

SUMMER 2021/2022 ISSUE

the cornflower

MND QUEENSLAND NEWSLETTER

The Glitz & Glamour of JoJo's Glitter Gala

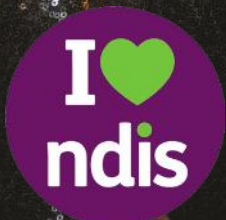
New Fleet Vehicles

Fight MND Equipment Grant

Life Stories Program

Meet Lisa - Client Services Manager

REGISTERED
PROVIDER



MND QUEENSLAND BOARD UPDATE - NEW PRESIDENT

Dear Staff, Clients and Members

I wish to advise you that I have found it necessary to resign my position as President of MND Queensland. Since accepting nomination to the Board in June 2020, I have also taken up an executive position for a national private aged care provider and moved interstate. The challenges of managing COVID and changes coming from the Aged Care Royal Commission recommendations have seen my capacity to invest the time required in MND Queensland diminished.



Pictured: (L-R) Former President Gaylene Coulton and current President Diana Melham.

The MND Queensland Board has unanimously supported Diana Melham, currently a Director on our Board, to accept the role of President and Board Chair until the AGM in the first half of next year. I am grateful for Diana's willingness to assume this responsibility and supported by a strong skill based Board I am confident that MND Queensland will continue to excel in its service delivery and support for the MND community in Queensland.

It has been an honour to represent such a committed team of people as our staff, and with the base laid by Ian as our current CEO and with the drive of Stacey as she steps into the new CEO role later this year, I will watch with excitement as a member of this Association in the years ahead. Thank you for the privilege of allowing me to serve.

Kind regards

Adjunct Professor Gaylene Coulton

CONTACT DETAILS & SOCIAL MEDIA

MND QUEENSLAND

ABN: 75 990 922 939

Street Address: Unit 1, 89 Factory Rd, OXLEY QLD 4075

Postal Address: PO Box 470, INALA QLD 4077

Web: www.mndaq.org.au

Email: info@mndaq.org.au

Phone: 07 3372 9004

Freecall: 1800 777 175



SOCIAL MEDIA - Please follow us and 'like' and share our posts

Facebook: www.facebook.com/MNDAQ

Walk to D-Feet MND: www.facebook.com/Walk2DFeetMNDQLD

Twitter: twitter.com/MNDQueensland

Instagram: [@mndQLD](https://www.instagram.com/mndQLD)

Linked In: www.linkedin.com/company/4869077

YouTube: www.youtube.com/channel/UCf5MA4DA7qGU7BThP9Pg-Cg

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.

Cover photo and page seven photos courtesy of Mark Button Photography www.markbutton.com.au



FROM THE CEO'S DESK - MERRY CHRISTMAS AND GOODBYE

My last Cornflower article as CEO. Retirement beckons. Time to catch up on the aspects of life that have been parked while in the workforce. It is an exciting time for me as plans are made for the next chapter and sad times as I say goodbye to an amazing team. I have been honoured to learn and grow in this role, to meet the heroes and champions (more of that later) and to gain a new perspective on life... taught to me by those whose diagnosis steals their life away.



My time here has been a leadership in service; for instead of the team of people here working for me, I have felt the responsibility of working for them... so they can work for you. Now back to these heroes and champions... I have felt and told many people with MND how they inspire me and it's true but I listened as one gentleman grumped that it really brashes him off to hear people say that about him because he doesn't feel inspiring, and everything he does, like just keeping on, and getting by... 'it isn't inspirational... It's normal... its what you do if you have MND!' And recently a great lady with MND was heard to say about this, that she wasn't special... (when everyone around her thinks she is), and that everyone can push on, make the most of the time they have, and be real. And so my 'near-to-retirement' brain has thought about this and I wonder if the rest of us who work with or observe the MND journey in those we love, see these lessons as belonging to others. Being inspired isn't just to feel admiration for someone else, it is to become motivated to do something different with your own life because of the lived examples they present while they are being "ordinary" and "normal".

My takeaway is that the example of people with MND has made me more conscious in how I live my life, how I spend the time I have. Thankyou.

I can reflect on where we have come from as an organisation over the last two years and feel confident that MND Queensland has a future and choices ahead of it that it did not have previously. Our team has grown, our service delivery has grown, our reputation has grown, our asset base and our premises have grown. We now deliver more services to more people with MND in more places and more often than ever before and this has been made possible, by the amazing team gathered here now. All of us need to remember that to be where we are today, we stand on the shoulders of those who have

gone before us... as we approach 40 years of service. There are volunteers and Board members, staff and community members who have come and gone over the years even during my time, and they have given so much of themselves to the cause... way beyond anything that could have been asked of them. Thankyou.

To our donors who have supported us through some very tough times, and our volunteers who keep showing up with their smiles and their good hearts... Thankyou.

To my Staff and my Board of Directors who have upheld me and kept the dream alive over the last two years, Thankyou.

To Stacey, to whom I am delighted to pass the baton of leadership, I know that the organisation is in expert hands to continue the dream. May the gifts that I have received in leadership of this great organisation be there for you and may you discover so many more.

Christmas is nearly here and with it hopefully a time for 'RE-gathering' of families, 'RE-union' with friends and a celebration of life that only exposure to this dreadful disease can teach us. May you all harvest many moments of joy in this season of good will that exists between the year that has been and the year that approaches.

So blessed, so grateful

Ian Landreth
Chief Executive Officer



MOTERING ON FOR MND - NEW FLEET VEHICLES PURCHASED

As MND Queensland has grown, so too has our need to be mobile. Our expanding team have been sharing one common fleet vehicle which has been in high demand. Our Equipment Service was also in need of a new delivery van. Thanks to a generous donation plus a grant, we've been able to add three new vehicles to our fleet and are now even more able to service Queenslanders with MND.

In 2019 the service we used to warehouse and deliver our vital equipment went out of business forcing us to rethink how we ran the service. We brought the service in-house and thanks to a donation of a passenger van with wheelchair lift, we were able to get our equipment out to those in need. But this van wasn't purpose built to be loading and unloading pieces of large, heavy equipment, so we had to find a better solution.

Along came Commercial Mine Recyclers (CMR) who are based in Mackay. The team at CMR saw one of our client stories late last year and wanted to know how they could get involved and help make a positive difference in the lives of people impacted by MND. CMR gladly made a major donation to MND Queensland which allowed us to purchase a new LDV delivery van which we've recently had wrapped with our branding which includes our distinctive blue cornflower emblem.

In the last two years our team has grown to include three Support Coordinators, two Occupational Therapists and a Speech Pathologist who along with our fundraising team needed to be



mobile and this was getting tricky when we only had one vehicle to share. We applied for a Gambling Community Benefit Fund grant and were successful in securing funding to purchase two new Kia Picanto hatchbacks which we've also recently branded.



We're sincerely grateful to the team at Commercial Mine Recyclers in Mackay for your generous donation which is going to make delivering essential equipment to people with MND much easier.

We also appreciate the wonderful support of the Gambling Community Benefit Fund as we wouldn't have been able to purchase these vehicles without their support.

Give us a wave if you see us out and about.



NEW EQUIPMENT ADDED TO OUR POOL THANKS TO FIGHTMND

FightMND are amazing at increasing awareness about MND through their annual Big Freeze and beanie campaigns. The organisation has raised millions for MND research over the years and they have also supported MND Queensland through providing grants for equipment purchases. We were very fortunate to recently win a grant of over \$400,000 from FightMND to help us provide vital equipment to people impacted by MND.

In 2021 FightMND has awarded \$2.3M to Australian organisations providing equipment to people impacted by MND. Since 2017 they have invested \$6.9M into care initiatives to help improve the lives of Australians living with MND and over the last five years FightMND have provided over \$1M in funding for care equipment for Queenslanders impacted by MND.

FightMND CEO Dr Fiona McIntosh said the importance of providing funding for the ongoing care of people with MND remains a focus for the organisation.

“In funding vital care equipment, FightMND is able to help improve the lives of those people currently living with the disease and assist them to live as independently as possible, for as long as possible,” Dr McIntosh said.

“We are proud to support the work of our MND allies, such as MND Queensland, to ensure equitable access to care equipment across the country and would like to thank the FightMND Army who through their generous donations, have made it possible.”

With FightMND's support MND Queensland has been able to purchase NeuroNode Trilogys, Cough Assists, Suction Machines, Obi Feeders, Lift Recliners, Air Chairs, five beds and more...

We hire our equipment at a low cost so that people impacted by MND can afford to have the equipment they need at the time that they need it. The hire could be short-term to help a client decide if the equipment is right for them before they purchase their own, or it could be a long-term loan, which is often the case for people who are diagnosed with MND after the age of 65 and don't receive the NDIS and often can't afford to purchase the equipment themselves.

MND Queensland doesn't receive any recurrent government funding and we are reliant on generating our own income through service provision along with donations, grants, bequests and community events. We are extremely grateful to Fight MND for helping to make this vital equipment available to Queenslanders.



Pictured: Our Equipment Officer Sue and some of the equipment purchased with the FightMND grant including folding wheelchairs, air chairs, a lift recliner, NeuroNode Trilogy and below is a robotic Obi feeder.



COVER STORY - MEET MND WARRIOR JO BOON

Jo Boon was diagnosed with MND in October 2019 and since then she has been a voice for MND by helping to increase community awareness and raising vital funds for MND Queensland. We recently met with Jo and her husband Peter to have a chat about Jo's MND journey.

Jo was working as a surgical nurse when she was diagnosed with MND. "It started with slow speech. I was actually at work and a cardiologist thought I should see someone. I didn't sound right. I came home after night duty and had a sleep and woke up and it was worse so I said 'I think I better see someone'. We went to our GP and originally he thought I had Myasthenia Gravis." Jo told us.

After going through treatments and tests Jo was told of her MND diagnosis at 6:30PM on 9 October 2021 "At first I thought 'nah' because being a nurse, I didn't have other symptoms of motor neurone." Jo said of her initial reaction to her diagnosis. Peter added "When we think about it now there were certain things... Jo did comment earlier in the year that she'd be sitting down and she'd get up she felt like she was sort of marching and she was getting headaches and she was getting dizzy spells and all those types of things. She went to the GP and they did some bloods and stuff and put it down to over-tired, vertigo, electrolytes imbalance... all those types of things."

It was earlier in 2019 that their lives were first touched by MND though when their son-in-law's father, Frank was diagnosed with MND.

"We did know it was a terminal illness but Jo's symptoms and diagnosis were a bit different because it was bulbar and we didn't know much about bulbar and how that occurred. Frank only lasted 14 months. So we went through that whole realness which was tough." Peter explained.

"While Frank was alive, I still had hope, we're going to be okay. But when Frank died so quick... But they think Frank had his for years." Jo said.

When we asked how her diagnosis has impacted on Jo she told us "I don't think it's sunk in if that makes sense." She went on to add "I still feel like me and every now and then it raises its head."

Jo isn't letting her diagnosis affect her positive attitude telling us her mantra "Don't keep on worrying about the ending or else you'll miss the main show." She also added that "Too many people want you to leave a legacy but I'm planning my future, not a legacy."

We all know too well that MND doesn't just impact on the individual diagnosed, it impacts on the person's family and loved ones too. When we asked Jo about how her diagnosis has affected her family she said "I see the sadness in their eyes." Talking about Peter she said "I feel like I'm a huge burden. I don't feel like he deserves this."



Losing independence is one of the hardest challenges for people diagnosed with MND and Jo said one of the hardest things was giving up driving "I was the main driver in this family. I did everything. For the girls' soccer, for babysitting... Even when we went out, I didn't drink, I drove. And to lose that, as small as you think that is, it's the worst! And then they say, electric chairs give you independence! Bullshit! I can't get out of my estate because the road's too busy, no paths, rainy weather... electric chairs don't give you independence." Peter added "You still have to get to places." which prompted Jo to say "And someone has to help. You never have independence."

Almost as soon as Jo was diagnosed they got involved with MND Queensland and Jo has her NDIS Support Coordination through MND Queensland. Peter said "We had involvement with those fundraising events. The trivia nights, Motor On out Ipswich way. We were involved with MND Queensland, but not like to the extent now. The support that you give now, it's like chalk and cheese compared to 2019... You've got OTs and Speech Therapists, you name it and obviously you've built your Support Coordination." Jo added "I don't feel like I can't approach you."

Over the two years that Jo and the Boon family have been supporting MND Queensland they have raised over \$20,000 (prior to their Glitter Gala). We asked Jo what she thought was the key to her success and she told us "People! My amazing JoJo's Legends and I think because I'm honest... and I'm also passionate. We're a family. People see that we're a loving family who give. So I'd like to say - genuine people."

We thank Jo and Peter for sharing their story with our readers. Read on to learn about JoJo's Glitter Gala - a hugely successful fundraising event put on by Jo's family to benefit Queenslanders impacted by MND.

JOJO'S GLITTER GALA - A FABULOUS FUNDRAISER

Moments where you can actually feel the love in a room are all too rare, but that's how it was at the Victoria Park Golf Club Marquee on Saturday 6 November for JoJo's Glitter Gala!

You've just read about Jo on the opposite page. Since Jo was diagnosed with MND she and her family have been amazing advocates for MND awareness as well as major fundraisers for MND Queensland having previously raised well over \$20,000. But they were driven to do more... and on the evening of Saturday 6 November the family hosted JoJo's Glitter Gala that had more than 300 people in attendance.

Tickets for the event sold out in just three weeks when they went on sale earlier this year. Unfortunately, due to COVID lockdowns, the event had to be rescheduled from October, but it eventually went ahead a month later and was a huge success raising over \$51,000.

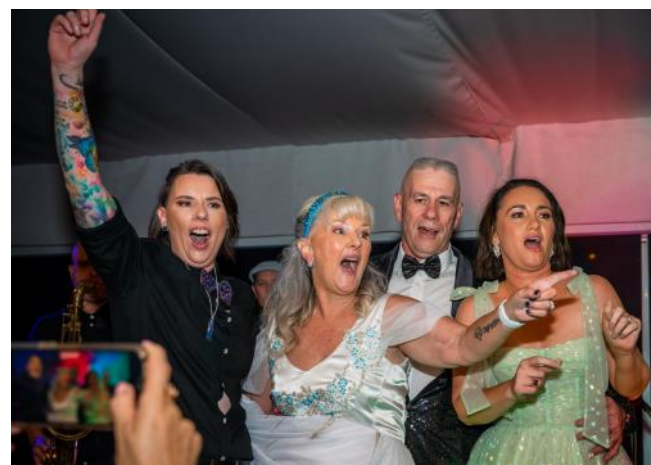
The glitter theme saw lots of sequins, shimmer and sparkles shining through the night with some glamorous outfits on display. There were speeches from Dr Annemarie van Heuven, Lois Quick from Metro South Health, our CEO Ian Landreth and Jo herself read out a

moving speech that had us both laughing and crying. The emcee was cricket legend and family friend Ian Healy. The Radio Club Band entertained the crowd and got the dance floor moving.

Jo told us "I said to one of my friends 'this is my wake tonight, I'm with the people I love.' she went on to say "Honestly, if I had died in my sleep I would have been at rest. Every face I saw looked so happy."

We asked Jo what motivated her to put on such a wonderful fundraiser and she told us "From day one I wanted to do something to give back." She was particularly motivated to get involved when she learned that people diagnosed with MND after the age of 65 don't qualify for the NDIS "I saw red and then I felt guilty. I want to give back to all of my friends. I love people and I'm meeting new people and I don't think it's fair that you work all your life and you get a disease that's got no cure and no help!"

Our sincere thanks go to Jo and the Boon family as well as her sponsors and supporters. Watch out for the return of the Glitter Gala in 2022 and be sure to book quickly!



WALK TO D-FEET MND TOOWOOMBA 2021 - A BLOOMING SUCCESS

It was a perfect spring day at Queens Park Botanic Gardens for the Walk to D-Feet MND Toowoomba 2021. Over 200 people gathered to increase awareness about MND and raise vital funds.

We've timed the Toowoomba walk to coincide with the Carnival of Flowers for the last few years which means that the Botanic Gardens are always looking spectacular in full bloom, and it was a great show again this year.

The park was filled with Carnival of Flowers attendees and our walk shirts really stood out in the crowd and helped to raise further awareness on the day.

Toowoomba Mayor Paul Antonio (who lost his wife to MND) spoke at the event along with Trevor Watts MP. Radio station Power FM added to the atmosphere with tunes to get everyone warmed up.

The Wilsonton Lions Club hosted a BBQ on the day and donated proceeds to MND Queensland and our friend Amanda from Vanochino was there again this year keeping everyone happy with hot drinks and banana bread and also donated back to MND Queensland.

The Rotary Club of Toowoomba East presented a \$1,000 donation on the day and along with event fundraising, over \$13,500 was raised from the walk.

The Top Fundraising Team Award went to Team McAllister who together raised \$2,631. The Highest Fundraising Individual Award went to Michelle Cossins.

We're grateful to all of our volunteers, supporters and participants, and of course your wonderful donors for supporting this event. We're already planning the 2022 Toowoomba walk so look out for that next year.



WALK TO D-FEET MND REDCLIFFE 2021 - A STROLL BY THE SEA

For the third time MND Queensland hosted the Walk to D-Feet MND Redcliffe at Suttons Beach on Sunday 17 October.

It was a gorgeous day by the sea with almost 200 people coming together in support of people with Motor Neurone Disease and their families to raise awareness about MND in the community and fundraise to provide vital support and services.

Minister for Health and Ambulance Services, Yvette D'Ath MP spoke at the commencement of the walk. The crowd were kept entertained by Bridge FM who did a live broadcast from the event.

The Pavilion at Suttons Beach supported our event again this year with a donation. In total almost \$17,000 was raised from the Redcliffe walk. What an amazing effort!

Team Bretto took out the Top Fundraising Team award having raised over \$2,600! Team Gary were runners-up raising over \$2,000. Bailey Magee from Team Bretto raised over \$1,500 making him the Top Individual Fundraiser.

We thank our fantastic volunteers, sponsors and of course everyone who attended and raised funds, and all those that donated.

After cancelling every walk in 2020 it's been great to see so many people come out in support in 2021 and we hope to see more of you at our walks in 2022. We're planning walks for the Gold Coast, Brisbane, Toowoomba, Redcliffe and for the first time... Cairns! Keep an eye out for more news.

Want to host your own walk? We can help you make it a success. Get in touch with Caitlin on 07 3372 9004 or email events@mndaq.org.au.



MND QUEENSLAND'S MULTIDISCIPLINARY CARE TEAM

Over the last couple of years, despite the pandemic and with the wonderful support of our community, MND Queensland has grown to provide a range of services to exclusively benefit Queenslanders diagnosed with MND.

Our multidisciplinary team come together to provide a service that reduces the burden on people impacted by MND and provide a service that looks after several aspects of care.

MND Queensland's services and supports for people impacted by MND include:

- MND Advisory Service
- NDIS Support Coordination
- Occupational Therapy
- Speech Pathology
- Voice & Message Banking
- Equipment Hire Service
- Education
- Support Groups
- Life Stories Program

With the permission of our clients, our MND Advisors/Support Coordinators, OTs and Speech Pathologist collaborate with each other, along with the client's Allied Health Team to coordinate care and achieve the best outcomes.

The team also work with our Equipment Officer to provide the right equipment from our pool which includes items such as:

- Power and manual wheelchairs
- Lift recliners
- Hospital Beds
- Hoists
- Cough assist machines
- Eye gaze and NeuroNode devices
- And much more...

Working together means our multidisciplinary team create a seamless service to get the most desirable results for people with MND.

If you have MND and want to talk about the support options available to you, get in touch with Queensland's MND experts by calling us on 1800 777 175 or email info@mndaq.org.au.



SIMONE MORISON
MND Advisor &
Support Coordinator



JASON RUSSELL
MND Advisor &
Support Coordinator



SANDRA BIFFIN
MND Advisor &
Support Coordinator



SALMA CHARANIA
Speech Pathologist



HANNAH WOODS
Occupational Therapist



JEREMIE ALEXIS
Occupational Therapist

EVERYONE HAS A STORY - LIFE STORIES PROGRAM

In a time of uncertainty and unpredictability, there is one thing that remains solid... that is our love for family and friends. The Life Stories Program provides a journey for people to travel back in time, reflect on their lives and share their thoughts and ideas. It gives people an opportunity to tell a story and relive memories in a celebration of their life, rather than focusing on MND.

MND Queensland have four wonderful volunteers recording people's stories, photos, ideas, words of wisdom and tales. These are beautifully bound in a photobook as a legacy for loved ones and a celebration of your life.

Volunteer Biographer Sally Courtney recently shared her Life Stories Program experience with us...

This year I retired from the workforce and asked myself "What next?". I always knew I wanted to volunteer but wasn't sure how to start. Then I read an advertisement for MND Queensland and the Life Story Program that they wanted to provide to their clients. It was a light bulb moment, so I applied, and I was fortunate to be selected.

I am partially deaf and not good in crowds, but one-on-one conversations are heaven for me. I love to talk to people about their life experiences and I am a very good listener.

Until I began with the Program, I had never met anyone suffering with MND, so I did some research and realised what I would have to consider when talking to someone whose speech is affected.

I thought about this for a long time... Would I be good enough?... Could I give true value to the objective?... but I knew from personal experience what this would mean to someone who wanted to leave their story for their family and loved ones.

When my mother-in-law Marie was in the early stages of dementia my partner and I put together a book of her story. Initially for her grandchildren and great-grandchildren who were still quite young, but also for her carer so that she understood the woman she was caring for, and for Marie herself so that when she was struggling with the everyday, she could look at the photos and remember the happy times during her life. This gave her great comfort. The joy we all experienced recounting the stories, the memories... it was priceless!

Some people may say "I don't have an interesting story", but in my experience everyone has a story and they're all interesting and important. From early childhood, school, university, career, love, marriage, children, family holidays, cherished friendships, hobbies, joys, and sorrows, and that "OMG!" moment.

It's all there in the memory, but we are so time poor and conversations about the past few and far between. However, we are curious about our heritage and our children and grandchildren will want to know/remember who we were and what we thought about things. Put it all together, with some photos, in a lovely book, and give it to our loved ones. We should all do it. I've already started mine.



I've begun transcribing a story for a lovely man who has lived all over the world. I hope I will do a great job for him. For me, volunteering in this way gives me a sense of giving, of being able to do something of value for someone, just because I can. It is my deep hope that I can continue to do this for many years.

If you'd like to participate in the Life Stories Program call 07 3372 9004 or email lifestories@mndaq.org.au.

AN EXCERPT FROM A CLIENT'S LIFE STORY...

When we arrived in Australia that was the beginning of a very different life for the three of us. We left behind everybody and everything. We were on a plane and not a boat which was quite something. We were so excited to fly across the world. We left behind a wet, cold, filthy England of factories, tenement houses and coronation streets, arriving in the spring. It was the middle of the night when we landed in Australia so we didn't know where we were going. We were put in a hostel in Heathcote, NSW. We thought what the hell this is? It was a tin hut. It had one single bed in one room and another room with just a click clack futon. It was very basic. There were rows and rows of them and we all shared one ablution block with I don't know how many families.

We woke up the next morning and the sun was shining. We looked around and we were in the middle of the desert. We were right out of Sydney in an old WW11 American Airforce Base. We were all in barracks. If you didn't have a car, there was no way you could go anywhere. It was a 5KM walk to East Hill Railway Station, through the bush. I got to go to school in great big coaches and we often had to fight our way on board. They took us to the local school which was full of immigrants. There were no Australian people there. My first day at school, I couldn't understand a word that anyone said and no one could understand me because of my broad slum northern Lancashire accent. You were teased mercilessly and my accent had to go very fast. I was nine at the time. (shared with the client's consent)

MND RESEARCH AUSTRALIA 2022 GRANTS ANNOUNCED

One of MND Queensland's strengths is that we are a part of a national alliance with other State-based MND organisations. We share ideas, information, resources and all have a common goal to provide support to people impacted by MND and to find the cause and a cure (and in the meantime, more effective treatments). We all come together under the umbrella of MND Australia and that also includes our research arm, MND Research Australia. MND Research Australia recently awarded their 2022 grant funding and it was great to see some really innovative projects receive funding.

Three Queensland projects received new grants and Dr Thomas Shaw from the University of Queensland continues to receive funding (through to 2023) for his research into ultra-high field MRI of spinal chord tissue in MND.

Dr Derik Steyn from The University of Queensland received a grant for his research into preclinical validation of macimorelin, a ghrelin mimetic, as a treatment for ALS.

Dr Tanya MacDonald, also from The University of Queensland won a grant to investigate energy balance in the progression of MND.

Dr Gabriel Trajano from the Queensland University of Technology won a grant to research high-density electromyography as a



new tool to monitor motor neurone changes in MND.

We congratulate these Queensland researchers and wish them well with their projects and hope that they are able to unlock the cause and a cure for MND, or at least in the meantime, more effective treatments that can extend lives and improve the quality of life for people diagnosed with MND.

You can read more about all of the successfully funded research projects from around the country by visiting www.mndaustralia.org.au/research/our-research/current-research.

MND QUEENSLAND MEMBERSHIP REMINDER

MND Queensland membership falls due at the beginning of the new year and you can find more information about renewing your membership at www.mndaq.org.au/Get-involved/Membership. Membership is free for people with an MND diagnosis and the cost is \$25 for all others.

For more information call Sonia on 07 3372 9004.



MND QUEENSLAND OFFICE CHRISTMAS CLOSURE

We would like to let our clients, supporters and the health professionals we work with know that we are closing the MND Queensland office for the Christmas/New Year break. Our Oxley office will be closed from 4:30PM on Wednesday 22 December and will reopen from 8:30AM on Wednesday 5 January 2022.

The lead up to the festive period can be a busy time for everyone and that includes the MND Queensland team. If you need to organise equipment, speak with an MND Advisor/Support Coordinator or get expert support from our Speech Pathologist or Occupational Therapists, we encourage you to get in touch soon so that we can respond to your request for support prior to the break. Get in touch by calling us on **1800 777 175** or email info@mndaq.org.au.

In case of an emergency (e.g. an equipment malfunction) we will have staff monitoring our phone line during the office closure period and we will let our clients know about the process to contact us over the break via email or SMS, so watch out for this message soon.

If you're looking for information about MND during the closure period we recommend that you visit www.mndaustralia.org.au/mnd-connect which hosts a range of resources for people diagnosed with MND, their families and friends and the allied health professionals that



support people with MND.

If you're looking for something to watch over the Christmas period why not check out our YouTube Channel? We've created lots of useful, educational webinars for people impacted by Motor Neurone Disease and you can watch whenever it's convenient for you. You can find a playlist of our Special Presentations at <https://bit.ly/3xyGgJ2>.

Finally we would like to take this opportunity to wish you all a safe and happy Christmas and New Year. We'll be back on 5 January and look forward to continuing to support Queensland's MND community in 2022.

Please donate to MND Queensland's Christmas Appeal & help create & nourish vital connections for people impacted by Motor Neurone Disease.

Your gift will help connect people with MND to vital services and supports, and continue to connect with family and friends through the support from our MND Advisors, assistive technology, Support Groups, OT and Speech Pathology Services and more...

Give online now at www.givenow.com.au/mndaq or if you're using a MasterCard or VISA you can call us on 07 3372 9004, or you can return the form on the back of this newsletter.



WE GIVE THANKS FOR SOME WONDERFUL SUPPORT

We are truly grateful for the support that we receive and we want to shine a light on those heroes that have recently supported our MND Community.

The **Bundaberg Early Holden Owners Club** had their annual Car Run in memory of John Eager on 19 September and raised \$3,000.



Ray Graham lost his beloved wife Alison to MND and raised \$5,000 in her memory. As a member of The Freemasons he got in touch with us to help apply for a dollar-matching grant from The Freemasons' charity **Hand Heart Pocket** which resulted in \$10,000 going to MND research.



Thuringowa Bowls Club in Townsville held another MND fundraiser recently and raised almost \$2,800.



Drink Tea for MND was promoted as a national week-long campaign for the first time in 2021 but unfortunately lockdowns across the country prevented people in some States from getting involved, but here in Queensland over \$16,000 was raised from various events with Meg and her Mum Anne organizing a huge event in Yeppoon.



The Courthouse Restaurant at Cleveland held a Ladies Oaks Day High Tea benefitting MND Queensland on 4 November. Everyone looked stunning in their race day frocks. Over \$2,500 was raised from the event.



Scody held the MND Over Matter - Ride in Honour of Jan event on 9 October which saw over 50 riders ride from West End to Brisbane's bayside and back. Over \$9,000 was raised from this event and Scody are continuing to support MND Queensland by producing branded activewear and you can buy shirts and cycling gear at <https://bit.ly/3H3vYp1>.



Brisbane City Council recently awarded us \$4,895 from the Lord Mayor's Better Suburbs Grant Program to purchase a new copier/scanner/printer.

We won a **2021 CommBank Staff Foundation Community Grant**. We'll receive \$10,000 to support the vital work we do in the community. Our thanks go to the staff at CommBank who participate in Workplace Giving - this grant wouldn't be possible without you!

We thank all of these wonderful supporters. If you would like to host an event or fundraiser, give Caitlin a call on 07 3372 9004 or email events@mndaq.org.au.

MEET LISA MCILROY- CLIENT SERVICES MANAGER

Earlier in this edition you would have read that our CEO Ian Landreth is retiring and Stacey Thorpe is stepping into the role of CEO. Lisa McIlroy recently joined MND Queensland and will now oversee our Services Team. We asked Lisa a few questions so you can get to know her a little.

Can you please tell our readers a little about your professional background?

I started my career as a nurse and then moved into management in the not for profit social sector managing large teams to deliver services or programs of work to support a range of different people. I have had the privilege of working with many different groups of people and enhancing their experience, for example patients receiving chemotherapy, blood donors providing much needed blood and blood products to the Australian community and more recently veterans.

Have you had any experience working with people with MND previously? If so, can you please tell us a little about your previous work with people with MND?

I have not had experience working with people living with MND but I look forward to learning about MND and how I can support the team to support those we are here to serve. My nursing background helps in understanding the impacts of MND on clients and their family and friends.

You've only recently started working at MND Queensland in the role of Client Services Manager. Can you please tell us what your initial thoughts are on MND Queensland's services and supports?

MND Queensland provides excellent services to the MND community and I hope that I can assist the organisation to build on what they have done already. It is an opportunity for me to bring my service delivery skills to enhance the already compassionate services that MND Queensland delivers.

What makes you want to work with people impacted by MND?

In all my roles I have always looked to make a difference in people's lives and I believe that MND gives me this opportunity to make a difference every day.



The nature of MND means that it's a difficult condition to manage. What do you think are the main strengths of MND Queensland's multidisciplinary team?

Even with my limited knowledge so far it is evident to me that the team are specialists in the field of MND support and services and therefore can provide the best advice and access to support and services that are tailored to the needs of the individuals. The team are compassionate, empathetic and in just these early days I can see that they are committed to providing the best support they can to those living with MND and their families.

What do you get up to in your spare time? Do you have any interests or hobbies?

There are no specific hobbies to speak of but in my spare time I like spending time with my two Maltese boys Samson and Chillie, they are rescue dogs and keep me on my toes.

Is there anything else you'd like to add?

Just that I look forward to meeting some of our clients and hearing their stories and suggestions on how we might improve or enhance our services to better meet the needs of the MND community.

WHAT'S ON

- 18 Feb - Mastermind for MND**, 6PM, fundraising trivia night at Metro Community Centre, Woolloongabba. Tickets online soon at www.mndaq.org.au or call 07 3372 9004.
- 17-18 Mar - Australian and New Zealand Research Symposium**, Brisbane. www.mndaustralia.org.au
- 19 Mar - MND Connect - Research Live Session** (part of the Research Symposium)
- 27 Mar - Walk to D-Feet MND Gold Coast**, 9AM, Hollindale Park, Main Beach. Register soon at www.mndaq.org.au
- 5 May - MND Queensland Golf Tournament** at Oxley Golf Club. Look out for more info soon.
- 22 May - Walk to D-Feet MND Brisbane**, 9AM, New Farm Park. Registrations open early 2022.
- 19 Jun - Start of MND Awareness Week 2022**, why not plan a fundraiser?
- 21 Jun - Global MND/ALS Awareness Day**, fundraise, share stories/posts on social media...
- 24 Jun - Blue Cornflower Day Tribute Ceremony**, see the Story Bridge lit in blue and pay tribute to those battling MND and remember those who we have lost to MND.

MND SUPPORT GROUP MEETINGS & SPECIAL PRESENTATIONS

If you've been impacted by MND you are welcome to join in on our free MND Support Group Meetings. The meetings sometimes have special guest speakers and you will get to meet other people who are experiencing, or have experienced MND so that you can share and learn from one another.

Due to COVID-19, we've introduced regular online support group meetings via Zoom. All clients are sent invitations to participate via email. Please make sure we have your current email address on file to make sure you're getting your invitations. If you would like an invite or support to use Zoom then email supportgroups@mndaq.org.au or call 07 3372 9004. You can participate in Zoom meetings using a computer, laptop, tablet or phone.

Gold Coast MND Support Group - Meets every second month at 1PM at Level 2, Kay House, 35-39 Scarborough St, Southport. Upcoming dates: 12 February. RSVP to Leigh on 07 3372 9004.

Monthly Carers' Support Group Meetings - Via Zoom, 1PM every fourth Tuesday. The next meeting is at 1PM on 14 Sep then the following meeting will be at 1PM on 7 December (and then every fourth Tuesday).

Online MND Support Group Meetings - For people with MND. 11AM every 2nd Thursday via Zoom.

MND Queensland Special Presentations - Educational and informative webinars with guest speakers are held every 2nd Thursday via Zoom at 11AM. The sessions are recorded and can be viewed on our website at www.mndaq.org.au/Get-informed/MND-QLD-Webinars and you can also find us on YouTube by searching for MND Queensland.

MND QUEENSLAND DONATION FORM - SUMMER 2021 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 or email info@mndaq.org.au

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