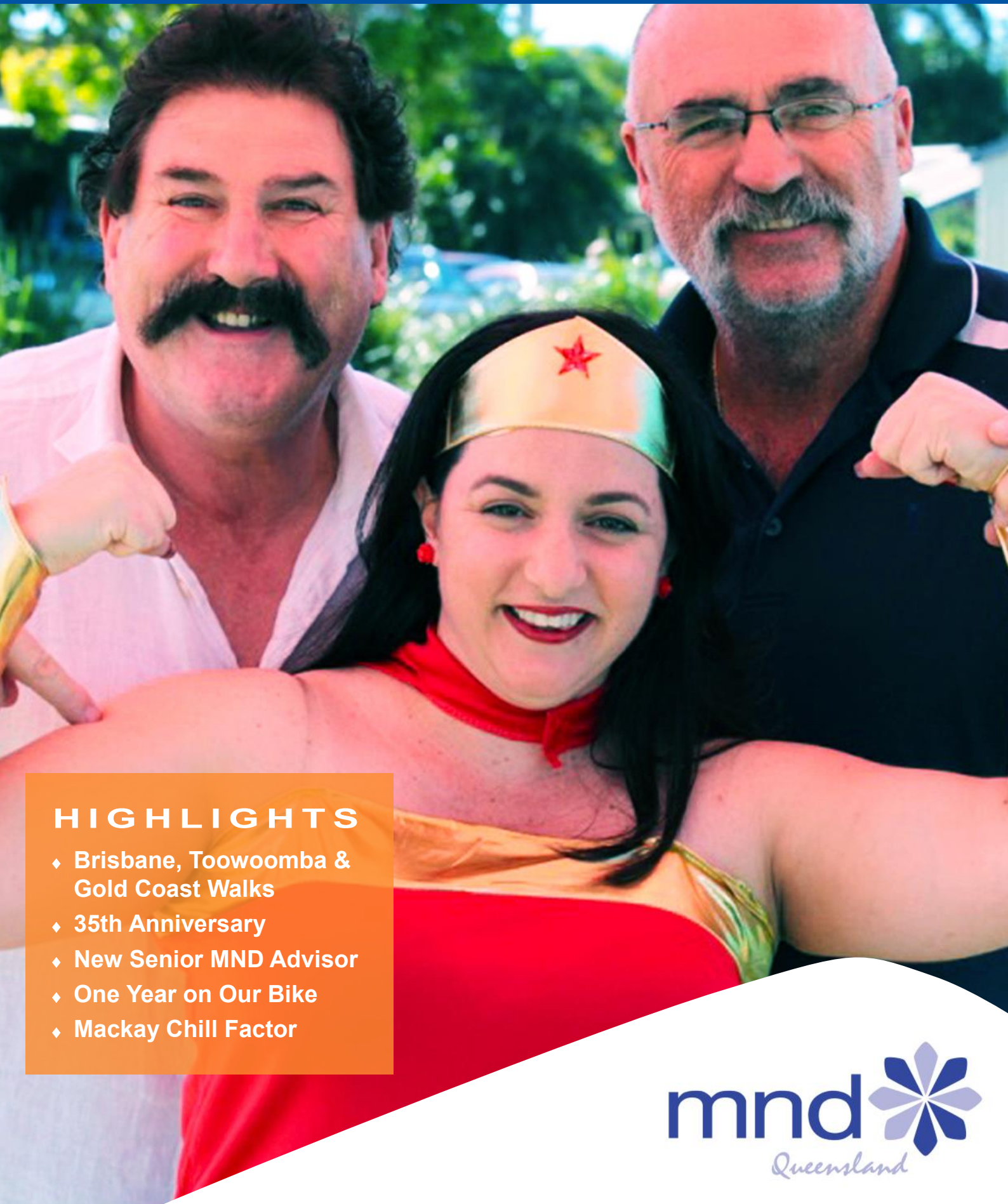


AUTUMN 2018 ISSUE

the cornflower

MOTOR NEURONE DISEASE ASSOCIATION OF QUEENSLAND NEWSLETTER



HIGHLIGHTS

- ♦ Brisbane, Toowoomba & Gold Coast Walks
- ♦ 35th Anniversary
- ♦ New Senior MND Advisor
- ♦ One Year on Our Bike
- ♦ Mackay Chill Factor

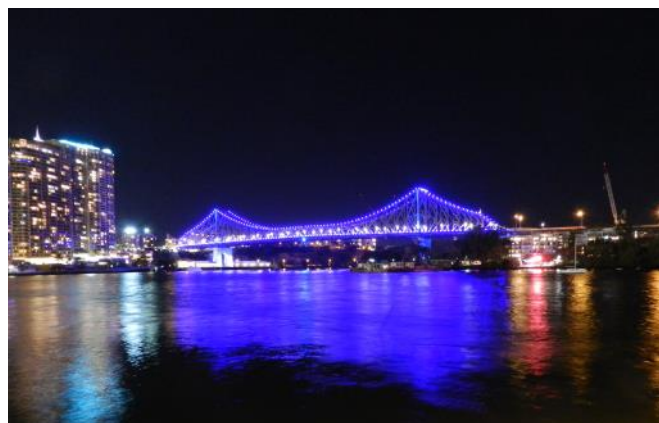
MND AWARENESS WEEK 2018

MND Awareness Week 2018 falls between Sunday 6 May to Saturday 12 May and Blue Cornflower Day will be on Friday 11 May.

In Brisbane, we'll have the Story Bridge, Reddacliff Place and Victoria Bridge lit up in blue on Monday 7 and Tuesday 8 May. If you're in Brisbane, we encourage you to go and have a look at these Brisbane icons lit in blue and take photos and post them on social media with the hashtag #MNDAwarenessWeek.

YOU CAN HELP US RAISE AWARENESS AND FUNDS DURING MND AWARENESS WEEK!

You might want to have a Drink Tea for MND event, host a gala ball, or come up with your own unique idea! If you're thinking about doing something for MND Awareness Week, pitch us your ideas so that we can help in any way we can. Give Jason Russo, our Fundraising and Communications Manager a call on 07 3372 9004 or email fundraising@mndaq.org.au. You can also



check out our website for more ideas
www.mndaq.org.au/Get-involved/Become-a-supporter.

This is a great chance to put the MND Queensland brand and cause in front of the general public and raise our profile, and much needed funding. We look forward to helping with your creative ideas.

MND QUEENSLAND CELEBRATES 35 YEARS OF SUPPORT IN 2018

CONTACT US

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Email: info@mndaq.org.au

Phone: 07 3372 9004

Freecall: 1800 777 175

Fax: 07 3278 9871



SOCIAL MEDIA

Facebook: www.facebook.com/MNDAQ

Walk to D-Feet MND: www.facebook.com/Walk2DFeetMNDQLd

Twitter: twitter.com/MNDQueensland

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.



WELCOME NEW MND QUEENSLAND CEO - LISA RAYNER



Since commencing as CEO for MND Qld in late 2017 the passion I had already developed for people living with MND and their families has continued to grow.

Reading about the disease is one thing, but speaking to clients, carers and family members who are bravely facing the challenges of MND is not only a learning experience but an inspiring one. Visiting Mackay and meeting clients at the first Mackay Support Group, being on call over the Christmas break, and meeting people at our Walk events has contributed to my understanding of what families are facing and giving me the ideas that wake me up at night!

We hope to provide additional support as the year progresses, and already we have planned new support groups in the Burdekin region, with some special information sessions in Brisbane to come soon. These sessions will provide additional support for carers, and family and friends struggling with the shock of the diagnosis and potential loss of a loved one. A session for those who have been recently diagnosed will also be held later in the year.

This is the start of a renewed and very supportive year for our deserving clients, which also includes the

appointment of a new Senior MND Advisor Eirlys Pijpers. Eirlys comes to us from the Netherlands, which is highly regarded in the health sector, and brings extensive qualifications and experience working with people with MND. You can read more about Eirlys in our Staff Profile section, and I encourage you to call her if you have any needs or queries, and if you are in Brisbane or surrounding areas you can also organise a home visit.

The NDIS began rolling out in some regional centres last year and has now started to roll out in South-East Queensland. Our National Office prepared a submission to the NDIA about issues and improvements needed based on feedback provided through our State Offices, and this advocacy will continue. We are keen to hear your feedback so please get in touch or pass on your thoughts to your Advisors so we can work to ensure the system works for you.

In order to deliver our services fundraising activities are crucial and we are extremely grateful to our donors and supporters, especially those who run significant events on our behalf. One such event was the Chill Factor Challenge and MND Ball in Mackay – with funds raised contributing to extra support groups in the area. This event was a shining example of what can be achieved when you have community and corporate support working with a charity to help people in their own community.

Thank you to all those who support us and we look forward to looking after clients and their loved ones even better with your help.

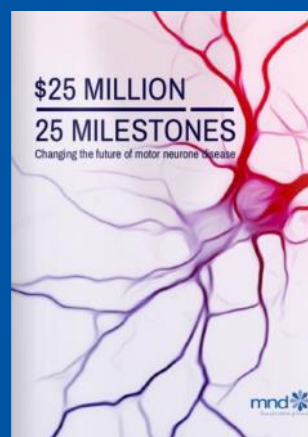
RESEARCH UPDATE

\$25 MILLION, 25 MILESTONES: CHANGING THE FUTURE OF MND

While there is still much to learn about MND, understanding of this complex condition globally has transformed over the last decade. The MND Research Institute of Australia (MNDRIA) has played an integral role in this transformation. More than \$25 million has been invested in Australian health and medical research over 30 years.

\$25 Million, 25 Milestones details the 25 high-impact MNDRIA-funded advancements, which are helping to change the future of MND and bringing hope to people living with MND. To read more visit:

[www.mndresearch.org.au/Discover-our-research/\\$25-Million,-25-Milestones-Changing-the-future-o.aspx](http://www.mndresearch.org.au/Discover-our-research/$25-Million,-25-Milestones-Changing-the-future-o.aspx)



MACKAY CHILL FACTOR CHALLENGE & BLUE TIE BALL

Early last year Kathy Carlsson was inspired to raise funds for Motor Neurone Disease after a family friend passed away from the disease. Kathy and partner Noel Lang, and their football club Magpies Mackay AFC planned a spectacular fundraising day to raise awareness and funds to support people living with the condition – and the Chill Factor Challenge and MND Blue Tie Ball was born!

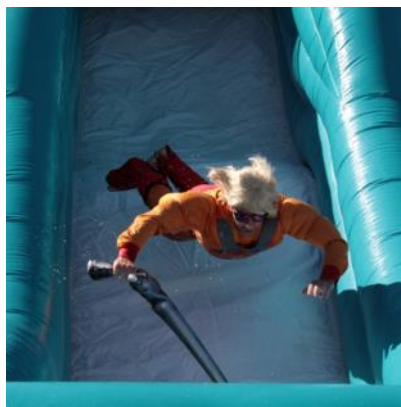
The first big supporter was Rio Tinto Hail Creek Mine providing the strong commitment to the local community for which Rio Tinto is known. They contributed initial dollars to help kick-off the event and fund extra local services for people with MND. Magpies Sporting Club, Star 101.9FM and the local Mayor Greg Williamson also got on board followed by a swathe of local identities and businesses who were invited to register and get sponsored for

taking a giant slide in chilly water into a pool of ice!

The Chill Factor was held in July on a Magpies Home Game Day, and was a huge success with participants raising thousands of dollars, donning crazy costumes and braving the icy slide.

Over-achiever and all-round good bloke Mick Scholer took out the award for highest fundraiser with support from family and friends. At the top of the list were also the five gutsy Rio Tinto mine managers who kept us amused with their antics, and impressed by the money collected from miners at the four Hail Creek Mines.

To add to the excitement of the day sporting larrikins Merv Hughes and Robert “Dipper” DiPierdomenico joined in the commentary and generally added to the fun of the day.



Merv & Dipper were also special guests at the MND Blue Tie Ball that night - a glamorous event to top off a fun day.

The Ball was a chance for supporters of the event and Mackay locals to dress up, kick back and enjoy an evening of food, wine, dancing, and a chance to win some great prizes plus enjoy the company of Merv Hughes and Dipper.

The Ball was held at Magpies Sporting Club and Merv and Dipper took to the stage for a Q&A recounting both serious and humorous tales of their eventful lives in the sporting spotlight. They mingled with guests and gave out multiple prizes that had been donated for the raffle and auction.

Thank you to all the prize sponsors, Chill Factor participants and their companies and supporters, merchandise sellers, and of course Kathy & Noel Carlsson and Magpies Mackay AFC.

More than \$32,000 was raised to support people with Motor Neurone Disease and their families across Queensland and in the Mackay region where those affected will now receive additional services.

You can read about the award presentation and Mackay support group on Page Seven as well as latest news about Chill Factor 2018!



Get your new 2018-2019 Entertainment Book now to start your savings & support MND Queensland!



The books contains hundreds of great offers that can save you thousands! There are books for Cairns, Townsville, Brisbane or the Gold Coast, and you can even purchase interstate books for a gift or to save while you are visiting on holidays! The books are only available by mail order, online at:

www.entertainmentbook.com.au/orderbooks/2221j21

A YEAR ON OUR BIKE - FAMILY OF FOUR RIDE FOR MND

Jozef and Diana Wolters, along with their two children Jack (12) and Cloe (13) have sold their home and business and left their old lives behind to ride around Australia on their bicycles to raise awareness of, and much-needed funds for MND.

Sadly the family were touched by MND when Jozef's father Jack tragically died of the disease last year.

Diana said "We are doing this to raise funds for MND as in July last year we lost Jozef's father to this horrible disease. Watching him slowly lose all ability to use his body, but be fully sound of mind was one of the hardest things our family had to endure."

The family set off on their epic ride from Bundaberg on January 28. The first leg sees them travelling north to

tropical Cairns.

They have had a sometimes challenging journey with all of the rainy weather in North Queensland recently. Several flat tyres, snapped tent poles and broken trailer joints are just a few of the other obstacles they have endured, but they are also enjoying the freedom of being on the road and the people they are meeting.

The Wolters have a goal of raising \$50,000 through their ride for MND Queensland through their fundraising page <https://give.everydayhero.com/au/one-year-on-our-bike>.

You can follow the family's inspiring ride on their Facebook blog and contact them through the page if you are able to billet them on their journey www.facebook.com/oneyearonourbike/.



The Wolters Family, L-R Jozef, Diana, Jack and Cloe. Photo credit News Mail.

WALK TO D-FEET MND BRISBANE
Sunday 27 May 2018 - Roma Street Parklands
To register visit www.mndaq.org.au OR www.facebook.com/Walk2DFeetMNDQld





MACKAY SUPPORT GROUP & PRESENTATION

One of the most satisfying outcomes of the Chill Factor Challenge & MND Blue Tie Ball in Mackay in July was our increased ability to support clients in Mackay.

A cheque presentation event was organised in October which was attended by CEO Lisa Rayner, the organisers, participants, and a strong contingent of Rio Tinto representatives who were a huge part of the success. The Presentation was followed by an afternoon tea which led into the first Support Group funded by Rio Tinto and the Chill Factor.

Clients and families past and present were invited to attend the presentation, and supporters and sponsors were able to meet some of the people affected by MND and see first-hand why the funds raised are so important. Everyone was touched by a poignant video of a local, recently diagnosed client, lovingly made by his daughter, a video production student.

Organisers Kathy Carlsson & Noel Lang on behalf of Mackay Magpies AFC presented MND Qld with a cheque for \$32,127 – an incredible effort! In appreciation, CEO Lisa Rayner presented etched “ice shard” trophies to Kathy & Noel and Magpies AFC, and major sponsors Rio Tinto, and certificates to other sponsors and winning partici-

After a lovely afternoon tea, the first Support Group commenced, facilitated by our North Qld Advisor Sharon Edwards, and the high attendance included local allied health professionals.

Existing clients and families attended plus a new client, diagnosed in New Zealand but who had recently moved to the area. He was not aware of MND Qld until a neighbour dropped a flyer into his letterbox, and will now be able to access our support when needed.

A 2nd support group has just been held - well attended with more to come later in the year. Thank you to Magpies Sporting Club for sponsoring not only the main event but both these support groups through discounted venue costs.

We have more exciting news – the Chill Factor has won the Rio Tinto Partnership Award for best partnership of 2017! Congratulations and thank you to all who made this possible. AND Rio Tinto along with WorkPac have already committed funds for this year. We are excited about the 2018 events and plan to change it up, so look out for more details soon!

RioTinto



2017 WALK TO D-FEET MND - TOOWOOMBA AND BRISBANE

We are pleased to report that the Brisbane and Toowoomba Walk to D-Feet MND events were held in 2017 and both were great successes!

The Toowoomba community were passionate about raising funds for Motor Neurone Disease and almost 200 people turned out to walk at Queens Park on Sunday 30 April 2017. Toowoomba walkers raised around \$15,000 for MND Queensland.

Brisbane's walk quickly followed the next weekend on Sunday 7 May at the Roma Street Parklands. More than 509 walkers turned out for a great day that saw the Gasoline

Alley HOGS lead the walk. Over \$53,000 was raised from the event by our wonderful walkers.

Many thanks to everyone who participated in these walks and everyone who donated. We look forward to seeing you all again in 2018. Keep an eye on our website or Facebook for upcoming dates.

NEWSFLASH!

The Walk to D-Feet MND Brisbane will be held on Sunday 27 May 2018 at the Roma Street Parklands. Registrations open soon. Check our website.



WALK TO D-FEET MND GOLD COAST 2018

The Walk to D-Feet MND Gold Coast was held on Sunday 4 March at the gorgeous Gold Coast Regional Botanic Gardens and was a great day out with fantastic fundraising success!

With the threat of an early storm passing we were lucky that it turned out to be a lovely day that attracted 230 walkers who completed either the 2km or 3km course. Many people filled in the fun botanical quiz along the route for their chance to win a prize.

The Lions Club of Burleigh Heads ran a sausage sizzle on the day and also sold our chilled MND bottled water. All profits from the BBQ were donated to MND Queensland.

We were also lucky to have the Coffee at The Gardens

van there on the day to energize our walkers and they also donated 10% of their takings from the day to MND Queensland.

At the time of writing, the Gold Coast walk has raised over \$25,500 with more money expected to come. This is a fantastic effort and far surpassed our goal of raising \$20,000!

We would like to congratulate all of our walkers on a great effort and thank your wonderful donors for supporting MND Queensland. Thanks also go to our fantastic volunteers. With your support we hope to grow the event in 2019!



MND QUEENSLAND - 35 YEARS OF CARE AND SUPPORT IN 2018

In 2018 MND Queensland reaches the milestone of 35 years of operation. That's 35 years of providing information, advice, care and support to thousands of people with MND and their families.

Since our beginnings, MND Queensland has grown to offer services right across the State. We are the leaders in MND care and support and we strive to continue to provide quality services into the future.

We have also supported research into the cause of MND, and a cure. We sincerely hope that our organisation becomes obsolete within the next 35 years when a cure for

MND is finally found.

None of this would have been possible without the support of people like you who have donated, attended events, or fundraised on our behalf, so thank you for your ongoing support.

We are also proud to announce that the **North Brisbane and Caboolture MND Support Group** turns 25 in 2018! The group still has three of its original founding members! We are glad to be able to support this group that has done so much for so many families.



Pictured: Left, One of our founding members Shirley Graham, wife of the late Charles Graham and their daughter Lesley Taylor (right).

MND QUEENSLAND AGM SAVE THE DATE Saturday 23 June

Mark your calendars for MND Queensland's Annual General Meeting which is set for 10AM Saturday 23 June 2018. Come early for morning tea and a chance to meet other members.

Formal notice will be sent to members soon. Stay up-to-date on all of our news and events on our Facebook page.
www.facebook.com/MNDAQ

THANKS TO GASOLINE ALLEY HOGS

MND Queensland was recently the fortunate beneficiary of a generous \$5,500 donation from the Gasoline Alley Harley Owners Group! We attended their meeting to receive the donation and also presented them with a medal to thank the group for their years of wonderful support.



CEO Lisa Rayner receives the donation from HOGS Assistant Director Maverick.

MEET OUR NEW SENIOR MND ADVISOR - EIRLYS PIJPERS

Eirlys recently joined the MND Queensland team from the Netherlands in the position of Senior MND Advisor and will be responsible for overseeing all of our client services in Queensland. She looks forward to meeting clients and families in the near future.

Tell us a bit about your previous experience working with people with MND?

I've been working with clients with MND for about three years as an Occupational Therapist, as a part of a multi-disciplinary rehabilitation team. Our department was acknowledged by the Dutch patients' association for neuromuscular disease as a specialised department. This included MND amongst other diseases. About half of my time at work was dedicated to patients with MND. Visiting them at home, seeing them in the rehabilitation department and making contact with other health care professionals in terms of advice and equipment and referrals.

What qualifications do you bring to the position?

I first studied a Human Movement Sciences degree and went on to do my Masters in that field. My Masters was specialised in rehabilitation and motor recovery. After that I realised I did not want to be a scientist and started to study a Bachelor of Health in Occupational Therapy. I received my degree in 2013 and have been working as an Occupational Therapist until I came to Australia a few months ago.

How did you end up finding MND as your particular area of professional interest?

It was a coincidence! I applied for a job in a rehabilitation centre in a Rotterdam hospital where one of the key areas was neuromuscular disease. When I started there I mainly saw patients with other conditions, but fairly quickly, I started working with people with MND.

Because MND is such a complex disease, new staff needed to show competency before working more directly with patients with MND. I found working with people with MND interesting and extremely rewarding and ended up specialising in this area.

What do you think is the biggest difference in regards to care and support for people with MND in Australia compared to your overseas experience?

I think that the distances in Australia are the main difference. The Netherlands is quite a small country that is highly populated, so distance seems to be a challenge in Australia. In Australia it is hard to get a specialised team focussing on MND because there are not enough clients



in one specific area.

Another big difference is that the health care and social security systems work totally differently, which impacts on a lot of aspects related to MND.

I'm interested to see whether the NDIS will improve the situation for clients in Australia.

Where do you see things heading for MND Queensland?

Maintaining our role as the leading agency in Queensland with the most specialised knowledge of MND. We can utilise this knowledge to inform both clients and health care professionals and raise awareness on the complex health care needs of people with MND.

I also hope to grow our equipment service so we can serve more of our clients. I see opportunities to expand our equipment service under the NDIS.

What is it about the sector that draws you to work with people with MND and their families?

I like the challenge of working with complex needs and the reward it gives me when I see people really appreciate the help. Clients with MND and their families go through a stressful time facing both the emotional challenge of coping with the uncertainty of the future and also needing to navigate and manage the health care system to meet their current needs. I find it personally satisfying knowing that my assistance can take away some of the worries that clients and families have.

What inspires you?

Meeting different people, and learning from them. It amazes me how much resilience people with MND and their families show. This is truly inspiring!

"I find it personally satisfying knowing that my assistance can take away some of the worries that clients and families have."

WHAT'S ON

NORTH BRISBANE AND CABOOLTURE SUPPORT GROUP ANNUAL FASHION PARADE FUNDRAISER – 2PM on 21 April at Burpengary Community Hall with afternoon tea included.

NORTH BRISBANE AND CABOOLTURE SAUSAGE SIZZLE – on 23 and 24 June you can catch volunteers at the Lindmar Open Garden, 130 Blewars Road, Morayfield. Phone Liz for more information on 0458 021 783.

MND SUPPORT GROUPS

Are you living with 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: Every fourth Wednesday
Time: 10:00AM to 12:00PM
RSVP: Anne Kavanagh 07 4426 4481 or 0400 739 674

TOWNSVILLE

Location: Kirwan Health Campus, 138 Thuringowa Dr, Kirwan
Frequency: Every six weeks, contact Sharon for dates
Time: 10:00AM to 12:00PM
RSVP: Sharon Gray, sharon@mndaq.org.au or 0424 408 657

MACKAY (proudly sponsored by Rio Tinto)

Location: Magpies Sporting Club, Glenella Road, Glenella.
Frequency: next group Tues 10 July – more 2018 dates TBA
Time: 10am - 12pm
RSVP: Sharon Gray, sharon@mndaq.org.au or 0424 408 657

BUNDABERG

Location: YMCA Take the Plunge Community Café, 7 Quinn St, Kepnock (off Elliott Heads Rd)
Frequency: Mon 30 Apr, Mon 25 Jun
Time: 10:00AM to 12:00PM
RSVP: Mark Whitley, mark@mndaq.org.au or 0450 212 010

ROCKHAMPTON

New info sessions & support groups coming soon!

GLADSTONE

Frequency: Mon 15 Apr, Mon 16 Sept
Time: Info session at 10:00AM, Support Group at 12:30PM
Location & RSVP: Contact Mark Whitley, mark@mndaq.org.au or 0450 212 010

MARYBOROUGH

Frequency: Mon 25 March, Mon 27 May, Mon 27 July
Time: 10:00AM to 12:00PM
Location & RSVP: Contact Mark Whitley, mark@mndaq.org.au or 0450 212 010

GYMPIE

Frequency: Mon 3 June, Mon 7 October
Time: Info session at 10:00AM, Support Group at 12:30PM
Location & RSVP: Contact Mark Whitley, mark@mndaq.org.au or 0450 212 010

BRISBANE NORTH & CABOOLTURE

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

SOUTH BRISBANE (in partnership with MND & Me)

Location: 5/28 Cavendish Rd, Coorparoo
Frequency: Thurs 5 Apr, Thurs 3 May, Thurs 7 June, Thurs 5 July
Time: 10:00AM to 12:00PM
RSVP: Paul Olds, services@mndandme.com.au, 07 3394 5333

IPSWICH (in partnership with MND & Me)

Location: Ipswich Central Library, Cnr East & South Sts, Ipswich
Frequency: Thurs 19 Apr, Thurs 17 May, Thurs 21 June
Time: 10:00AM to 12:00PM
RSVP: Paul Olds, services@mndandme.com.au, 07 3394 5333

GOLD COAST (sponsored by Maylake Pty Ltd)

Location: Gold Coast Business Hub, Level 2 "Kay House", 35-39 Scarborough Street, Southport
Frequency: Bi-monthly, 14 April, 9 June, 11 Aug
Time: 1:00PM to 3:00PM
RSVP: Lorraine on 0408 661 212 or Dianne on 0411 742 265

MND QUEENSLAND DONATION FORM

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

Alternatively, if you are using a credit card you can call us on 07 3372 9004 or donate online at www.givenow.com.au/mndaq