

the cornflower

MOTOR NEURONE DISEASE ASSOCIATION OF QUEENSLAND NEWSLETTER



**REGISTERED
PROVIDER**



**Jared's Bridge to Brisbane
Effort & Drag Queen Bingo**

**MND QLD - Now a Provider of
NDIS Coordination of Supports**

**Redcliffe & Toowoomba
Walk to D-Feet MND Events**

**Interview with MND Researcher &
MNDRIA Grant Winner Dr Shyuan Ngo**

**Meet Shaun Gannon MND
Advisor & Support Coordinator**



VALE ANNE COLLETT

With sadness we advise of the passing of Anne Collett, Past President of our Association in 2013 who first joined the Association's Management Committee in 2007.

Anne very generously contributed her invaluable experience from 25 years in business, communications, marketing and strategy, to a role that she fulfilled with passion and integrity.

Anne was very committed to improving the experience of those living with MND by building the Association's capacity to help our clients live better for longer and was a driving force behind the establishment of our MND Advisory Service. Anne was a truly warm personality with a rare generosity of spirit, full of enthusiasm that was infectious.

Anne passed away peacefully on Friday, 27th September 2019. Our thoughts are with her family.



Anne Collett, former President of MNDQAQ



NEWSFLASH! The **Walk to D-Feet MND Gold Coast** is planned to take place from 9AM on **Sunday 29 March 2020** at Hollindale Park, Main Beach. You can register and start fundraising now at www.mycase.com.au/events/walktodfeetmndqld2020. The **Brisbane walk** will be on **Sunday 24 May 2020** and a new **Ipswich walk** will be at the start of MND Awareness Week on **Sunday 3 May** and it will coincide with a national walk effort with all of our partner organisations around Australia! Watch our Facebook page for more information.



CONTACT US

MOTOR NEURONE DISEASE ASSOCIATION OF QUEENSLAND INC.

ABN: 75 990 922 939

Street Address: 35 Wedgetail Street, INALA EAST QLD 4077

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

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.

COVER IMAGE - L-R Sal Monella, Jared Ashcroft and Melony Brests at Jared's Drag Bingo fundraiser in Maleny



CHRISTMAS CLOSURE DATES

Please note that the MND Queensland office will be closed from 5PM Friday 20 December 2019 until 9AM Thursday 2 January 2020.



FROM THE CEO'S DESK



The last few months has seen my education into the MND Community continue. I have learnt from Carers and Clients, from my Team and from the Board. I have learnt about laughter, and courage and anger and frustration. I have seen how Government policy supports those with MND through the NDIS and how it discriminates against those with MND over the age of 65.

It is this learning and the opportunity to speak to a parliamentary committee on ageing that saw Stacey Thorpe (our Director of Services) and myself addressing six MPs about the systemic discrimination against those people over 65 who are diagnosed with MND. My opening remarks to the Politicians are included.

Denise Plunkett-Mansell was our longest serving staff member and has left the organisation now after many years of dedicated service to those with MND.

Our recent registration with NDIS for Coordination of Supports means that we can assist any of you with your NDIS applications and reviews. Anybody with a recent diagnosis or who are looking for help to coordinate their care with changing needs, should give us a call. We have an awesome team here that is growing to meet the demand for our services.

Christmas time is approaching and for families touched by MND, it will be a very special time. For some it will be about memories, for others it will be making new memories. Sometimes it will be sad and other times you may find yourself in celebrating the triumph of love and the human spirit. But there are a few things that I have learned in this job already that I hold on to every day:

1. The journey is different for everyone... It is your journey and it is a privilege to be invited to share it with you.
2. MND makes life real; bringing into focus so many aspects of life that are usually overlooked.
3. Never Give Up!

With those lessons foremost in my mind, I wish you all a wonderful Christmas.

My Opening Remarks to the Queensland Parliamentary Committee - 13 Sept 2019

Motor Neurone Disease is an insidious and dreadful disease that has no known cause or cure. The average length of survival from diagnosis is two years with a progressive loss of muscle strength and nerves controlling muscles. Imagine sitting beside someone you love, perhaps strapped into a wheelchair to keep you upright so you can breathe having no ability to communicate anything to them, not how you are feeling, not something you need, not an idea you have had... for all of those things will be going on in your mind... You remain a thinking, feeling, creative soul with an intellect that is alive and yet unable to communicate. That for many MND sufferers is what they experience in a decline day after day.

Our organisation and its national network raise funds for research in the search for a cure and we raise funds for the care and support of these Queenslanders until such a break-through is made.

What we wish to highlight to this Committee is the systemic discrimination against an MND sufferer because this is something that can be solved by the political leadership of this Parliament, if you have the will... because you, unlike many MND sufferers, are able to express and act on that will.

The National Disability Insurance Scheme provides for a client focused management and care plan, and equipment and support to facilitate that if you have a disability registered with NDIS before your 65th birthday. However, if you were diagnosed after your 65th birthday, the only financial funding available is through a My Aged Care Grant which is not designed to support a disability, it does not cover equipment or coordinated care planning, it is means-tested and requires a co-contribution and at its highest may be only 30% of the level of NDIS funding available to you if you hadn't just had your 65th birthday, and the time it takes to be granted this funding is often longer than the client has to live.

The only support these >65-year-old Queenslanders and their families and carers get is from organisations like ours from fundraising, donations and bequests. These charities save Queensland Health millions of dollars a year and Queensland Health's contribution has been zero.

Queenslanders with MND need your political might to address the age and disability discrimination created by these government funding structures. They need you to fix it and they need Queensland Government support in the meantime, until it can be.

MEET DR SHYUAN NGO - AWARD-WINNING MND RESEARCHER

Dr Shyuan Ngo is has been researching MND for 10 years and recently won MNDRIA's Betty Laidlaw MND Research Prize to further her MND research work. We caught up with Shyuan to chat about her project and learn a little more about this researcher that is so dedicated to the MND community.

We asked Shyuan to explain her award-winning research project for us in plain language and she explained that it's focussing on how motor neurons might die in MND. She said "So we know that motor neurons die, we just don't know how that happens. One of the things that you see in almost all cases of MND patients after they've deceased is you see these protein clumps inside the neurons and they're in an area of the neuron that they're not meant to be. So usually this protein is in the nucleus of the cell, where all of the DNA is packaged, but what you see in MND is it moves out of the nucleus and into the cytoplasm which is essentially the environment inside the cell, but outside the nucleus. What happens to the protein there is it starts to form clumps, and we don't know why the protein clumps, we know that it's probably got to do with how it's processed overall, but we get these clumps and essentially they become a bit toxic to the neuron, and then they close the cell and die."

She further explained "Usually these protein clumps are sort of managed by an internal garbage disposal system in the cell. So you can think of it as you've got garbage trucks going around the city picking up rubbish, and that's what's clearing the rubbish in the cells, but if the truck drivers go on strike, you get a buildup of the rubbish and the city gets a bit... yeah (*laughs*). So that's what's happening inside the neurons, you get these protein clumps."

"That truck driver system is dysfunctional in MND as well, so you get the buildup of these clumps. So there's research into targeting that pathway, but the current Betty Laidlaw project that we'll be working on is really looking at the interaction of these protein clumps with a specific little structure in the cell called the mitochondria, which is the powerhouse of the cell. This little organelle, it generates all of the energy that the cell needs to function and survive. We think that these protein clumps are interacting with these powerhouses and causing for them to be dysfunctional. It changes the way the network is established or formed in the cell, or how the network is maintained and then it causes for these powerhouses to become dysfunctional which means they don't generate energy as efficiently and so the cell can't function at its optimum and over time it's going to work harder and harder and harder to do its job, it's going to burnout and then it's going to die. So that's the interaction that we're looking at, to see whether or not this happens in all cells that we generate from patients with MND and whether or not it's something we can target." she said describing her research project.

We asked Shyuan what inspired her to concentrate her career on MND research and she responded "Once I finished my PhD I wanted to work in something that was more translational, because I was stuck in the lab, and



Pictured: Dr Shyuan Ngo with her Betty Laidlaw MND Research Prize 2020 Award

there's nothing wrong with being in the lab because there's a lot of discovery science that goes on in the lab, I wanted to see how the research that I was doing in the lab would be more applicable in the real world, so I went for a position with the two researchers at the Royal Brisbane Women's Hospital who oversee the MND research clinic there and neurologists are interesting people, but Pam and Rob were just so dedicated to helping the patients that they were looking after, and not only in supporting their care and managing their symptoms throughout the disease, but also, conducting research to look for that cure and they just had this whole package thing and they were just so dedicated to the people so I thought 'so if I'm going to move into something that's a bit more challenging, then this is where I want to be, because obviously Pam and Rob know where they want to go, and I want to be a part of that."

Shyuan's partner Dr Frederick Steyn (or Derik) is also an MND researcher, and we asked her how it was living and working together, coming up with ideas and theories over dinner. Shyuan laughed at this question and said "We do! (*laughs again*) And it's not just at dinner, it's lunch, everything! But I think it's a really good place for us to be. I think a lot of people find it interesting, that we can work well together. I think we work well together because we're on the same page, in life and research, and so we're very open to heavy criticism from each other and that helps us develop our research ideas. But I think what's also really good about it is work is work, and life is life for us, so when I do criticise him, or he criticises me about our research ideas, it's not personal. We don't take it personally. It's just about the science because we both work in the clinic as well with patients and we understand that what we're trying to achieve is essentially better outcomes for patients, so we put our egos on the backseat and it might hurt my feelings every now and then but you know, we step away from it and in the grander scheme of things it's all geared towards what we want to achieve. So we do talk a lot about research and I think that it's not really taxing for us to do that because we both love it, so it just comes naturally and I think there are times when ideas just pop up in our head and it's easier just to talk to someone just then and there to get some clarity around it rather than saying 'well, I'll write that down later' and then you forget about it."

Read the full and unedited interview online at <https://bit.ly/35xmUVO>.

MNDRIA 2020 RESEARCH GRANTS ANNOUNCED

Along with Dr Shyuan Ngo's Betty Laidlaw MND Research Prize (opposite) MNDRIA recently awarded almost \$2.9 million to support the best MND research commencing in 2020. Queensland-based researchers performed well in the latest grant round with nine of the 31 funded projects coming from Queensland. The following briefly touches on the rest of the Queensland MND research projects.

Dr Richard Gordon - University of Queensland Col Banbrik MND Research Grant

Dr Gordon's research project will be targeting inflammasome-driven neuropathy and motor neuron death in MND using a clinically approved cancer drug.

Dr John Lee - University of Queensland MNDRIA Innovator Grant

Dr Lee will be investigating the therapeutic inhibition of SCCR2 as a disease modifying treatment for MND.

Professor Pamela McCombe - University of Queensland MNDRIA Innovator Grant

Professor McCombe's project will be looking at possible gut-derived toxins in ALS: prevalence and effects on outcome.

Dr Frederik Steyn - University of Queensland Fat Rabbit MND Research Grant

Dr Steyn's research will focus on preclinical testing of a compound with multiple actions to slow disease progression in MND.

Dr Adam Walker - University of Queensland MNDRIA Innovator Grant

Dr Walker will look into new mouse models of TDP-43 pathology.

Assoc. Prof. Anthony White - QIMR Berghofer Medical Research Institute NTI MND Research Grant

Assoc. Professor White's grant funds his project which is looking at boosting microglia phagocytosis as a therapeutic approach to treat MND.

Assoc. Prof. Trent Woodruff - University of Queensland MNDRIA Innovator Grant

Assoc. Professor Woodruff's research will focus on transcriptomic and function evaluation of immune-activated monocytes in MND.

Britt Berning - Queensland Brain Institute MNDRIA PhD Scholarship Top-Up Grant 2018 - 2020

Britt is looking into sub-cellular dysfunctions associated with pathological TDP-43 in MND: disease mechanisms and therapeutic relevance.

We would like to congratulate all of these Queensland researchers on their MNDRIA grant wins and we look forward to your research helping to unlock some of the mysteries of MND.

You can find the full MNDRIA grant recipient list online by visiting www.mndaq.org.au/Discover-our-research/Latest-research/Research-reports.aspx.

JARED'S DRAG QUEEN BINGO MND FUNDRAISER

Jared Ashcroft signed up for the Bridge to Brisbane this year and chose us as his nominated charity as he had lost a good friend Joyce to MND and wanted to do something to honour her life and to help others who are impacted by this terrible disease.

Sharing his fundraising page far and wide and running small fundraisers, Jared's fundraising total was ticking along nicely, as was his training. As a part of his fundraising, Jared also hosted a fun Drag Queen Bingo night with the support of the Maleny community. A huge thanks to Melony and Sal from Melony's Drag Queen Bingo for their support and entertainment. Together they raised a whopping \$8,224.74 from the night.

When added to his other fundraising, it meant that Jared ended up raising \$13,025.41. This made him the 3rd highest fundraiser overall for the Bridge to Brisbane!

Unfortunately, Jared broke his arm just before the big run and then the day before, his beloved Grandfather passed away. Many others would have quit faced with these challenges, but Jared, along with the support of friends, completed the event. We are beyond grateful for the lengths you went to Jared. To follow up on your commitment to raise funds in memory of Joyce, amidst the challenges you were also facing, is such a show of character and strength. Well done and thank you!



WALK TO D-FEET MND TOOWOOMBA 2019 - BIGGER THAN EVER!

On Sunday September 8, we held the Walk to D-Feet MND Toowoomba in Queens Park. We were blown away by the support, with the park bursting with a beautiful community of 344 walkers, plus their supporters. This is around double the number of walkers from 2018, and together they raised an amazing \$30,874, which is almost four times last year's total!

The atmosphere was lovely despite the windy conditions, with music from local artist Kerryanne adding to the vibe. Walkers enjoyed the gorgeous location, walking the pathways around the lush green oasis of the Botanic Garden and getting a sneak peek at all the flowers coming into bloom for the Carnival of Flowers. We were all kept well fed by the Lions Club of Toowoomba West; and coffees and hot chocolates by Amanda from Vanochino kept everyone warm and happy. Amanda generously donated all her takings for the day to us and the Lions Club then fol-

lowed suit, kindly donating their profits from the day. Such a lovely and unexpected gift from them both. Thank you! Our volunteers also deserve a special thank you for making the day run so smoothly. Without their support, we couldn't put on these great events.

It was wonderful to see so many people connecting and rallying around the people they care for. Our biggest group were the St Joseph's College community, rallying around their beloved teacher, Dan O'Neill. They held a sausage sizzle and a wear orange day prior to the walk to raise awareness and funds, and between SJC and Dan's family and friends, they raised over \$12,000.

Thank you and congratulations on a fantastic effort Toowoomba! We are so grateful for your support and fundraising efforts.



WALK TO D-FEET MND REDCLIFFE 2019 - A BEAUTIFUL DAY OUT

The Walk to D-Feet MND Redcliffe was held on Sunday October 13, along the beach front at Suttons Beach. We saw a great turn out of 185 walkers coming out to support their family and friends battling MND and remembering those they have lost to this terrible disease. In the process, the community raised over \$15,500, which is about two and a half times the amount that was raised at last year's walk.

The day kicked off with some live music from local singer Mabel McCormack, who along with Brendon Hofmeier of Beat Connection, created a lovely atmosphere and entertained our supporters waiting for the walk to begin. We were also lucky to have Luke Howarth MP come along and support us on the day, and he took the honour of starting the walk for us. After the walk, our medal winners were announced, with the highest fundraising award going to the McMahon Team, who smashed their \$3,000 goal, by raising \$3,775.50.

We couldn't have organised such a great day without our Board members, Liz and Graeme Holyer, and the rest of the crew from the Brisbane North and Caboolture MND Support Group. They supported us by helping organise and promote the event, as well as coming along to volunteer on the day. Their efforts, along with our bunch of dedicated regular walk volunteers, meant the day ran like clockwork and everyone had a great time. So thank you all! We'd also like to acknowledge Moreton Bay Regional Council for their support by allowing us to use the venue free of charge and for donating a prize for our raffle. Thanks to Suttons Beach Pavilion for donating a portion of their sales from the day back to MND Queensland.

Well done everyone who walked, donated, sponsored or volunteered and thank you for your generous support.



AMAZING THIRD-PARTY FUNDRAISING NEWS

Tweed Heads South Bowls Day

On Sunday 21 July, the Tweed Heads Amateur Fishing Club put on a Bowls Day fundraiser on our behalf at South Tweed Sports Club. Their fundraising efforts saw them handing over a cheque for \$1,279.50 to MND Queensland.

Tweed Heads Bowls Day

The Tweed Heads Bowls Club hosted a Bowls Day fundraiser on our behalf on 30 July, raising \$1,500. Thank you for your efforts and your support.

100 Miles for MND

Earlier this year, Mark Chad signed up to Everyday Hero to run 100 Miles for MND. Running 100 Miles is an achievement in itself, but in the process Mark also managed to raise \$6,000.

Bridge to Brisbane 2019

This year we had 30 people run for us in the Bridge to Brisbane. Jared Ashcroft, mentioned earlier in this edition, placed 3rd on the overall fundraising leader board for the event, and we also had a big contingent from Redpath Mining run and raise funds to support their workmate who has been diagnosed with MND. Redpath Mining Australia matched their fundraising efforts, with a cheque sent to MND QLD for \$3,999.40. In total we received \$19,674.84 from this event. Congratulations to all the Bridge to Brisbane participants and thank you.

Townsville MND Charity Bowls Day

Thuringowa City Bowls Club member Lorraine was diagnosed with MND so the club decided to run a Charity Bowls Day on 25 August. The day was a roaring success with lots of fun and laughs and money raised in the process. A sincere thank you to the club and the lovely Roz for organising the day and raising \$1,560. We gather they had so much fun on the day, that they have decided to make it an annual event. Our Regional MND Advisor Sharon attended and said that it was lovely to see so many people coming together to support MND QLD and their friend Lorraine.

Portofino Spring Fashion Parade

Each year, the Brisbane North and Caboolture MND Support Group runs a fashion parade fundraiser, revealing the Portofino Spring Fashions. The event was held this year on 25 August and they raised an impressive \$1,750! Around 80 ladies turned up to see the fashions on parade at Burpengary Community Hall and enjoyed a lovely afternoon of fashion, food, raffles and lucky door prizes.

Shop Counter Fundraising Tins

We recently received a cheque for \$1,551.75 from the Brisbane office of Airport Retail Group, who run the food outlets at both Brisbane Airports. They had kindly chosen to put collection tins out at each restaurant/café for the previous month to collect donations from customers.

Regis Aged Care Whitfield Fete

Many thanks to Regis Aged Care Whitfield (Cairns) for hosting a fete on 21 September and raising awareness on MND as well as much-needed funds for MND Queensland. After recently caring for one of our clients and seeing the terrible effects of MND, the staff and residents were motivated to raise money for us, so we can support others as they face this journey. The team raised over \$8,500 from the fete, with bric-a-brac stalls, lucky dips, plant and art sales, motor cycle rides, a monster raffle and some great food stalls. Also, a big thank you to Anne Kavanagh who volunteered to represent us at the event.

Have you got a fundraising or event idea? Get in touch with us and we can help you make it a reality, plus, you'll be contributing to the vital support of people with MND in Queensland and helping us further research to find the cause and a cure! Get in touch with Georgia by emailing events@mndaq.org.au or call her on 07 3372 9004.

Carnival of Flowers Open Garden Fundraiser

For the 3rd year running, John and Heather McGuinn have chosen MND QLD as their charity beneficiary for their Toowoomba Carnival of Flowers Open Garden. This year over the weekend of 21/22 September, they collected \$464.45 in donations from the hundreds of visitors they had. Over the three years of supporting MND QLD, the McGuinns have raised almost \$1,500! Many thanks John and Heather.

Endeavour Kirwan Cent Sale

After being inspired by one of their longest serving volunteers Lorraine, the Endeavour Foundation Op Shop in Kirwan (Townsville) decided to run a fundraiser for MND QLD. Thank you Naomi Smith and all your crew and volunteers for holding a fabulous fundraising day on 21 September and raising \$1,300!

Bundaberg MND Car Run

The Bundaberg Early Holden Club Inc. held a Car Run on 15 September and raised over \$1,000 for MND QLD! This is the second year the Club has run an MND fundraiser and they are keen to do it again in 2020. Many thanks to the organisers, volunteers and participants for making this year's event a success.

Jackson Charity Cricket Match

Eight years ago, after a six year battle with MND David Garnett's best mate Grant passed away. He was only 41 and left behind his wife and two young children. Now, each year, David and his mates run an NRL tipping competition and a Cricket Cup in his honour. All proceeds from this are kindly donated to MND QLD, with us receiving \$510 recently. Thank you for honouring your friend's memory and raising vital funds.

Lorraine Lynch Dyes Her Hair Blue for MND

Lorraine is a long-term MND QLD supporter and decided to dye her hair blue to fundraise for MND research. She collected donations and raised \$1,140. Well done and thanks Lorraine!

Driven not Hidden Car Show

On the 11 August, Queensland Cruising held the 'Driven not Hidden' car show at the Highvale Showgrounds (near Samford) raising \$250 for MND Queensland.

Morning Tea for MND

One of the doctors from Eastbrook Medical Clinic in Burleigh Heads recently lost a family member to MND. To honour their loved one and support MND QLD, they hosted a Tea for MND fundraiser. They had a lovely day and many patients supported their cause, buying merchandise and making donations, with their fundraising total coming to \$295.60 by day's end.

13 Horrors of Fitness

There is a new gym in Salisbury and one of their team has been touched by MND, with his father being diagnosed. Steel and Stone Gym owners, Graham and Adam, were keen to support their mate and his dad, by organising a fundraiser. They developed a unique event to run on "Black Friday" 13th September. Thank you for the \$380 you raised.

Emergency Services Motor Cycle Club of Queensland

The Emergency Services Motor Cycle Club of Queensland recently raised \$1,000 for MND QLD. The money was donated as a sponsorship to the top fundraising team in the recent Motor On for Motor Neurone Disease Car Rally. The Club's President, Paul Tattersall, said they are keen to be involved with the Rally next year and are also doing ongoing fundraising on our behalf. Thanks guys!

INAUGURAL MOTOR ON FOR MOTOR NEURONE DISEASE RALLY

Our Inaugural Motor On for Motor Neurone Disease car rally event was held recently, with 22 cars carrying 83 people joining us for a day full of laughter, cryptic thinking and cooperation. No one knew quite what to expect from our first scavenger hunt rally, including us, but the overall feedback was that people had a lot of fun and laughs.

Congratulations to Carolyn Nicholas-Ashman and her crew for being our Highest Points winners. They collected over 1,000 points along the way. Following them closely was one of our own staff teams (they didn't even cheat) and right on their heels were the awesome MND Bashers team, who besides raising nearly \$2,000 and coming in 3rd, also had the most fun car of the day and enjoyed

cooling everyone down with their built in water sprayer. In other prize winning categories, Highest Fundraisers and Best Dressed Crew, were originally awarded to the MND Bashers, but in a beautiful moment of community spirit, they decided they wanted Jo Boon to have the Highest Fundraising Award and her colourful and tropical crew were awarded the Best Dressed, which was well deserved due to spiffy outfits, their effort to get 5 cars registered in the Rally and for raising over \$1,500.

Altogether, \$7,200 was raised, which is an awesome effort. We want to thank those of you who endured cryptic riddles, poor poetry and a long route, and you still thanked us for the day and had smiles on your faces at lunch. Look out for the event again in 2020.



Pictured: Motor On participants gathering at our rally end point for a picnic and awards.

EXCITING NDIS UPDATE - COORDINATION OF SUPPORTS

Since the last newsletter, we have made a huge leap forward in expanding the services we can offer to our clients. In October, we received notification that our application to register as a Support Coordination service with the National Disability Insurance Scheme (NDIS) was successful.

We have made the decision to combine the role of MND Advisor with Support Coordinator so that any of our clients who are entitled to funding through the NDIS can receive this service from someone who also has specialist knowledge of MND. Assistance to access the scheme and pre-plan for meetings with the NDIS is also on offer to any of our clients who require it.

As a member of the national network of State MND associations, we are very fortunate to have access to shared resources and expertise and this latest development brings us in line with the service offerings of our sister organisations in New South Wales, South Australia and Victoria.

Being part of this network, recognised nationally as the leading authority on Motor Neurone Disease, also means that we are able to talk directly with senior staff at the National Disability Insurance Agency to provide a voice for people with MND and help shape the scheme, to ensure it

meets the needs of our community. This has allowed us to influence the timeframes for accessing the scheme for people with MND, to reflect the progressive nature of the condition and the urgency, with which people recently diagnosed with the condition need funding and support services.

Whilst we are very excited to be able to offer this additional service, we are also keen to ensure that all of our clients, regardless of age or funding, continue to be able to access expert advice from our service. We are continuing to advocate for those diagnosed with MND over the age of 65 to be included in the NDIS so that they can access adequate funding to meet their support needs.

Our Advisor/Support Coordinator, Shaun Gannon and Director of Services, Stacey Thorpe are both available to take calls from any clients needing support or advice. Between them both, they have a wealth of knowledge on MND, the services available to people living with MND and both NDIS and My Aged Care funding.



MND EQUIPMENT SERVICE REPLENISHED BY GRANTS

MND Queensland's Equipment Service is one of our biggest, most important, and most costly services that we offer to people with Motor Neurone Disease.

The cost of this program runs into the hundreds of thousands of dollars each year, and that's before we even look at replacing old, broken or worn-out equipment.

We were therefore very grateful to win some major grants recently to help replenish our equipment stock so that we can offer our clients an improved range of equipment to hire.

In May this year we were awarded \$93,350 from the Gambling Community Benefit Fund's Commemorative Grant Round. We've recently started to take delivery of some of these items including cough assist machines, hoists and slings, air cushions, lift chairs and a very special adjustable wheelchair. We are grateful for this grant.

We also won a grant of \$9,350 from the Mazda Foundation which is allowing us to purchase an additional cough assist machine to add to our range of rental equipment.

Our equipment is available to all of our clients to rent, whether or not you are on the NDIS or an Aged Care Package.

If you need equipment, please speak with your Occupational Therapist or Allied Health Specialist about your needs and accessing our equipment as requests need to come from your professional. More information including an application form can be found on our website www.mndaq.org.au/Find-help/Equipment.

It is thanks to these grant bodies, and our donors, fund-raisers and people who have left gifts in their Wills over the years that we are in a position to offer this equipment service to our clients which saves them thousands of dollars at a time when they are sometimes already struggling with the bills due to having to leave work and the increased costs of their MND medications etc.



BECOME AN MND QUEENSLAND MEMBER

Why? Our valued members are at the heart of our work. By becoming a member you'll join a group of people with a common interest – Motor Neurone Disease (MND). Our members play an important role in everything we do and who are - determined to make sure that all Queenslanders affected by MND get the support they need, when they need it.

Features of membership include always receiving our quarterly newsletter, *The Cornflower*, and being kept up-to-date with all of the latest news, events and support group meetings in your area. In addition to receiving invitations to special MND Queensland events and the Annual General Meeting (AGM).

The AGM is an ideal opportunity for members to get together and hear about the last year's work and what's planned ahead. As well you can have your say in the future direction of the organisation and vote for our Board of Directors.

One of the greatest benefits of membership is often not appreciated, and that is, when you get a large group of people together, they have a strong voice at all levels of government. Members who are actively involved in the organisation can influence the content of that voice.

Also as a member you are demonstrating your ongoing

support of the aims and objectives of the Association and are a part of a collective generating better outcomes for people with MND.

Membership is only \$5 a year for people with MND who live in Queensland, or who receive direct services from us. If you do not have MND but want to support the association you can join by paying an annual membership fee of \$25.

The membership payment helps to cover the cost of our membership program and allows us to reach out to more people with MND and their families.

We also ask that you encourage family members and friends to join, as our members are all ages, from all walks of life and generally are people with MND, their families, carers and loved ones as well as health professionals.

So join us today and help shape the future of MND Queensland by completing the enclosed form or downloading the form from our website and returning it to us with your payment. www.mndaq.org.au/Find-help/Membership



MEET SHAUN - MND ADVISOR & SUPPORT COORDINATOR

Shaun Gannon started working at MND Queensland as an MND Advisor in July this year. We were recently approved to provide Support Coordination under the NDIS and Shaun's role has transitioned to MND Advisor/Support Coordinator. We recently interviewed Shaun so you can get to know him a little better.

Can you please tell us a little about the skills you bring to the role and any previous experience of working with people with MND or people with disabilities?

I have unfortunately experienced MND from both sides of the road. My mother was diagnosed with MND when I was a senior in high school. Later in life when I became a registered nurse I had two people under my care with MND. I found that the lack of understanding of MND leads to a lot of issues around supporting and understanding. My current role allows me to share my skills and my knowledge to health care workers, care staff and families to help those with MND live better for longer.

MND Queensland is now a provider of Support Coordination under the NDIS and along with your MND Advisory tasks, this is one of your areas of work.

Can you please tell us a little more about how you help people with NDIS Support Coordination?

Becoming a registered provider of Coordination of Supports has been a huge achievement and we are really excited to be able to deliver this service to our clients. The short explanation is a Coordinator of Supports or (CoS) is a personal assistant in accessing and utilizing your NDIS plan, we can connect you with providers and suppliers that best suit your needs.

I personally have found that I draw on my clinical and personal experiences a lot more than I expected. Unfortunately, MND doesn't fit the mould for the NDIS model, so having the backing of someone who understands the challenges of MND but also has the backing of the national advocacy for MND to push for what's right has been invaluable.

What are the common issues you see that people with MND are experiencing with their existing NDIS

plans that you can help correct?

The most frustrating is the inadequacy of plans for forward planning.

It's the unfortunate nature of MND to be very unpredictable and without having a safety net it can create stress at times that you really don't want to have to deal with it. Having that specialised knowledge of MND allows me to push for that safety net when developing plans to prevent the stresses of shortfalls.

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

Having seen both sides of the road so to speak, it arms me with a fair bit more knowledge that I can ultimately put to use within our membership. And if someone can get benefit from that, I am all for sharing.

What is the most rewarding part of working for MND Queensland?

Working with some incredible people from varied backgrounds with a common goal. Helping those with MND live a better quality of life.

Are there any other comments that you'd like to share?

I have always said to work in this sector you must have a passion, without it you're just another quack in a funny shirt... and I prefer funny socks! I have lucked into an organisation that is overflowing with passion, dedication, drive and most importantly, heart.

To get in touch with Shaun please call 07 3372 9004 or email him at shaun.gannon@mndaq.org.au



MND Queensland Christmas Appeal

Donate now to help families like Joanne's battling MND this Christmas. You can read Joanne and Veronica's stories at <https://bit.ly/33Xe0Av>.

Please donate at www.givenow.com.au/mndaq or by calling **07 3372 9004**, or by sending a cheque (made out to MND Queensland) to: MND Queensland, PO Box 470, INALA QLD 4077. *Thanks for your support.*



Please give a gift to help people affected by MND this Christmas.



WHAT'S ON

7 Feb - MND QLD 'Trivia With a Twist' Fundraiser, Brisbane. Register at: www.stickytickets.com.au/JYRNC

29 Mar - Walk to D-Feet MND Gold Coast, 9AM, Hollindale Park, Main Beach. Register now and start fundraising at www.mycause.com.au/events/walktodfeetmndqld2020

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: Bayoo Room, Cairns North Community Health, 381 Sheridan St, Cairns North.
Frequency: 25 Mar, 27 May (note: 27 May in Yoomoon Room)
Time: 10:00AM to 12:00PM
RSVP: Anne Kavanagh, 07 4226 4481, 0400 739 674 or email <mailto:Anne.Kavanagh@health.qld.gov.au>

TOWNSVILLE

Location: Carlyle Gardens Restaurant & Bar, 60 N Beck Drive, Condon
Frequency: 23 Jan, 5 Mar, 16 Apr
Time: 10:00AM to 12:00PM
RSVP: Sharon Edwards, sharon@mndaq.org.au, 0424 408 657

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

Location: Pine Rivers Health Centre, 568 Gympie Road, Strathpine
Frequency: Normally held on the 4th Sat of the month (except Dec). 25 Jan, 22 Feb, 28 Mar, 18 Apr
Time: 9:30AM to 11:30AM
RSVP: Graeme & Liz Holyer 0458 021 783

GOLD COAST *(sponsored by Maylake Pty Ltd)*

Location: Gold Coast Business Hub, Level 2 "Kay House", 35-39 Scarborough Street, Southport
Frequency: Bi-monthly, 8 February, 11 April
Time: 1:00PM to 3:00PM
RSVP: Lorraine 0408 661 212

MAJOR MND SUPPORT GROUP MEETING NEWS COMING SOON!

We know the value of MND Support Group Meetings and how sharing knowledge and experiences with other people going through the same situation is an opportunity for you to learn from peers and help you feel connected and less isolated.

MND Queensland is currently working on supporting and expanding our MND Support Group Program and we look forward to sharing news on the developments early in the new year. Please keep an eye on our Facebook page www.facebook.com/MNDAQ and our website www.mndaq.org.au/Find-help/Social-Support-Groups for further news.

MND QUEENSLAND DONATION FORM - SUMMER 2019/2020 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 fundraising@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