Spring 2021

MNDnews

The newsletter of the Motor Neurone Disease Association of Tasmania

OUR PARTNERSHIP WITH TRIPLE M AND HIT

mnd Tasmania

Until there's a cure, there's care

MESSAGE FROM THE PRESIDENT

We are very excited to announce that we have formed a partnership with Southern Cross Austereo (SCA), who you may know better as the Triple M and Hit radio stations. You may have already heard about this as our own Tracey Dickson featured on the Jimmy and Nath breakfast show on HIT, and with the Spoonman on Triple M, to formally announce the agreement.

In this partnership, they are generously providing us with media support for the coming year to raise the profile of MND Tasmania within the local community, and to help create interest in our fundraising events. We have recently signed off on two radio commercials, so listen out for us on the radio.

You may have also heard Adrienne Reeve-Wells chat with Spoonman about how MND has impacted her life since 1986 when she lost her grandfather to this horrid disease. We are so grateful for Adrienne's willingness to share her story to raise awareness on familial MND. She was a great spokesperson for MND Tasmania, and we hope to be able to provide other opportunities for Adrienne and others impacted by MND to share their story. We would also like to say a huge thank you to Shannon Wells from Par Avion for donating a voucher for two for their Wineglass and Wilderness tour. Spoonman surprised Adrienne with this voucher live on air.

We are very humbled to have SCA helping us get the word out, and we appreciate their support. See our Facebook posts to listen to Tracey Dickson talking with Jimmy and Nath on Hit; and Adrienne with Spoonman on Triple M. We look forward to sharing more about this partnership throughout the year.

We are also working hard on redeveloping our website to have a fresh look and feel, and to make it easier for you to find the information you need. We expect this to be completed in the coming months. Let us know if you have any suggestions!

Please write and share your stories, opinions, questions, or any thoughts about this newsletter. Email me at info@mndatas.asn.au or see our contact details on the back page.

Kate Todd
President

MND TASMANIA SAYS THANK YOU

Donation Boxes

We have been busy placing donation boxes in businesses throughout our community.

We say a huge thank you to each and every business which has so generously allowed us to take up some of their valuable retail space to raise funds. If you know of any business that would like to assist MND Tasmania in this way and support those affected by MND, please get in contact with us today.

Southern Cross Austereo Partnership

As Kate touched on in 'From the President', we are delighted to have partnered with Southern Cross Austereo (SCA).

It is a fantastic opportunity to help raise more awareness of MND Tasmania and to educate the general community on the essential service we provide to Tasmanians living with MND. We are very grateful to SCA for their support thus far and for the exposure we have already had on HIT and Triple M. We cannot wait to continue this partnership and see what the future holds.

Stix Fishing Competition

When the weather started cooling down in late May, the fundraising started to heat up, with Shane Ling and team taking to Lake Macintosh for another of the infamous 'Stix Fishing Competition' events.

This event is held in honour of a great friend, and has raised a significant amount of money over the years. This year was no different with $4,710 raised in total. We are told these guys really know how to put the FUN in fundraising.

MND TASMANIA SAYS THANK YOU

Laura Reale, Catherine Blizzard's group, PhD student

Everyone at MND Tasmania is passionate about MND research. One of the most difficult things about MND is that there is no known cause, treatment, or cure, so research into these areas is essential. Laura Reale is one of the current PhD students from the Menzies Centre who is studying MND. Here is a short interview we had with her about her research.

When did you start working on MND and why?

I started working on MND in 2018 when I studied my honours degree in Dr. Catherine Blizzard's lab group. I was really interested in neuroscience and neurodegenerative diseases during my undergraduate degree, and knew I wanted to focus on research in this area. I worked as a pharmacy delivery driver to nursing homes at this time and learnt about MND from the people that worked there. This experience made me realise that the treatments available for MND are just not good enough, so I spoke to people at Menzies in research and got in touch with Dr. Blizzard. From our first chat I was certain I wanted to work in her lab group and contribute to the vision of a world free of MND.

What is the current focus of your research?

My research is currently focussing on how the major pathological protein in MND - TDP-43 – causes dysfunction in the motor cortex and spinal cord. I have a model where we can express this dysfunctional protein predominately in the motor cortex, and I can investigate how this dysfunction spreads through the system, and down to the spinal cord.

What are some of the recent findings from this work?

My research has identified that expressing dysfunctional TDP-43 predominately in the motor cortex causes a loss of lower motor neurons in the spinal cord. This is significant for disease, as it is these lower motor neurons that when lost, cause a loss of muscle innervation, and therefore loss of voluntary movement. My results suggest that dysfunction can spread through the system in MND, in a manner of forward propagation. I have also identified some pathways in the spinal cord that are affected by this expression of TDP-43 and will aim to recover these pathways in the final years of my PhD.

What is the most interesting aspect of this work?

I enjoy the focus my research has on the circuitry of the spinal cord. This circuitry is so complex, and I am constantly learning about new pathways or cells that are involved. Our model allows me to ask really specific questions about how the spinal cord circuitry may be affected in disease, and this is the part of my project that I find the most interesting.

What other research based activities are you involved with?

I have been involved in helping to organise the 2019 Annual National Brain Bee Challenge undertaken by year 10 students. I have participated in Hobart's 'Walk to D'Feet MND' annual walk in 2018 and 2019 and the international 'Global Walk to D'Feet MND' in Perth.

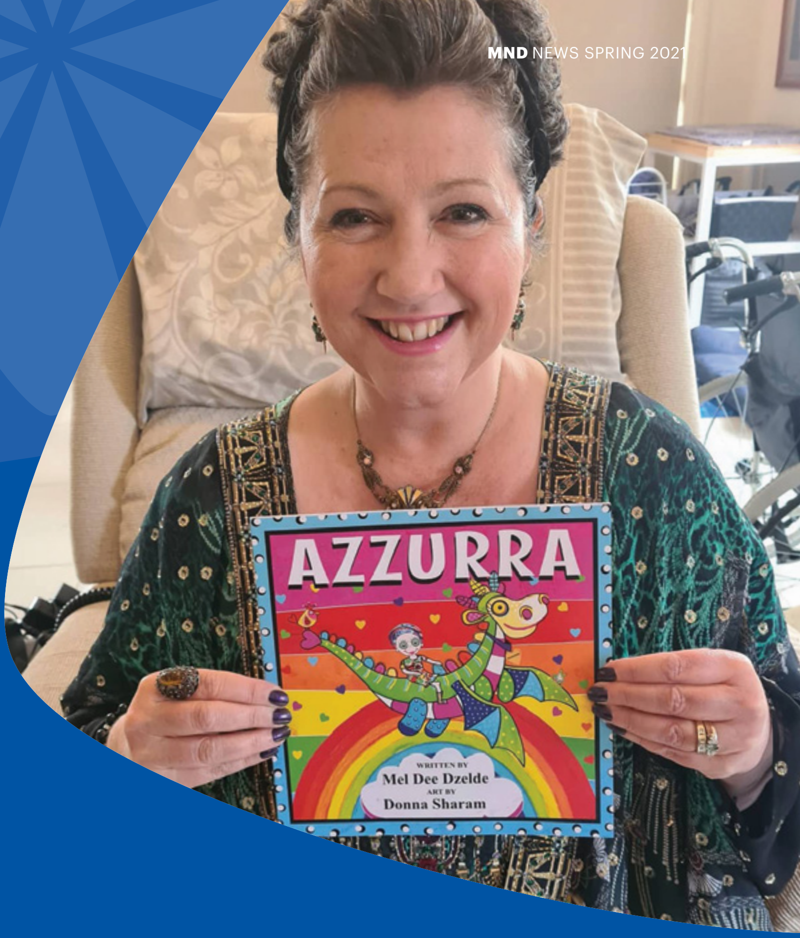
I have presented my work at a number of conferences including the 31st International MND/ALS Virtual Symposium, the 3rd Macquarie Neurodegeneration Meeting and at the 30th International MND/ALS Symposium where I was shortlisted for poster prize and awarded joint Best Poster Presentation award for this poster.

I have attended and assisted in hosting the Masonic Foundations annual general meeting at Menzies Institute for Medical Research and have presented my work at another Masonic Foundations annual general meeting. I have also presented my work at the Motor Neurone Disease Association of Tasmania's annual general meeting.

What do you enjoy doing in your spare time?

In my spare time I enjoy cooking at home for my friends and family, and often try to find and attend cooking classes. I also enjoy going to the gym, going for runs, and spending time with my beautiful niece.

PERSONAL STORY



Like all other Australians living with MND, Mel receives services from her local MND Association. Please contact your local State Association for more details on the services they provide.

Mel Dee Dzelde

My MND diagnosis came in January 2021 after already being in a fight for my life for four years. In 2017, I was diagnosed with stage IV rectal cancer, with secondaries in my liver.

Since my cancer diagnosis, I've had multiple operations, weeks of radiotherapy, and multiple rounds of chemotherapy. 2020 meant a year of doing round after round of chemo and, with each round, I became weaker and less tolerant of the treatment. As I'd done chemo before in previous years, my oncologist wasn't sure why it seemed to hit me harder than before. I had to give up my beloved radio career, and my dropped foot that started in November 2019 was also becoming more noticeable and more of a problem. This sinister symptom, initially thought to be a side-effect of the chemo, was my first sign that MND was about to be added to my list of health challenges.

Like many, it seemed to take ages and multiple visits to doctors and specialists before two neurologists confirmed what felt for me the most unfathomable diagnosis. Even when confirming the news to me, my neurologist said, "I can't believe I have to tell you that you have MND and cancer!" It all felt so unreal.

I remember feeling completely numb at first. I knew that I needed all of my strength to stay strong and fight this new disease, but I was already weakened beyond comprehension.

Fortunately, I have a very strong mind and I'm surrounded by love and support. I quickly snapped back into a way of being that had helped me through four gruelling years of cancer treatments, and got back to the business of healing.

My belief in the power of positivity and keeping my vibration high is how I stay happy and grateful. I honestly wake up every day feeling so blessed for all that I have and for all that I am. Having two terminal illnesses keeps me focused on the now. I don't project and I don't allow others to talk about what my future may hold. I honestly believe that there's not a soul on this planet who knows what's ahead for me. If I'd listened to my initial prognosis in 2017, I wouldn't be here today.

Surrounding yourself with support is extremely important and that's where MND South Australia have been amazing. Whilst I don't look ahead in a gloomy way, I'm still aware that I need to put things in place to make my life easier for me and my loving husband, Chris. The team at MNDSA have been wonderful in helping me with equipment and advice. Just having a kind understanding voice on the other side of the phone has also been such a relief as the disease has progressed.

MNDSA have also supported me in continuing with my life's dreams. I wrote a children's book last year and have published it this year. It's a bright, beautiful book called 'Azzurra', encouraging children to find their "Inner Dragon" to help them when facing life's challenges.

I'm also very passionate about raising awareness of MND. I was initially shocked at how little most people knew about the disease. Since my diagnosis, I've spoken about the need for more funding and awareness on radio and TV. With my media background, I would like to contribute more in this way.

Having MND isn't something I would ever choose or want, but there are still blessings to be found in every experience, including this one. I'm more grateful for each day. I'm careful to fill my precious time with people and things that I love and which give me joy. Plus, because I believe I have a duty to myself and others to stay positive and not allow fear to change who I am, my time is now so much happier and more on-purpose than it's ever been.

In these COVID times, we've all learnt to pivot. For those of us with a terminal illness - or two - we've been doing this all along. Life is meant to be lived fully and attitude is really the key to making sure that happens.

LIVING BETTER

Caring for your Mental Health

Being diagnosed with motor neurone disease (MND) can be devastating, and managing emotions can become hard

Living with a life limiting illness, and having the daily challenges that come from increasing physical disability, can cause stress and other concerns. Maintaining connections with family and others might get difficult too. Your emotions and moods, general state of mind, and relationships with others, are all important. There are, however, positive ways to deal with emotions and your overall wellbeing.

Doing things each day to look after you can make a positive difference to your mental health and living with MND. Being proactive in exploring MND management options, and looking after your mental health, can have a large impact on your physical health and how you feel each day.

Getting plenty of rest when you can, building on the things which you enjoy, and other strategies, can help make you feel more relaxed and able to deal with MND. Talking with mental health professionals may be a useful source of support as well.

By doing your best to look after yourself, you're likely to feel a greater sense of control, and lift your moods. You're also more likely to enjoy time with others, your interests, and other things important to you.

o can help?

Not everybody wants to talk about what they are going through. While people living with MND have some things in common, they also have very different experiences of the disease. There is no 'right' way of dealing with MND. Some things you feel and do with MND, however, may be signs that you might benefit from some extra support. These things can include:

- panic attacks (extreme anxiety and strong physical sensations of fear)
- persistent irritability
- problems concentrating
- being easily distracted
- persistently avoiding other people
- angry outbursts
- difficulty accepting and/or adjusting to the diagnosis and disease related changes
- persistent sadness
- persistent feelings of being overwhelmed
- when feelings interfere with ability to carry out usual activities
- avoidance of usual activities and connections

These responses are understandable and can be a common reaction to the situation you are experiencing, but the behaviours can have a negative impact on you and those around you. You may find it helps to talk to people who you know and trust about how you feel. It is not always easy to do this, but seeking support is a great first step to feeling better.

If you are finding it hard to talk to people close to you, it may help for you to talk to someone more distant about what's going on, such as:

- your doctor
- your MND Association Advisor or Support Coordinator
- a mental health professional (e.g. counsellor or psychologist)
- others going through similar experiences (people at support groups for example)

People with MND have individual support needs rather than 'a one size fits all'. Your local MND Association Advisor or Support Coordinator will be able to guide you towards the support you need.

This article has been adapted from the MND Australia webpage 'Caring for your mental health'. To view the entire resource, visit www.mndaustralia.org.au/mnd-connect/living-with-mnd/caring-for-your-mental-health or scan the QR code on the right.

Tips to help care for your mental health

- **Start slow and small:** when making changes to how you look after your mental health, it can help to change one thing at a time.
- **Find ways to work around challenges:** living with MND can be a challenge, but you're likely to be already finding ways to adapt and live with the disease, and there are things you can do to manage new or extra challenges if they arise.
- **Relaxation:** doing things that you enjoy and find relaxing can lift your mood, such as listening to music.
- **Managing sleep as best you can:** sleeping well is important for managing emotions and wellbeing. However, sleeping with MND can become difficult, so talk to your health care team so that they can support you and work to improve the particular issues that are impacting your sleep.
- **Stay connected:** try to keep enjoying and maintaining your relationships with your family, friends, and others in your social circle who matter.
- **Keep active:** with MND, it becomes harder to physically move, but that doesn't mean that you can't find ways of being active that work for you. Don't forget to speak with your OT or physiotherapist if you need some assistance with being active.
- **Keep learning:** learning new things, or learning how to do usual activities another way, can help you gain confidence and feelings of satisfaction and achievement. Learning may also provide a greater sense of purpose and give you an improved ability to get the most out of life.

Important things to remember

- Be kind to yourself. Everyone is different and there is no right or wrong way to feel.
- Feeling overwhelmed is not about being weak, it is about being human.
- It may take a little while to find a person who you feel comfortable to talk with, but don't give up. It is okay to see different professionals until you find the right person for you. Some psychology service's websites have a section with short biographies of their practitioners which can help guide you in deciding who may be the best person for you to see.
- Others in your family may be feeling the same way.
- Others in your family may not understand the changes they see in you, so it may be useful to explain to them what is happening to you.

MND RESEARCH

Exploring the impact of communication and cognition on healthcare involvement and decision making in MND

Communication and cognitive impairments are known to negatively impact health outcomes generally. Also, they are recognised as barriers to shared healthcare decision making. Shared decision making involves patients, their families and healthcare professionals sharing information and knowledge so that decisions and choices match with patients' values and preferences. This process highlights the importance of everyone working together to facilitate tailored management of MND symptoms and to maximise quality of life. People affected by MND (that is, people living with MND as well as family members and carers) face changing needs as the disease progresses and this can impact decision making[1]. Decision making in MND has been described as an ongoing cycle because people need to react and adapt to ongoing change [2].

In this study, 19 people living with MND and 15 family members were interviewed one to three times. Participants were asked to describe their experiences of making healthcare decisions. They were also asked how changes in their speech, communication, or thinking skills changed the way they were doing things or changed the way they interacted with healthcare professionals.

The main theme identified in this study was communicating takes effort. This encapsulates the effort required by people living with MND to cope with symptoms or circumnavigate impairments, the effort family members provide in support, and the effort healthcare professionals make to accommodate for changes in communication abilities.

People living with MND described how slurred speech, respiratory weakness, and fatigue makes talking so effortful they sometimes avoid it. This means they ask healthcare professionals fewer questions, provide short answers, or do not fully express their opinions. People reliant on communication aids (e.g. email, writing or eyegaze technology) recognised it was time-consuming which sometimes presented problems in busy clinical environments. People who used communication aids reported frustration if others second-guessed their responses: especially if it was incorrect. People living with MND whose speech was difficult to understand, used the National Relay Service, email, and text messaging to manage healthcare appointments independently.

The support provided by family members was essential for many people living with a communication and/or cognitive impairment. Examples of practical support for communication tasks included answering the phone, managing medical and clinic appointments, filling out forms, and liaising with community disability support services. People who used communication devices often needed family to set up devices and show staff how to use them. Examples of emotional support were: being present in clinical appointments, providing personally relevant information, and encouraging the implementation or use of high-tech communication devices.

Participants in this study described many ways healthcare professionals adjusted their practice to accommodate a communication impairment. Examples provided were allowing extra time, conducting joint sessions with another clinician, and using email instead of telephone. Without this support, involvement in healthcare appointments would have been reduced. Some participants described occasions where support wasn't provided which negatively impacted their input in decision making.

Being able to explain MND-specific care needs was imperative and it caused anxiety for some participants to have new paid carers or nursing staff unfamiliar with MND. Being able to communicate to facilitate 'difficult conversations' meant that some participants completed medical-legal issues (e.g. documenting Powers of Attorney or Advanced Care Plans) whilst communication skills were intact. Others, however, stated that the onset of communication impairment would be the trigger to start planning.

To summarise, this study shows the considerable effort people living with MND and their carers undertake to maintain or maximise their involvement in healthcare. Much of this effort is largely 'invisible' activity because it occurs outside of medical or healthcare appointments. Despite the effort, healthcare involvement and communication can be compromised. Healthcare professionals and health services can make accommodations or adjustments to minimise any impediment to involvement in healthcare decision-making for people living with MND and their families. These results demonstrate that communication is everyone's business.

Camille Paynter, B.SpPath (Hons)

PhD Candidate, The University of Melbourne

NHMRC/MNDRA Postgraduate Scholarship

References:

1. Hogden, A., et al., Development of a model to guide decision making in amyotrophic lateral sclerosis multidisciplinary care. Health Expectations, 2015. 18(5): p. 1769-1782.
2. King, S.J., M.M. Duke, and B.A. O'Connor, Living with amyotrophic lateral sclerosis/motor neurone disease (ALS/MND): decision-making about 'ongoing change and adaptation'. Journal of Clinical Nursing, 2009. 18(5): p. 745-754.

UPCOMING EVENTS

Our BIGGEST fundraising event of the year – Walk to D'Feet MND

The annual "Walk to D'Feet MND Tasmania" will be held on Sunday 31 October 2021 at the Domains Athletics Centre in Hobart.

Walk a lap of the track or run the full 5km. All funds raised will stay in Tasmania to care for and support those individuals and their families currently living with MND.

Numbers will need to be restricted due to COVID-19, and door sales may not be available this year if numbers are met with pre-registrations. To avoid being disappointed, register today and kick off your fundraising to support this fun event. We hope to have all of the usual activities such as face-painting, sausage sizzle, and games on the oval, to make this an enjoyable day for all ages. We look forward to welcoming you all.

Register now at www.mycause.com.au/events/walktodfeetmndtas or scan the QR code on the right.

Walk to D'Feet Raffle

We are currently organising our "Walk to D'Feet" raffle and feel very lucky to have so many businesses that continue to support the cause year after year.

We would like to send out a special thanks to Blundstone Footwear, Elite Appliances, Edge Running, Anytime Fitness, Daci & Daci, The Woolstore, Bream Creek Winery, Shambles, Spencers, Pennicott Tours, and Harvey Norman, for their continued support.

We are also very fortunate to be supported this year by Spa180, Peattie Events, Glaetzer-Dixon Family Winemakers, Hill Street Grocer, Michael O'Keefe Photography, and Zoo Doo.

Look out on our Facebook page (www.facebook.com/MNDTas) or contact fundraising@mndatas.asn.au to purchase your tickets in this fabulous raffle.

UPCOMING EVENTS

MND Support Groups

The MND Support Groups in Tasmania are independently run by community members for community members. We appreciate their willingness to devote their time in volunteering for such a worthy cause.

North West MND Support Group

The NWSG in Ulverstone invites all MND Tasmania members and supporters to its meetings.

WHEN: At 11 am on the first Wednesday in the month, except January

WHERE: Ulverstone Returned Servicemen's Club Back Room, 21 King Edward Street, Ulverstone

CONTACT: Junene Stephens is the secretary and can be contacted on 0428 252 763 or email: jstephens@berendsen.net.au

Northern MND Support Group

This is an informal coffee and catch-up style group, where members come together to talk all things MND and Kennedy's Disease, as well as share experiences and helpful tips.

WHEN: Every second Tuesday at 10 am

WHERE: Selah Café at the Door of Hope,
50 Glen Dhu Street, South Launceston

CONTACT: Deb Beyer is the coordinator and can be contacted on 0418 462 369.

Drink tea for MND

Calling upon our TEA-riffic community! "Drink Tea for MND" is a fun (and delicious!) way to raise awareness and funds to support MND Tasmania.

Your DT4MND event can be held ANYTIME, ANYWHERE that suits you! You can host your tea your way, on the date of your choice. It could be a morning tea at work, a virtual afternoon tea, a luncheon - the ideas are endless!

Please register online at
www.drinkteaformnd.org
or scan the QR code on the right.

Raise awareness and funds for Motor Neurone Disease while catching up with friends...

GIVING

Why give?

MND Tasmania is a volunteer organisation receiving no government funding. We are dependent on the generosity of our community and would like to acknowledge and sincerely thank our donors.

This quarter we were fortunate to receive a generous donation of $1,000 from the Samaritan Projects Grants from the Archdiocese of Hobart.

We have gratefully received continued support from Margaret Eldridge and Kevin Burgess; and received donations in memory of Terrance Roles and David Greenwood.

Thank you to our community

As with many organisations, our income from donations was heavily impacted in 2020, with the cancellation of, and/or absence of, many fundraising events due to COVID-19. We were, however, still fortunate to have received a number of generous donations from our community. With these funds, we were able to continue to contribute to the operation of the MND Advisor service in Tasmania, provide member support by way of equipment and home modifications, and donate to MND research.

Every single contribution made to MND Tasmania, regardless of its size, helps to make a difference in the lives of people living with MND.

So we say a big "thank you" to you, our MND Tasmania community, for your continued generosity and support.

If you are in a position to support us, please visit https://donate.mycause.com.au/charity/6483 or scan the QR code on the right

MND ADVISORS AND NDIS SUPPORT COORDINATORS

Client Numbers

We are currently supporting 46 registered members:

North West Region Tasmania	8
North Region Tasmania	20
Southern Tasmania	18
TOTAL	46

CURENTLY SUPPORTING
46
REGISTERED MEMBERS

DELIVERED
686
HOURS OF SERVICE

Above: Emma Forsyth
Left: Jenny Fuller

MND Advisors and NDIS Support Co-ordinators

Northern Tasmania: Emma Forsyth (Mon, Wed, Thurs):
p: 0456 182 551 or e: eforsyth@mnd.asn.au

Southern Tasmania: Jenny Fuller (Tue, Wed, Fri):
p: 0412 599 365 or e: jfuller@mnd.asn.au

Team leader: Eric Kelly (Mon-Fri.):
p: 0421 323 850 or e: ekelly@mnd.asn.au

FREECALL 1800 777 175

This number is at the MND Victoria office (Monday - Friday, 9 am - 5 pm). To assist the volunteer receptionist, please say that you are calling MND Tasmania. If you wish to speak to a Board member or an MND Advisor, you will be asked for your contact details and your call will be returned by that person as soon as possible.

Board Members:

MND Tasmania has a volunteer Board and no paid staff.

President: Kate Todd

Senior Vice President and Fundraising: Michelle Macpherson

Vice President & Public Officer: Chris Symonds

Secretary: Lucy Polizzi

Treasurer: Julie Driessen

Member Support: Elisa Howlett

Ordinary Directors: Tracey Dickson, Steve Issac

Ex-officio Support: Libby Cohen

mnd Tasmania

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