

the cornflower

MND QUEENSLAND NEWSLETTER

MND Queensland's New Home

AGM Update & New President's Message

Equipment Grant from Fight MND

Meet Jason - MND Advisor & Support Coordinator



REGISTERED
PROVIDER



ENTERTAINMENT MEMBERSHIPS CAN SAVE YOU THOUSANDS

Who doesn't love a bargain? The Entertainment App has hundreds of discount offers on dining, shopping, entertainment and experiences which can save you thousands of dollars! Plus, every membership that MND Queensland sells helps to fund our work to provide support and services to Queenslanders impacted by MND.

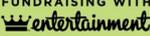
Unlike the old Entertainment Books, you now carry the Entertainment App with you wherever you go with your phone, which makes grabbing a discounted offer super-convenient! Most users find that the savings pay for the membership within just a few uses, plus there are new discounts being forwarded to your app all the time.

You can choose a Single City/one-year membership, Multi City (21 cities inc. NZ and Bali) or a Multi Plus (21 cities for two years). Purchase your membership between 1 Dec 20 - 31 Jan 21 and MND Queensland receives an extra \$10 for Single City memberships and an extra \$20 for Multi Year/ Multi Plus memberships.

Memberships are valid from the date of purchase, so get yours today and start saving at www.entertainment.com.au/orderbooks/2221j21.

A time for giving & getting together

Buy an Entertainment Membership to help us raise **MORE** this festive season.

FUNDRAISING WITH 



2021 MEMBERSHIP RENEWALS ALMOST DUE

Annual membership is due from 1 January 2021. Watch out for your renewal notice coming soon by email or post. For more information contact our Membership & Community Liaison Officer, Leigh Gilbert by calling 07 3372 9004 or email info@mndaq.org.au.

CONTACT US

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

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

FEEDBACK AND CONTRIBUTIONS

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

DONATIONS

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



FROM THE CEO'S DESK

OUR INVINCIBLE SUMMER

"In the depth of Winter, I finally learned that within me there lay an invincible summer." Albert Camus.

How true is this as a metaphor for the year we have had and for those of our dear MND community that are trying to navigate an understanding of their diagnosis? What a year! As an organisation we have experienced the winter of change; COVID-19, change on the Board and on our staff, change in where we work and how we work, change to our budget as the cancellation of events bit deep into our reserves, loss of dear friends.

But then we also discovered our "invincible summer"; how to let go of things that don't help us move forward, how to say goodbye and how to say hello and welcome. We discovered in our "invincible summer" the legacy of those who have gone before us and laid the foundations of the organisation that we have become, those whose names are now remembered on plaques but have travelled with us to a new home. We have discovered in our "invincible summer" the joy and determination in life and we have discovered and rediscovered that through those people living with MND, their families and carers, their Allied Health Professionals and their Support Workers. We have discovered in our "invincible summer" how to face fear with courage, uncertainty with belief and pain with resilience.

I have heard some people say they believe we have lost our way. I would always welcome a conversation with anyone who feels like this and is willing to open their eyes and ears to what we are doing. I want to understand why they think that and I want to make sure they know the facts so they can see what I see:

- This year I have seen the staff keep going through the COVID-19 lockdown and not miss a step in their provision of service to those who need us
- I have seen the staff grow to meet increased demand where other charities are closing their doors or restricting services
- I have seen our equipment come from the darkness of dispersed sheds to the light and cleanliness of a single beautiful warehouse facility
- I have seen clients and carers and Health Professionals visit us on-site for support, equipment and services
- I have seen brand new equipment arrive via generous grants and donations and leave us quickly to go clients in regional and remote areas
- I have seen us providing our first Allied Health services through the development of our OT services, the first steps on the way to an inter-disciplinary specialist MND team.
- I have seen a rapidly shrinking financial reserve shored up by our wonderful MND Community and



Service Group donations

- I have seen breakthroughs in MND Research and close working relationships develop within the MND Alliance across Australia

Yes it has been a tough and hard winter but our "invincible summer" has arrived. In the physical world we will see floods and fires again and I want all of you to be ready... not waiting to see what happens. Have your plans in place. Make sure that you have a plan to get out if you have to, that you have notified neighbours and the SES if you need to move a person with mobility challenges, and that you are ready to leave quickly to a place that is safe. If any of you need help to prepare then give us a call or look on our website or Facebook to get advice on a Summer Emergency Plan... make sure that this is an "invincible summer" for you all.

From myself and my wonderful Team at MND Queensland, we hope that you and your loved ones find some joy and laughter over the Christmas and Holiday season, that you get the chance to meet and enjoy the company of people you may not have seen for a long time.

Bless your generosity and your courage and I look forward to 2021 being an easier journey for you than 2020... and I look forward to sharing it with you. We are here if you need us.

Kind regards
Ian Landreth
Chief Executive Officer

A MESSAGE FROM OUR NEW PRESIDENT GAYLENE COULTON

In my first message to you all as the newly elected President of MND Queensland, I just wanted to say “thank you” for the opportunity to serve. There are many people in this organisation, Board members, staff, volunteers, who give generously of their time, all committed to lessening the impact of MND in our community and to support MND Queensland. In the five months that I have previously served on the Board as Treasurer, I have seen massive change in the organisation under Ian’s professional and transformative leadership and a dedicated team navigating the challenges of a COVID environment with a significantly reduced revenue stream and still managing to extend services to those who look to us for support.

I am sure most of us will reflect on 2020 as a year that we are glad is nearly over. It’s had some wonderful highs and horrible lows for so many of us, but I believe it has also reinforced for most people the importance of family and friends and an appreciation of truly simple things in life. After a few years of living interstate and never getting home to my parents and family in Brisbane, I had already set a goal of spending more time there this year. I am thrilled that my work in aged care is now bringing me to Queensland regularly and I have the opportunity to spend valuable time with them. I know a lot of MNDQA service recipients and their carers will also have a huge appreciation of their loved ones and simple pleasures throughout the difficult journey they are on.

I would like to thank outgoing President Peter Forday who stepped up mid-year and accepted the position without hesitancy (well maybe a little!). Peter has provided the leadership and guidance needed to tackle some big strategic initiatives over the last five months and he will be missed. I would also like to thank my Board colleagues – Secretary Megan Peach, Directors Evan Nunn and Elyse Maberley. Megan with her indefatigable energy and drive makes sure we meet all our commitments from a good governance perspective and is fun to boot! I am thrilled that Evan and Elyse are also able to continue on the Board and accept positions as Treasurer and Vice President respectively. As people with busy full-time jobs and busy lives I am very appreciative of their volunteer commitment to MNDQA.

I am also delighted to introduce Ms Sue Graham who was elected to the Board at the AGM. Sue is CEO of Multicultural Communities Council Gold Coast and along with her diverse skills and experience she will continue to ensure that people from a culturally and linguistically diverse background are considered around our Board table.

We are grateful that Members supported changes to the



MNDQA Constitution at the November AGM. These changes were absolutely necessary to remain compliant with legislative changes, remove outdated clauses or phrasing, enable the Board to be responsive and practice good governance and enable greater Member benefits and engagement. There are further additional changes to the Constitution that the Board believe are needed and it is likely we will hold a General Meeting of Members in May 2021 to propose these changes.

In an economic recession and without funding from Government, the year ahead will continue to be a challenging one but with the newly elected Board and an awesome staffing team, we are up for the challenge! The new Board and the current Management Team are committed to enhancing engagement with you as our Members and service recipients. We want to hear from you if you have a story to tell us, an idea to share, a complaint to make. You are the voice that we need to hear and your calls or emails will always be welcomed and responded to.

I refer you to the Christmas Appeal if you haven’t already found it. The much needed funds raised through these kind donations enable us to provide services to those who cannot afford the equipment and support that they need and for whom there is limited financial assistance.

I wish you all a safe summer and hopefully the opportunity to connect with your family and friends to enjoy some simple pleasures in our lives.

A handwritten signature in cursive script that reads "Gaylene Coulton".

Adj Prof Gaylene Coulton
President

COVER STORY - MND QUEENSLAND'S NEW HOME IN OXLEY

In September this year, MND Queensland moved into a larger office and warehouse facility in Oxley.

The move to our new site took weeks of work, but we've settled in now and our essential services for people with MND continued uninterrupted during the move.

Our old base, Charles Graham House at 35 Wedgetail St, Inala was our home for many years. The small, three-bedroom house with a storage shed out the back was getting a little tight for our growing team and our equipment was spread over five sheds, including four storage sheds that we hired offsite which was difficult for our small team to manage.

It was major a move to shift the office after so many years in Inala, but it's already paying off with a more streamlined Equipment Service. Having all of our equipment under one roof means we can get a better idea of what's available to hire out, what needs maintenance or cleaning etc. One site also makes equipment deliveries and returns much easier.

Our new office means that all of our staff can be located



under one roof making it much easier to liaise with one another and this is also an improvement in our service.

The move has been very exciting for us and we welcome you to drop in to visit us at 1/89 Factory Road, Oxley. We're not far from Bunnings Warehouse Oxley.

2020 ANNUAL GENERAL MEETING UPDATE

Thank you to everyone who responded for online voting and joined in the AGM! It was fantastic to achieve our goal of greater overall participation across Queensland by our Members in Association decision-making and/or attendance at our AGM (up by 33%), despite the constraints of COVID. All resolutions were carried; meeting minutes and records can be found on the website.

It was a milestone AGM for launching the 2020-2023 Strategic Plan; reflecting record revenue in our financial reporting; and enacting required Constitutional reform; plus welcoming Wayne and Louise Stanford as Life Members, in recognition of their consistent and tireless volunteering efforts in support of many events over the years.

A strong legacy of the Association and our collective purpose together was acknowledged during the meeting, as well as celebrating a snapshot of achievements for the period and recent milestones such as moving into a new home under one roof. We also recognised the above and beyond efforts of our Chief Executive Officer Ian Landreth and the amazing MND Queensland team. 2020 has been a very challenging year for the operation and yet our tireless team provided continuous service as well as new and extended supports to people living with MND.

We also excitedly welcomed Sue Graham to our motivated, passionate, highly skilled team of serving Board Directors now inclusive of Gaylene Coulton (President); Elyse Maberley (Vice President); and Evan Nunn (Treasurer). Planning for 2021 has already begun!

We encourage our Members to become involved in the Association in any way that suits you – please never hesitate to call the office, or contact the Board, with any queries or ideas.

We wish everyone the peace of the season. May your days be merry and bright.

Warmly
Megan Peach
Company Secretary



MARK YOUR DIARIES - FUNDRAISING EVENTS PLANNED FOR 2021

What a year it has been! For many the pandemic has affected the way we live, work and conduct ourselves every day. For MND Queensland this has meant that fundraising has taken a hit! More than ten annual events including the Walk to D-Feet MND events, the Motor On for Motor Neurone Disease Car Rallies, the Mackay Chillfactor Challenge and MND Blue Tie Ball and more were all cancelled. This resulted in approximately \$220,000 in lost income. The support MND Queensland receives via funds raised through community events is vital for us to continue to support Queenslanders with MND.

However, 2021 is looking bright! We've been busy planning a range of events and we're looking forward to the year ahead. Following are just some of the events that we'll be hosting in 2021:

Walk to D-Feet MND Events

Our walks are a way to pay tribute to those families affected by MND and remember those who we have lost to this terrible disease. We have five walks planned, including the national walk (Sunday 2 May) which will see all the States across Australia walking for MND.

- Gold Coast : Sunday 21st March. Register now at: www.mycause.com.au/events/walk2dfeetmndgc2021
- Brisbane : Sunday 18th April. Register & fundraise: www.mycause.com.au/events/walktodfeetmndbrisbane2021
- National (Springfield Central, but if you want to walk in your location, we can support you to do that too) : Sunday 2nd May: Register now at: www.mycause.com.au/events/walk2dfeetmndsfield2021
- Toowoomba : Sunday 12th September
- Redcliffe : Sunday 17th October

Motor On for Motor Neurone Disease

This fun, car scavenger hunt is a great family day out and returns in 2021 with the first rally concentrating on the

south-east/bayside region of Brisbane.

- Sunday 21 February. Register & fundraise at: www.mycause.com.au/events/motoronforMNDsummer2021
- Sunday 18th July. Registration site to come.

Roaring 20s Reimagined – MND Gala Event

The roaring 20s are back! Join MND Queensland from 6PM on Saturday the 29th of May for an evening of glitz and glamour in the aim of increasing awareness and raising vital funds.

Hosted at the lavish 'Mirra' in Fortitude Valley, dress to impress in your Gatsby gear as you enjoy a cocktail style fundraiser that will transport you back to a time where the party never ended! Prepare to be dazzled by performers, decadent food and beverages, and exclusive entertainment. Try your luck on the casino fundraising roulette table, poker or money wheel.

Tickets include a cocktail on arrival, followed by a three-hour drinks package, canapés and decadent treats, plus an incredible array of entertainment and \$20 worth of funny money for the casino experience. Sponsorship Packages are also available for a VIP experience!

Get your tickets now for an evening to remember at <http://tix.yt/mnd-qld-gala>.

Whitsundays Kayak Challenge for MND

This one's for the adventure lover... we're planning an exciting kayaking tour of the Whitsundays which will be taking place in August with more details to come soon. Watch Facebook for further information.

If you would like to hold your own fundraising event, or if you have any event queries, please contact our Events & Fundraising Coordinator, Caitlin Mulcahy by calling 07 3372 9004 or email events@mndaq.org.au.

MND QUEENSLAND GALA FUNDRAISER

ROARING 20S REIMAGINED

6PM, SATURDAY 29 MAY 2021

Join us for a 20's-themed cocktails & canapes gala fundraiser with fabulous entertainment, casino games, auctions, a raffle & more at Mirra, Fortitude Valley

Get your tickets now at <http://tix.yt/mnd-qld-gala>

AN UPDATE ON KEV & LEANNE'S TREK ACROSS OZ

Since leaving their home in Deception Bay on the 4th of September this year, Kev and Leanne have travelled right up to the northernmost tip of Australia on their 'Travelling with MND' trek.

Kev was diagnosed with MND in January 2020 and decided that he wanted to do what he loves, while he can, and bought a fancy caravan so that he and Leanne could still enjoy the little luxuries while they may their way across Australia to Perth where they plan on resettling. At the time of writing, they have just arrived in Broome.

Ticking Cape York off his bucket-list was high on Kev's agenda when he left, and we were thrilled to see him reach the tip of Australia recently. After this they went south again and stayed in Townsville for around a week where they held a fundraiser at the Townsville Tourist & Lifestyle Village before heading west. Kev's next bucket-list item is to go scuba diving in Coral Bay (WA).

Over the course of their trip, Kev and Leanne have generated quite a bit of television and print media attention which is helping to increase community awareness about MND and help demystify the disease.

So far Kev and Leanne have raised \$2,681 of their \$10,000 fundraising goal to help MND Queensland provide support and services to other families impacted by MND across the State. You can donate to their My Cause donation page at <https://bit.ly/3aEvi9H>.

You can also keep up with Kev and Leanne's Trek Across Oz, by following their Facebook blog www.facebook.com/Traveling-with-M-N-D-100439588404273.

If you would like to help increase awareness on MND and raise vital funds to provide essential services, contact Caitlin Mulcahy, Event and Fundraising Coordinator by calling 07 3372 9004 or email events@mndaq.org.au.



Pictured: (above) Kev and Leanne celebrate their conquest of Cape York. (below) Their vehicle proudly promoting MND awareness.



10AM, Sunday 21 February 2021

Start your engines for the *Motor On for Motor Neurone Disease* car scavenger hunt on Sunday 21 February. This fun, family event will see teams searching for clues across the south-east side of Brisbane and end with a picnic and awards (e.g. first team to complete, best-dressed team, best decorated car...). Register your team now and get sponsored to raise vital funds to support families impacted by MND.

www.mycause.com.au/events/motoronforMNDsummer2021

MND QUEENSLAND SERVICES - MAKING WISHES COME TRUE

Patricia was diagnosed with MND in July this year. Her diagnosis came late in her progression as she had other health problems that she thought might be causing her balance issues and hand cramping and there were lengthy time lapses before any neurologist could determine her condition. She felt a definite lack of support in those early stages, and her frustrations were only compounded by the COVID-19 restrictions which meant that she also couldn't see her family in Shellharbour, NSW.

Patricia's family had a bundle of joy delivered in November 2019 with the arrival of her grandson Liam, the son of her only son Stephen. While Patricia and her husband Colin travelled south through bushfires and drought for Liam's birth, her MND symptoms and COVID-19 restrictions prevented her from travelling down again for Liam's christening and for his first birthday. But with MND Queensland's help, once the border restrictions were lifted Patricia and Colin were able to reunite with their family and cuddle Liam once again.

She described her difficulty in finding support when she was first diagnosed, "As soon as I was diagnosed with MND I was devastated and bewildered. Who could help me? Where do I go for help? Online websites about the condition were so very depressing and painted a very grim prognosis."

When asked about how MND Queensland supported Patricia to make her trip south she said, "The most wonderful thing that happened to me and my husband this year was the support of MND Queensland which enabled me to be reunited with my family in Shellharbour."

As soon as she was in touch with us, MND Queensland's support services were quick to step up to assist Patricia coordinate her NDIS package and provide her with the support she needed. She said, "I joined MND Queensland and immediately I was contacted by phone and then visited by an MND Support Coordinator. The Coordinator was very helpful and other MND support workers urged me to apply for NDIS funding. They supported me quickly and informed me thoroughly on how to apply and what I could apply for in terms of the MND diagnosis and prognosis... I was immediately interviewed online by an Occupational Therapist from MND Queensland who wrote an extensive report that enabled me to receive full NDIS funding to support my immediate and ongoing needs."

MND Queensland staff are specialists in providing support to people diagnosed with this awful disease and they can also make people's MND journey's a little less stressful, and they can even help wishes come true... Patricia told us "through MND Queensland and my NDIS funding I was



able to hire a wonderful power wheelchair and a disability vehicle to cart me and all of my equipment down to Shellharbour. The funding also paid for all of my equipment so that I could get about in the apartment in Shellharbour and at home. There is so much more that MND Queensland have supported me with since my diagnosis and I am thankful for those special people like Miriam, my OT extraordinaire and Sandra, my amazing Support Coordinator who works hard making sure my funding covers everything I need and may need, and if it doesn't she gets onto it presto pronto! Down in the main MND Queensland office, Stacey, the Director of Services makes sure all is going as it should and organises online informative webinars with specialist guests to help and support MND sufferers with physical and emotional needs. Without MND Queensland and the special people who work there, I doubt I would be as well informed or supported to undertake this holiday to see my grandson."

Patricia is very grateful for the support she has received, passing on the following message, "Thank you MND Queensland for your ongoing support and specialist care. It is the staff and their expertise and concern for MND sufferers that have made a difference in my life. People make the difference – support MND Queensland staff."

Making wishes come true is so rewarding for our team and we are so happy to see Patricia reunited with her family. If you have any MND support needs, please contact our office by calling 07 3372 9004 or email info@mndaq.org.au.

MND RESEARCH AUSTRALIA GRANT RECIPIENTS ANNOUNCED

Our national research body MND Research Australia, recently awarded almost \$3 million to support innovative research projects in Australia that are set to commence in 2021. Among the grant recipients were quite a few Queensland projects as shown below. Congratulations to all the grant winners. We wish you well with your important research projects. You can find the full list of recipients at <https://bit.ly/36bYBQ4>.

POSTDOCTORAL FELLOWSHIPS (2021 – 2023)		
Recipient	Grant	Project
Dr Thomas Shaw University of Queensland	Bill Gole MND Postdoctoral Fellowship 2021 – 2023	Ultra-High Field MRI of Spinal Cord Tissue in Motor Neurone Diseases
INNOVATOR GRANTS 2021		
Dr Shyuan Ngo University of Queensland	Charcot Award, funded by the NTI MND Research Grant awarded to the highest-ranking innovator grant application	MND in space and time: deciphering the spatio-temporal landscape of cell-autonomous and non-cell-autonomous drivers of motor neuron death in MND
Dr Victor Anggono University of Queensland	Judy Mitchell MND Research Grant	Molecular mechanisms underlying the cytoplasmic aggregation of the RNA binding protein, SFPQ, in ALS
Dr Robert Henderson University of Queensland	Col Bambrick MND Research Grant	A Novel PET Imaging Marker of Astrocytes and Glutamate Reuptake in Brain and Spinal Cord in ALS
Prof Pamela McCombe University of Queensland	Run MND NSW Research Grant	Revisiting excitotoxicity in ALS: how does this occur?
Dr Frederik Steyn University of Queensland	MonSTaR MND Research Grant	N-acetyltransferase 1, a modifier of disease outcome in patients with MND
Dr Adam Walker University of Queensland	Fat Rabbit MND Research Grant	Defining the involvement of ubiquilin-2 in MND
MNDRA LINDA RYNALSKI BRIDGE FUNDING GRANTS 2021		
Recipient	Project	
Dr Richard Gordon University of Queensland	Targeting inflammasome-driven neuropathology and motor neuron death in MND using a clinically approved cancer drug	
Dr Trent Woodruff University of Queensland	Transcriptomic and Functional Evaluation of Immune-Activated Monocytes in MND	

WALK TO D-FEET MND GOLD COAST 2021

9AM, Sunday 21 March, Hollindale Park, Main Beach
www.mycause.com.au/events/walk2dfeetmndgc2021

register now & start fundraising
funds raised support people with MND

WALK TO D-FEET MOTOR NEURONE DISEASE

mnd Queensland

WALK TO D-FEET MND BRISBANE 2021

9AM, Sunday 18 April, New Farm Park

Register now, get sponsored & help make a positive difference in the lives of people with MND
www.mycause.com.au/events/walktodfeetmndbrisbane2021

mnd Queensland

WALK TO D-FEET MND

FIGHT MND GRANT WIN TO PURCHASE ESSENTIAL EQUIPMENT

MND Queensland was recently a recipient of a major grant from Fight MND which was used to replenish our equipment pool.

Fight MND has provided grant funding direct to MND State Associations across Australia to enable the purchase and distribution of equipment. This takes Fight MND's contribution to improving the quality of life of those suffering from MND to \$4.58 million since 2017.

Fight MND Co-founder and Care Director, Pat Cunningham says the importance of providing funding for the ongoing care of MND sufferers is a key focus of Fight MND.

"We know MND is a beast and through this funding we can improve the quality of life of those battling the disease as well as assisting those wonderfully inspiring people that care for them," Cunningham said.

"MND Queensland have been doing incredible work providing care solutions over many years for people with MND and we are pleased to be able to commit some of the Fight MND Army's generously donated funds to support that further. In consultation with MND Queensland, the most pressing and urgent needs were identified to ensure the people that require equipment could access it without delay."

Peter from Queensland, diagnosed with MND in April 2019, is a recipient of a new hospital bed to make life more comfortable courtesy of the Fight MND grant.

"I'm in that bed for 12 hours a day, so it's half my day they're supporting," Peter said with a smile.

"There's nothing else that supports me that much. It's really very comfortable and keeps me in the right position," he said.

MND Queensland would like to thank Fight MND for this generous grant which will benefit so many Queenslanders with MND.



GENETIC TESTING FOR MND: TELL US ABOUT YOUR EXPERIENCE

Genetic testing is becoming more widely available for people with MND. Currently, not everyone with MND is offered genetic testing. However, this may change in future if testing results guide future treatment clinical trials. Genetic testing may also provide information for other family members about their risks and help them plan their future. Not everyone proceeds with genetic testing, and there are no specific guidelines for how genetic testing should be offered to people with MND and their relatives.

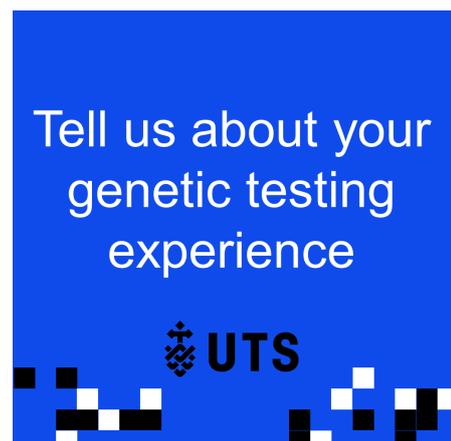
If you, or a family member, have been offered genetic testing, researchers from the University of Technology Sydney would be interested in interviewing you at a time of your choice. Interviews can be done by telephone, video conference, text or email.

The researchers hope to learn more about your experience of being offered (and if relevant, undergoing) genetic testing for MND, and your suggestions for improving experiences in the future. They plan to use this information to create guidelines for genetic testing and counselling for people with MND.

If you are interested in taking part or would like more information, please either complete the form here: <https://redcap.link/qs0liv24> or contact Ashley Crook by email Ashley.K.Crook@student.uts.edu.au.

This study is part of a PhD project and has been approved by the Human Research Ethics Committee, University of Technology Sydney (Approval no. ETH20-5122).

Ashley will be presenting more on the topic of genetic testing and genetic counselling at our January Online MND Support Group meeting. If you would like more information about genetic testing for MND, visit www.mndaust.asn.au/Get-informed/I-have-MND/Familial-MND-and-genetic-testing or speak to your doctor.



MEET JASON - MND ADVISOR & SUPPORT COORDINATOR

Jason Russell commenced with MND Queensland in the role of MND Advisor and Support Coordinator in September this year. We thought we'd ask him a few questions so that you can get to know him a little more.

Can you please tell our readers when you started at MND Queensland and a brief background on your professional life and any relevant skills that you bring to the role?

I have been with MND Queensland a little over two months now. My recent previous roles were as a nursing assistant in theatres at a large private hospital supporting patients in a surgical setting. I also volunteered at Life-line on the crisis line and worked at the Salvation Army in homelessness accommodation assisting vulnerable people in the community transition from homelessness to long-term housing. Prior to this I spent 15 years+ in engineering steel fabrication in various roles including project management, purchasing, quality assurance, HR and accounts.

I bring to the MND role the knowledge acquired from my studies in psychology combined with a varied range of employment positions over the past 25 years. I have a real passion for assisting people, particularly those who are vulnerable, under pressure and in crisis to achieve their goals in many different settings. I definitely also bring the desire, motivation, skills, personal attributes and ability to learn and adapt to understanding and helping people with MND in my role as an Advisor and Support Coordinator.

Your title is 'MND Advisor and Support Coordinator'. What do you find is the greatest demand of your time in your role?

Finding suitable support services that not only understand MND, but also meet the critical timeframes for services needed for people diagnosed with MND. Given that MND is a fairly unknown disease with unpredictable progression rates, finding support services that can provide quality service and expertise in a timely manner is sometimes not easily found (particularly in remote areas of Queensland) and presents a great challenge on timeframes for myself and the team.

What do you find rewarding about working for MND Queensland?

That's an easy one, but I would say two things... Learning about the people we support and building relationships with them is very rewarding. Also, being part of a small tight knit team that works extremely hard to not only help people with MND, but offer each other help, advice and support no matter how busy we are!

Helping people get the best value from their NDIS packages must give you satisfaction. What tips can you give people who are new to the NDIS about getting the best value for money from their packages?

I highly recommend pre-planning with an MND Advisor and Support Coordinator after NDIS access is granted. This will help you better understand the NDIS process and get you thinking about what you need for support before you have your official NDIS plan meeting. Also,

look closely at your three areas of NDIS funding domains and the types of service providers you are going to need for funding not only now, but over the entire duration of your plan.

What about people that have been on the NDIS for a while... is there any advice you would give them about getting better value out of their packages?

Never be afraid to ask questions and get advice from your Support Coordinator and the NDIS! Especially if you feel you are not getting value for money or any benefit from a service provider or if the quality of your service providers is not up to the standard you deserve. A Support Coordinators role is to get you value for NDIS funding, so we will always be ready to help and support you to change to a more suitable or different type of service provider, but only if you tell us!

MND is such a complex condition to manage. What is one of the biggest learnings you've had since working at MND Queensland, or, what have you learned from this experience that you hadn't expected?

I think learning about how people cope with MND and the amazing strength and brilliant resolve they have living with MND was most unexpected. The extremely difficult and frustrating processes of mountains of paperwork and difficulties dealing with everyday appointments must be so hard for people MND. But after getting to know people with MND over the past few months you learn how tough people really are. MND does not get in anybody's way to do what they need to do and then find time to tell you how much they still enjoy life and share a laugh is something truly special to be a part of.

What do you get up to in your spare time? Any interests or hobbies?

I do enjoy football, fishing, golfing, motor bike riding but I have a two-year-old and struggle to sneak out of the house without her as she's too clever now! But really, I just enjoy anything we do as a family like going to the park, beach or playing anywhere that involves us getting out of the house together for either a trip or BBQ anywhere with family and friends.

Is there anything else that you'd like to share with our readers about your role at MND Queensland?

I am extremely lucky to have been given an opportunity to pursue such meaningful employment at a special place like MND Queensland, which aims to help to improve the quality of life, skills and independence of those living with MND. I feel very passionate about making a real difference in people's lives and find great inspiration in helping people with MND to continue to live their best life, their way, for as long as possible until we find a cure.



