are very important to the organisation's ability to provide quality support and services to people affected by MND.

When asked what words of encouragement he'd give others thinking about getting involved and making a difference, Steve said "You can make a difference too by entering to run in a marathon for MND Queensland, hosting your own event, or joining in on an event like the Walk to D-Feet MND."

You can be a hero for MND too by hosting your own event, or fundraising through events like the Bridge to Brisbane (which can be found on platforms like Everyday Hero and Go Fundraise). For more information or to chat about your idea and how we can support you to make it a success, contact our Fundraising and Communications Manager Jason Russo on 07 3372 9004 or email fundraising@mndaq.org.au.



Steve Beck in action! Pictured are just a few of the fundraising activities Steve's been involved in to raise money for Motor Neurone Disease.

WALK TO D-FEET MND BRISBANE 2018

The Walk to D-Feet MND Brisbane was held on Sunday 27 May and was a huge success with almost 600 people in attendance!

Walkers turned out in their hundreds to stroll around the beautiful Roma Street Parkland on a lovely cool morning. Thankfully the rain kept at bay right until the end of the day when the awards were being handed out.

The event raised over \$56,000 so that MND Queensland can continue our important work to make life a little easier for those affected by MND.

The Parkland was a sea of orange after everyone had put on their freshly designed t-shirts. It was also great to see some go to the extra effort of creating their own costumes and dressing up, or dressing up their dog.

Our highest fundraising team, Team Bailey, raised almost \$5,000! They were one of 13 teams who managed to raise over \$1,000! Our highest fundraising individual was Rod Loughheed who walked in memory of his late wife Annette.

The crowd was kept happy with coffee from The DNA Coffee Company (who donated \$160 from part of the proceeds they made on the day), the Lions Club of Brisbane Inner North filled everyone with sausages (and donated \$455 from the BBQ) and Jacko from Bay FM kept the crowd entertained with an outdoor broadcast.

We would like to thank everyone who participated, contributed, donated or volunteered to make the walk such a success. Watch our for the event again in 2019.





HOW A NEW IDEA ARTICLE STARTED MND QUEENSLAND

As we commemorate 35 years of support and services in 2018, we look back on our history and share with you the story of how the Association began.

Charles Graham was diagnosed with MND in 1981. It was a huge shock but it motivated him to try to discover as much as he could about this terrible disease. He was

frustrated by the lack of information available, until he read an article in the magazine New Idea.

The November 1982 New Idea article was about Ian Coates, a former VFL umpire who had MND. By reading the article Charles discovered that an MND Society existed in Victoria, so he wrote to them and joined the Society and this led Charles to begin considering how he could set up a similar society in Queensland.

Letters were sent to newspapers to announce that those interested could join a meeting at the Oxley CWA Hall on Sat 26 Feb 1983. Twenty-one people attended the meeting that day and when the meeting closed at midday, the Motor Neurone Society of Queensland had been born.

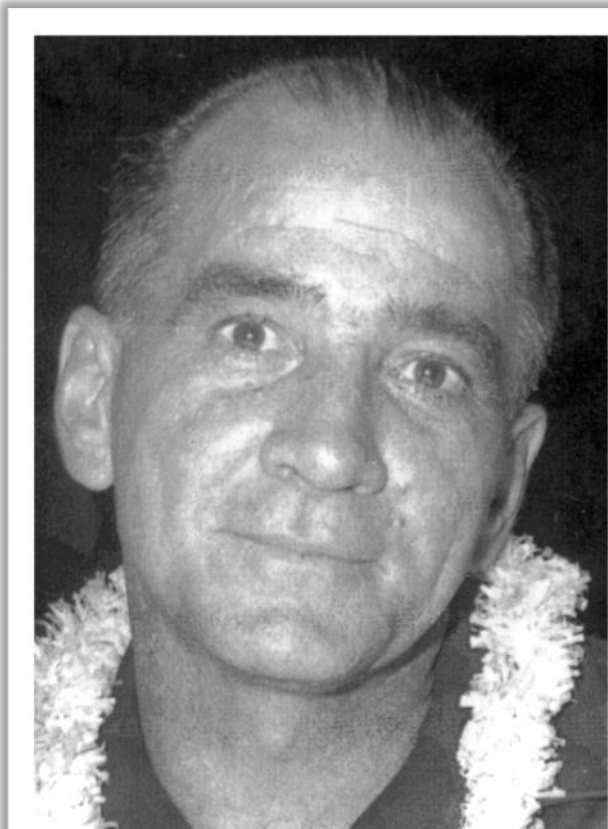
The meeting Chairman, John Wearne (who also became our first President) pointed out the need to bring MND to the attention of the general public and the government, as a means to raise funds to promote research in Queensland, and provide equipment for sufferers.

Our founders decided on the motto 'Hoping and Helping'.

Sadly, Charles Graham passed away on 11 July 1983, but his legacy lives on in the Motor Neurone Disease Association of Queensland.

Despite 35 years of effort, we still have a long way to go to raise awareness in the community (and government) and we still rely on fundraising activities to sustain our efforts.

We pay tribute to our founders and thank all of our past and present Board, staff and volunteers.



Pictured: Our founding father, the late Charles Graham.

THANKS TO TOOWOOMBA LIONS CLUBS

MND Queensland was the recent recipient of two major donations from Lions Clubs in Toowoomba. In April our Fundraising and Communications Manager Jason Russo was presented with a \$2,000 cheque by the Lions Club of Toowoomba West. Then in July we were gifted \$5,000 from the Lions Club of Toowoomba Wilsonton. Both clubs have lost members to MND and have an understanding of how devastating MND can be, as well as an appreciation of the support that MND Queensland provides. These donations, along with many others received recently from other service Clubs in response to our appeals mean a lot to us and we are very grateful to all of the Clubs across Queensland that support us.



Jason Russo receives the donation from Lions Club of Toowoomba West members.



Mary and Narelle Watchman pictured with two Wilsonton Executives

MEET OUR NEW EQUIPMENT OFFICER - RICARDO BRULE

We would like to introduce you to our new Equipment Officer Ricardo and hear from him a little about this important service provided by MND Queensland.

Tell us a bit about your background and your experience of working with medical aids.

I completed a Biomedical Engineering Degree which saw me specialise in healthcare technologies. When I finished that degree, I worked for a company that sells medical equipment in Chile where I'm originally from. After three and a half years there, I moved on and started working for an operating theatre unit in one of the seven biggest hospitals in the country. I worked there for a year and a half before coming to Australia to study on a scholarship.

Can you tell our readers a little bit about the MND Equipment Service?

Along with our Advisory Service, it's one of the two main services that we provide, and it's highly utilised. At the moment we have 411 pieces of equipment out on loan.

Our equipment ranges from patient hoists to wheelchairs – manual and electric – hospital beds, and communication devices such as eye-gaze machines.

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

I enjoy the fact that my job involves creating tangible support for people with a terrible disease. I like to know that my work is helping people live a better quality of life. We're filling a gap where people don't get help for this type of situation.



Compared to my experience of working in the commercial sector for companies that make a lot of money selling medical equipment, my success working at MND Queensland isn't related to profit, but the benefit of clients and the burden that you help to alleviate.

I'm glad to be a part of a structure that helps people suffering from this disease because I feel useful and feel like I'm doing something that matters!

"I feel useful and feel like I'm doing something that matters!"

At the moment we just charge an affordable one-off fee that covers the equipment loan. However, this fee barely covers the delivery and collection costs, let alone warehousing, maintenance and service coordination. Without the support of our donors, the equipment service wouldn't be possible or we would have to charge much higher rates.

Presently, I'm working Tuesdays and Thursdays each week and I have to fit a lot into this time. I have to coordinate the delivery and collection of the equipment, repairs, and answer queries from clients, occupational therapists and allied health workers as well as keep our equipment register up-to-date.

What have you learnt about MND since working at MND Queensland?

That it's a random, cruel disease. Last month one of our clients passed away and she was about my age (33). It felt so close, so real, something that could happen to anyone.

What would be one piece of advice you could give to people to help streamline their access to our equipment service?

The main advice would be as soon as they get diagnosed, they should register with MND Queensland, so as soon as they need equipment, the process will be easier and take less time. Also, clients need to have a referral from an Occupational Therapist or Allied Health worker to access our equipment service.

YOU CAN MAKE A POSITIVE DIFFERENCE IN THE LIVES OF PEOPLE WITH MOTOR NEURONE DISEASE

How? It's easy... You might have an idea for your own fundraising event or activity, or you might prefer to get involved with an existing event like a marathon or fun run, you could host an event like Drink Tea for MND, volunteer for an event like a Walk to D-Feet MND, or organise a work raffle or school gold coin event. Get in touch with our Fundraising & Communications Manager to discuss your idea and find out how we can help you make it a success.

Contact Jason Russo, fundraising@mndaq.org.au or 07 3372 9004

WHAT'S ON

16 Sept - Walk to D-Feet MND Toowoomba, 9AM Queens Park Botanic Gardens. Register on the day or at www.mycause.com.au/events/walk2dfeetmndtwb

26 Oct - 5:30PM - 8:30PM, Allan Cooney Art Exhibition fundraising for MND Queensland at the office of Creevey Russell Lawyers, 580 Ruthven St, Toowoomba

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: Cairns North – Community Health (Bayoo Room) 381 Sheridan St, Cairns North

Frequency: 19 September, 31 October

Time: 10:00AM to 12:00PM

RSVP: Anne Kavanagh, Anne.Kavanagh@health.qld.gov.au, 07 4426 4481

TOWNSVILLE

Location: Kirwan Health Campus, 138 Thuringowa Dr, Kirwan

Frequency: 19 September, 31 October

Time: 10.30 AM to 12.30 PM

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

MACKAY (proudly sponsored by Rio Tinto)

Location: Magpies Sporting Club, Glenella Road, Glenella.

Frequency: 13 November (TBC)

Time: 10am - 12pm

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

BUNDABERG

Location: Cafe 1928, 6 Mount Perry Road Bundaberg

Frequency: 29 October

Time: 10:30AM to 12:30PM

RSVP: Mark Whitley, mark@mndaq.org.au, 0450 212 010

HERVEY BAY

Location: TBA

Frequency: 26 November

Time: 11.00 AM to 1.00 PM

RSVP: Mark Whitley, mark@mndaq.org.au, 0450 212 010

SUNSHINE COAST (in partnership with MND & Me)

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

Frequency: 9 October

Time: 10.00 AM to 12.00 PM

RSVP: Eirlys Pijpers, eirlyspijpers@mndaq.org.au, 07 3372 9004

BRISBANE NORTH & CABOOLTURE (carer support & fundraising)

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

Frequency: Held the 4th Saturday of every month (except Dec)

Time: 9:30AM to 11:30AM

CONTACT: Graeme & Liz Holyer 0458 021 783

NORTH BRISBANE (in partnership with MND & Me)

Location: Chermide Library, 375 Hamilton Road, Chermide

Frequency: 11 September, 13 November

Time: 10.00 AM to 12.00 AM

RSVP: Eirlys Pijpers, eirlyspijpers@mndaq.org.au, 07 3372 9004

SOUTH BRISBANE (in partnership with MND & Me)

Location: 5/28 Cavendish Rd, Coorparoo

Frequency: 4 October, 1 November

Time: 10:00AM to 12:00PM

RSVP: Eirlys Pijpers, eirlyspijpers@mndaq.org.au, 07 3372 9004

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

Location: Wolston Park Golf Club, Ellerton Dr, Wacol

Frequency: 20 September, 18 October, 15 November

Time: 10:00AM to 12:00PM

RSVP: Eirlys Pijpers, eirlyspijpers@mndaq.org.au, 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, next on 13 October

Time: 1:00PM to 3:00PM

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

MND QUEENSLAND DONATION FORM - SPRING NEWSLETTER

I would like to donate: \$.....(write amount)

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

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

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