

the cornflower

MOTOR NEURONE DISEASE ASSOCIATION OF QUEENSLAND NEWSLETTER



HIGHLIGHTS

- Moranbah to Mackay Ride for MND
- MND Queensland AGM
- Walk to D-Feet MND event success
- Welcome to our new CEO
- Meet our Director of Services

MND QUEENSLAND 2019 ANNUAL GENERAL MEETING

The Association's Annual General Meeting was held on Saturday 29 June 2019 at the Mt Ommaney Community Hub.

Along with adopting the 2018 Annual Review (which can be downloaded at www.mndaq.org.au/About-us/Annual-Reviews) members also voted on our Board and welcomed our newest Board member Megan Peach.

Former Queensland politician Henry Palaszczuk MP (father of Premier Anastacia Palaszczuk) was sworn in as a new Vice-Patron and is dedicated to helping us increase awareness on Motor Neurone Disease and improve the services available to people affected.

Long-time supporters of MND Queensland - Anne Thompson and Jane Milward - were deservedly awarded Life Membership of the Association.

Special guest speaker Dr Robert Henderson (Associate Professor UQ Centre for Clinical Research) gave the attendees an update on the latest research being conducted into MND. MND Queensland's Director of Services Stacey Thorpe spoke about some of the new di-



Pictured: MND Queensland Board Members as at the 2019 AGM



Pictured: President Peter Denham and new Vice-Patron Henry Palaszczuk

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SOCIAL MEDIA

Facebook: www.facebook.com/MNDAQ

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

Twitter: twitter.com/MNDQueensland

Instagram: @mndqld

FEEDBACK AND CONTRIBUTIONS

Please send your feedback or story ideas to fundraising@mndaq.org.au.

DONATIONS

You can make a donation by credit card by calling 07 3372 9004 or at www.givenow.com.au/mndaq. You can also post a cheque or money order (made out to MND Queensland) to the postal address above. Donations \$2 and over are tax deductible.

COVER IMAGE - Walk to D-Feet MND Brisbane 2019 participants



WELCOME TO OUR NEW CEO - IAN LANDRETH



Hello to the MNDQA Family. I began my journey as the new CEO on 29 July and it has been an exciting and very warm welcome. I have come from a background of 20+ years in executive roles in the Health Sector, particularly Primary Health Care and service integration. I have worked extensively with Doctors, Researchers and Allied Health Professionals of many disciplines.

As I take my first steps into the Disability sector my first impressions are these:

- Patients become Clients and Clients become friends very quickly.
- I love learning and there is lots to learn.
- The sector and particularly MNDQA has a rich history of care, concern, compassion and advocacy.
- It is the generosity of people who have been touched by or lost a loved one to this insidious disease, that has created and sustained this organisation and this makes me feel very committed to add to this legacy.
- The respective layers of Government have been on the fringes of support for the disability sector and recent years have seen them playing an increasing role but it is early days and some of their attempts to support this sector will require guidance and refinement from those of us on the ground.
- The staff that I have inherited as my Team are wonderful, skillful and generous people and I am very blessed to have such a Team around me.
- The Board found me and recruited me and now supports me and teaches me and for that I am very grateful. They are a Board with commitment and knowledge and are active in the MND Community and networks.

I have several goals that will dominate my attention in the next year in this position:

- I want to see the NDIS Commission paying us for the service we provide to clients so that we can provide a greater range and reach of services.
- I want to attract Corporate Partners to stand beside us in the years ahead in a way that allows us to plan with a much greater horizon.
- Research and Coordinated Care need to co-exist and inform each other in the MND space. Research has traditionally informed care but we need to also have research informed by quality care and innovative practice. This often happens at the hands of carers and loved ones and so doesn't connect back to inform research... we should make that possible.
- The people and equipment here need a larger premises. We would like to be able to plan and deliver more services and support as well as to be able to welcome members, supporters and clients into our premises for social and educational events, perhaps to try out equipment but most certainly to connect with others in this wonderful family. The house at Inala was a wonderful and generous gift and this house has provided a home and the wherewithal to get to where we are today. The success enabled by many people over many years has meant though that we have outgrown the premises we are in and need a base to continue this growth.

Thank you for all that you do for us so we can do more for others. This disease is so tough, perhaps that is why the ripples it creates forge such a close knit group of people as the MNDQA community.



CAUSE CARE CURE
Never Give Up!

HELPING TO ACCESS THE NDIS & ASSISTIVE TECHNOLOGY

Since the start of this year MND Queensland has been offering our Equipment Service to those utilising NDIS funding to rent assistive technology. While there have been some wrinkles to iron out, we are glad to report that we now have many clients accessing our Equipment Service under the NDIS.

This doesn't at all negate those over the age of 65 who are on (or waiting for) Aged Care Packages and cannot access the NDIS. We continue to strongly support people with MND over the age of 65 with our low-cost equipment rentals as well as a new advisory role.

For the most part, the NDIS has brought significant benefits to people with disability under the age of 65. It has helped people take control over their own care and be involved in community life.

MND Queensland has been able to generate a new income stream under the NDIS to help us to become more self-sustaining by offering our Equipment Service products to be rented through a persons' NDIS funding package. Increasing our service sustainability will only strengthen our ability to offer quality services into the future and will also allow us to purchase new equipment to continually improve our service delivery.

In addition to our Equipment Service, we are now in the process of registering to provide Support Coordination so that we can assist our clients with MND to make the most of their NDIS plans and achieve their goals.

In the meantime we can offer NDIS pre-planning services to help our clients understand how the funding works and to ensure the planning process is as smooth as possible.

Our expertise on MND means that we can ensure that adequate information is provided to NDIS planners to allow them to develop plans that factor in the changing nature of MND and include in their plans what they may



Pictured: (left) Sue with Seth and some of our equipment available for hire

need in the future.

MND Queensland recently employed Shaun Gannon and his role will be to predominantly support people on the NDIS.

Denise Plunkett-Mansell is taking on the advisory role for those over the age of 65 to ensure we continue to support those who cannot access the NDIS that still need our support and services.

It is thanks to our 36 years of experience in helping people with MND that we are placed to be specialists in this field and experts on how to provide the best possible care and support to people with MND.

As you'll read on the opposite page, we recently had a generous donation of a van which is allowing us to take more control of the delivery of our equipment in South-East Queensland. As you read further on in this issue you'll see that we've received a few grants which have helped us to boost the range of equipment available to our clients across the State.

We are committed to ensuring our services are responsive and meet the needs of people affected by MND across the State.

Drink Tea for MND

Make a positive difference in the lives of families touched by Motor Neurone Disease by hosting your own fundraiser! You can raise money to help MND Queensland provide quality support and services and help further research to find a cure! Just gather some friends, provide some catering and ask guests for donations to MND Queensland. Your party can be as big or small as you like! For more ideas or information please call Georgia on 33729004 or email events@mndaq.org.au or visit www.mndaq.org.au/Get-involved/Become-a-supporter



CAUSE CARE CURE



IN-MEMORIAM VAN DONATION TO ASSIST PEOPLE WITH MND

We recently met with Cath Douglas who generously donated a Toyota HiAce van with a wheelchair lift to MND Queensland. Cath had purchased the van with her late husband Don who sadly passed away from MND earlier this year.

Cath and Don had nicknamed the van the 'Thunderbird' and in between medical appointments and daily routines, it gave them the freedom to continue to get out of town and back to nature, something that they loved doing as a couple.

"Even up until December last year, we were going on rainforest tracks with the wheelchair up at Mt Tamborine. We didn't focus on the disease we focused on life. His goal was to live. We knew what the outcome was going to be, but all we could do was focus on life and just try to make every day as beautiful as we could make it." Cath told us when we were collecting the van.

We asked her what advice she would give to others going through the same situation and she said, "Don't be afraid to reach out. Let people know what your biggest challenges are. Know that you're not alone, that you have an MND family. There are people working at the Motor Neurone Disease Association of Queensland that I've met; whether they are volunteering or being paid for their time, they want to help. Communicate and let people know what your greatest challenges are so that those needs can be met."

Don benefitted from MND Queensland's Equipment Service too and Cath said "I'll always remember how the organisation provided essential equipment for Donald, and in a timely manner, and it was such a great benefit to our daily lives. We'll always be grateful for that."

Cath and Don wanted to donate 'Thunderbird' to MND

Queensland to support families living with MND. The van will assist in the delivery of our vital equipment and possibly allow us to assist MND clients and families in other ways.

When Cath took the van to Motorama Moorooka to get a roadworthy check before signing the van over to MND Queensland, Terry from Motorama was so moved by her story and generosity that he paid for the safety certificate himself! Thank you Terry for joining the generosity.

Cath also recently donated Don's eye-gaze communication system to MND Queensland to benefit others with speech difficulties. MND Queensland is very grateful to Cath for her generous donations in Don's memory.

If you would like to donate to MND Queensland, please call us on 07 3372 9004 or email fundraising@mndaq.org.au.



Pictured: (left) MND QLD President Peter Denham with Cath Douglas and 'Thunderbird'

A banner for the 'Walk to D-Feet MND Redcliffe 2019' event. The banner features a group of people walking on a beach. The text on the banner reads: 'Walk to D-Feet MND Redcliffe 2019', '9AM, Sunday 13 October, Suttons Beach, Redcliffe', and 'Register, get sponsored and help people with Motor Neurone Disease'. At the bottom, there is a logo for 'WALK TO D-FEET MND', the slogan 'Never Give Up!', the website 'www.mycause.com.au/events/walktodfeetmndredcliffe2019', and the MND Queensland logo.

Walk to D-Feet MND Redcliffe 2019
9AM, Sunday 13 October, Suttons Beach, Redcliffe
Register, get sponsored and help people with Motor Neurone Disease

WALK TO D-FEET MND

Never Give Up!

www.mycause.com.au/events/walktodfeetmndredcliffe2019

mnd Queensland

BRISBANE WALK TO D-FEET MND 2019 - A GREAT DAY OUT

It was a cool, foggy start at Roma Street Parkland on Sunday 26 May for the Walk to D-Feet MND Brisbane, but the morning turned into a great day out.

Around 500 people were in attendance for the walk and this year's event raised more money than ever with an income of around \$62,000!

Jacko from Bay FM kept the crowd entertained from his live broadcast van and the Lions Club of Brisbane Inner North fed our hungry participants with a sausage sizzle. The very cute No. 1 Coffee Bug served up hot beverages to warm us up and Lissy from Physio One provided massages and an assessment for our attendees for a small donation to MND Queensland.

The walk was led by Liam from the Brisbane Boys College Pipe Band who added a very special tone to the

event playing the bagpipes.

Walk events are very important to us as not only are they major fundraisers so that MND Queensland can continue to provide quality services and support to families affected by Motor Neurone Disease, but they are also important to help us raise awareness in the wider community to help educate people about this mystery disease.

Many thanks to all of our participants, donors, and volunteers for making this our biggest fundraising walk yet! We look forward to growing the walk even more in 2020.

If you missed the Brisbane or Gold Coast walks, you might be interested in attending the Walk to D-Feet MND Redcliffe from 9AM on Sunday 13 October. You can register online now at www.mycause.com.au/events/walktodfeetmndredcliffe2019



RECORD-BREAKING GOLD COAST WALK TO D-FEET MND 2019

This year's Walk to D-Feet MND Gold Coast saw us at a new venue - Hollindale Park, Main Beach - which turned out to be a beautiful, breezy seaside walk on a perfect day out.

Around 260 participants turned out for the walk on Sunday 31 March and overall around \$45,500 was raised, setting a new record for the Gold Coast walk! This is a significant fundraising result from the event and we are so grateful to everyone who registered and raised funds on behalf of MND Queensland. All funds raised through our fundraising events help MND Queensland provide information, advice, referrals, support groups, loan equipment and more to assist Queensland families affected by Motor Neurone Disease.

The Lions Club of Southport supported the event with a

sausage sizzle and were busy feeding everyone. Our friends from The DNA Coffee Company brought their coffee van and served up tasty hot drinks and also donated part-proceeds from their sales on the day to MND Queensland.

We've had some great feedback about the new venue and we hope to hold the 2020 walk at Hollindale Park again.

Our volunteers worked hard on the day to ensure that everything ran smoothly and we are so grateful for their time and effort.

We'd like to congratulate all of our participants for a fantastic effort and thank everyone who supported the event.



BRIEF (BUT GREAT) NEWS

This year has seen an increase in third-party fundraising activities and we are so grateful for everyone's fantastic efforts and contributions. On top of this we've been the beneficiary of a few philanthropic grants that we'd like to share with you too.

Major Grant to Purchase Equipment

MND Queensland was one of the few fortunate recipients of a major Gambling Community Fund Commemorative grant this year which is allowing us to purchase more equipment to offer Queenslanders through our Equipment Service.

Lord Mayor's Grant to Purchase Hospital Beds

We were also one of the lucky beneficiaries of Brisbane City Council Lord Mayor's Charitable Fund grant (\$6,365) which funded the purchase of two hospital beds to offer to MND clients in the Brisbane Region.

Lifted Up by a Mazda Foundation Grant

In May we were notified that we had won \$9,350 from the Mazda Foundation to purchase a hoist and sling set to offer through our Equipment Service.

Rotary Club of Toowoomba North High Tea

The Club held a fundraising high tea on Saturday 30 March in Toowoomba and raised \$1,375 for MND Queensland. Below is MND Qld's Seth Launder accepting a cheque from the Club's President Robyn Jeffery.



Day for Dan - Newtown Football Club Fundraiser

The Toowoomba-based Club held a fundraiser to honour one of their members who had been diagnosed with MND and raised almost \$20,000.



JezStock07

An afternoon of music was held on 6 July at The Bearded Lady in West End. The day raised almost \$2,000.

Matt's Memory for MND Fundraising

Kelli, Jacob, Lara and Sian Downey have raised more than \$9,200 through various activities in the Boyne Island/Tannum Sands region over the past 12 months in memory of their late husband and father Matt who passed away in June 2017 at the age of 40 after a courageous 30-month battle with MND. Fundraising under the banner of "Matt's Memory for MND", the Downey family hosted a successful football day and jersey auction in April with the support of the Tannum Seagulls Senior Rugby League Club. Matt was a life member and well respected former player and coach of the club. Other fundraising efforts included a multi-affle and money boards at the Boyne Tannum Sharks Senior Football Club and a blue cupcake and jelly cup sale, supported by the St Francis Catholic Primary School community.



Lindmar Open Garden

Our Brisbane North & Caboolture Support Group volunteers hosted a sausage sizzle during the Lindmar Open Garden weekend and raised over \$1,200.

Moda Dinner

40 guests were treated to a special dining experience at Moda Restaurant (Petrie Terrace) on 13 June. Hosted by Dean Palmer, David Schwarz and Kate Avery, and sponsored by their companies Kare Lawyers, Skybound Fidelis and Tucker & Cowen Solicitors, over \$10,000 was raised for MND Queensland. Guest speakers were Sallyanne Atkinson AO and Dr Adam Walker from QBI. Special thanks to Simone Mulvey, Camaron De La Vega and to Moda.



Lions Club of Wilsonton

This Toowoomba Club are great supporters and recently donated \$5,000 to MND Queensland at their annual changeover dinner event in July.

We thank everyone above for your support of MND Queensland and the people right across the State that we support. Your energy and enthusiasm to help others is genuinely appreciated. If you would like to make a positive difference in the lives of people affected by MND by hosting your own event or fundraiser, contact Georgia on 07 3372 9004 or email events@mndaq.org.au.

INAUGURAL MORANBAH TO MACKAY RIDE FOR MND A SUCCESS

Mick Scholer has been our highest Chillfactor Challenge fundraiser for the past two years. This year Mick wanted to start a new 235KM, one-day bike ride fundraising event. We were so excited about this massive challenge and gave our full support and we're glad to report that it was a huge success raising over \$30,000!

Mick's enthusiasm to help people with MND and make a positive difference is infectious! His passion to help others assisted him to recruit sponsors, 12 riders, plus volunteers to make his ride idea a reality on 20 July.

Organising an event of this scale is no small task. Mick ensured that all boxes were ticked to make sure that the

ride ran safely and smoothly. We would like to thank Mick for all of his hard work in making this inaugural event such a huge success and look forward to an even bigger and better 2020 ride.

We also acknowledge the fantastic contributions of those who sponsored the ride including: *Gold Sponsors* - Fulton Hogan and Surelift Cranes; *Silver Sponsors* - FKG Group, Corry Cycles and ABC Heavy Engineering; *Bronze Sponsors* - Muscle Garden and NGV Services along with *Event Sponsors*, On The Run, Tincone, Civeo, and the CQ University Mackay Health Clinic.



Pictured: Riders participating in the inaugural Moranbah to Mackay Ride for MND 2019

MACKAY CHILLFACTOR CHALLENGE AND MND BLUE TIE BALL

For the third year running, local volunteers again organised a day of MND fundraising at the Magpies Sporting Club in Mackay on Saturday 27 July.

The day kicked off with the Chillfactor Challenge which saw participants take the icy slide. Around \$10,000 was raised from the Challenge.

Later in the evening was the MND Blue Tie Ball with around 180 people enjoying a great meal and drinks plus entertainment from AFL legend Robert DiPierdomenico and champion jockey Greg Hall. Guests were also entertained by illusionist Duck Cameron and danced the night

away to the band Mango Junction.

We sincerely thank the participants, guests, volunteer organisers and sponsors for making these events a success. We acknowledge the fantastic support of our Major Sponsors: Glencore, WorkPac Group, Elastomers Australia and Magpies Sporting Club, along with Event Sponsors Let's Jump, Magpies AFC and Events by Ramona.



KINDRED TALES - RECORDING FAMILY HISTORIES

Kindred Tales is a video production company specialising in capturing living history. Providing a unique opportunity to video record your grandparents, parents, siblings, friend or even your own story. They offer a variety of specialised services designed to capture different stages of people's lives.

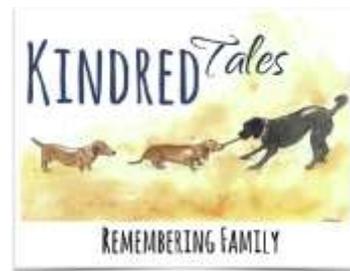
The owner of Kindred Tales, James Terry said, "this is more than simply recording engrossing family memoirs, it gives you the opportunity to leave an everlasting message of love and joy to your loved ones and future generations". He added, that, "through discovery and understanding what has gone before, it can provide us with an avenue for reconnection and enhanced family wellbeing".

People are complex, their lives are hectic and families can be spread far and wide. So when it comes to family history and remembering our loved ones, it's often put in the *I'll do it later* basket. Unfortunately for many of us, the desire to discover more about our history comes too late. As a result, when a family member dies, so goes your connection to discover their past. As Dr Seuss said, "Sometimes you will never know the value of a moment until it becomes a memory".

If you feel that these tales are important for future generations to hear, reflect on, learn and understand where they come from, and, what impacts others' lives, then maybe the time to act is now.

Kindred Tales have tailored a specific package especially for MND Queensland clients including a 20% discount. They recognise the circumstances that people diagnosed with MND and their families find themselves in and acknowledge time is of the essence.

To find out more about Kindred Tales, you can find them at www.kindredtales.com.au or email James directly at james@kindredtales.com.au and ask about the **MND Queensland** package.



Walk to D-Feet MND Toowoomba 2019

9AM, Sunday 8 September, Queen's Park Botanic Gardens
Register, get sponsored and help people with Motor Neurone Disease



Never Give Up!

www.mycause.com.au/events/walktodfeetmndtwb



Motor On for Motor Neurone Disease

Join us for a fun car scavenger hunt around Brisbane. It's going to be a great day out for the whole family. There will be prizes for best dressed team, best decorated car, highest fundraising team & more! This FUNdraising event will assist MND QLD provide quality support & services & further research for a cure!

When: 10AM, Sunday 3 November 2019

Cost: \$40 per car

Register & fundraise at: www.mycause.com.au/events/MotorOn

Queries: call Georgia on 07 3372 9004 or email events@mndaq.org.au



MEET OUR DIRECTOR OF SERVICES - STACEY THORPE

Stacey Thorpe commenced with MND Queensland as Director of Services in May and brings with her a wealth of knowledge and experience which is already benefiting our clients. We recently interviewed Stacey to help you get to know her a little more.

Please tell our readers a little about your background in working with people with MND or people with disabilities?

I have worked in the disability field for just over 8 years. That time has been spent in coordination and management roles relating to direct service delivery. Supporting people to ensure their daily personal care needs are met so that they can maintain as much independence as possible. Whilst most of those clients were people with spinal cord injuries, I had worked with some people with MND and so had some awareness of the complexities of the disease and how much support was needed for the whole family.

What do you believe are some of the biggest issues facing people with MND and how do you think MND Queensland can best respond to these issues?

I think that generally people are facing a wide range of both emotional and physical challenges and that needs can change really quickly but I think it is also really important to remember that people are individuals and we all respond to things differently. I believe that we need to ensure that our service is not generalist but tailored to each individual and that we really listen to the people we are supporting so that we can grow our service offerings to meet ever changing needs. It is also important that all of our supports are provided in a timely manner by well trained staff who have a good understanding of MND and its impacts.

Currently undertaking a small survey and will continue to ask the people we work for what they need from us and show that we are listening.

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

I think that it is mostly because the needs of someone with MND are so great and so real and therefore if we can contribute in some way to meeting those needs and making the lives of our clients and their families a little easier then that is really important work. There is a lot in the sector that is positive in terms of the introduction of individualised funding but there is much more progress required before our clients' needs will be met and I'm keen to ensure that people with MND have a collective voice in expressing that need.

What is the most personally rewarding aspect of working at MND Queensland?

I have never experienced such a sense of community as I have since joining MND Queensland. Whilst MND is an awful disease, the response from people living with it, their families and wider community seems to consistently be, 'what can I do to help?' In a world where tragedy and violence are all around us, I am grateful that I get to see humanity at its very best.



I have never experienced such a sense of community as I have since joining MND Queensland. Whilst MND is an awful disease, the response from people living with it, their families and wider community seems to consistently be, 'what can I do to help?'

What new directions are in store for MND Queensland?

My current focus is on developing the services we offer through the NDIS and the first step is to provide Supports Coordination services. With the introduction of the NDIS, the way services like ours are funded has changed drastically and we need to change with the industry. This will enable us to develop the quality of the supports that we offer and whilst our clients who are aged over 65 don't have access to NDIS funding, we will ensure that our services are available to everyone regardless of age or funding.

From there, I am keen to understand what supports our clients want from us and respond to that so we are cur-

Any other comments or insights that you'd like to share?

As the manager of services I don't always get the opportunity to talk to all of our clients but I really do want to hear about any ways that we can broaden or improve our services to better meet the needs of the people we support so a phone call or email will always be welcome!

To get in touch with Stacey to discuss MND Queensland's services, please call 07 3372 9004 or email [Stacey at head-mnds-services@head-mnds-services.org.au](mailto:Stacey@head-mnds-services.org.au).

