

MND ADVISOR AND SUPPORT COORDINATOR SERVICE

Emma Wilkinson-Reed (based in Launceston) supports people living with MND in the North and North West Tasmania regions.

Jenny Fuller (based in Hobart) supports people in the Tasmania South region.

They both work in the role of Regional Advisor & Support Coordinator and continue to work very hard to support their clients, providing information, support and advice and connecting them to supports and services. They are also in regular contact with local health, disability and community service professionals and agencies to provide information and support to them as they work with people living with MND. Emma and Jenny are working hard to create supportive and collaborative relationships.

Emma and Jenny have been working together to support each other, and cover for each other when one of them is on leave. They are in regular contact with the MND Victoria staff as well, to increase their knowledge about MND and systems that they both work with such as NDIS, My Aged Care and specialist MND clinics.

COVID-19

This time of social isolation has provided many challenges to our work. Both Emma and Jenny are now working from home and are having no face to face contact with clients. We have been increasing our knowledge and expertise in working to support people from a distance using video, phone, and email. Zoom is our preferred video platform, but we can adjust to support our clients using the platform that best suits them.

We were very disappointed that the scheduled MND Health Professional Forum (March 27) was cancelled due to COVID-19. One of the added benefits that has come from COVID-19 is that we are now offering information via other methods including Zoom and live streaming on social media etc. Examples of this are MND client information sessions held in Melbourne which are now being zoomed and are open to those living in Tasmania to

be involved. During MND awareness week, events like "Ask the Experts" about research advances in MND from the Florey Institute, were live streamed and available to all in their homes. This can be accessed on www.facebook.com/MNDVic

If you need further information about access services or information contact either Emma, Jenny or myself or email the information team at info@mnd.asn.au

BEREAVEMENT

During COVID-19 we are very aware of the challenging experiences families must be experiencing with grief and bereavement. We are temporarily offering additional support to bereaved family members during this challenging COVID-19 time, where isolation and loneliness provide such difficulty for people who need to be well connected and supported.

The MND Advisor & Support Coordinator is providing this support and will communicate with each newly bereaved family during this time. Please feel free to discuss with Emma or Jenny if further information is required.

KEEPING CONNECTED

At this time, we also have been reviewing our Keeping Connected program which supports people with slower progressing MND. Jenny Fuller has been leading this project. The review should be completed in the next few weeks and we hope it comes up with recommendations to improve our services and connection with all of our clients, especially to clients who have slower progression or are over 65 years of age.

We look forward to when Emma and Jenny can get back to visiting clients face to face again and the restrictions of social isolation are relaxed. Until then we will continue to offer support.

Eric Kelly, Team Leader, Regional Advisor & Support Coordinator

As mentioned, a lot of our important events have been cancelled as a result of COVID-19. We expect to have these updated by the time of the next edition.

NORTH WEST TASMANIA MND SUPPORT GROUP

No meetings until further notice. The contact person is Junene Stephens at 1800 806 632 (message) or email info@mndatas.asn.au

NEW MEMBERS

We welcome new members living with MND and their families to our community, network and services. We encourage you to contact any of the MND Tasmania team, including the Board and our MND Advisors (who are also our NDIS Coordinators of Support).

VALE

We extend our heartfelt condolences to the family and friends of those who have recently passed away, including Robert Bushell and Leslie Jones.

CLIENT NUMBERS

We currently support 37 registered clients in Tasmania:

North region—14

North-west—9

South—14

BOARD

MND Tasmania has a volunteer Board and no paid staff.

A member of MND Australia and of the Neurological Alliance of Tasmania.

President: Michelle Macpherson

Vice President and Secretary: Kate Todd

Public Officer: Chris Symonds

Treasurer: Julie Driessen

Ordinary Directors: Libby Cohen & Joyce Schuringa

MND ADVISORS & NDIS SUPPORT COORDINATORS

Northern Tasmania, Emma Wilkinson-Reed (Mon, Wed, Thurs): 0456 182 551, ewilkinson-reed@mnd.asn.au

Southern Tasmania, Jenny Fuller (Tues, Wed, Fri): 0412 599 365, jfuller@mnd.asn.au

Eric Kelly, Team Leader MND Advisor & Support Coordinator (Mon – Fri): 0421 323 850, ekelly@mnd.asn.au



CONTACT DETAILS

Emma Wilkinson-Reed

(photo top right)

Email: ewilkinson-reed@mnd.asn.au

or phone: 0456 182 551

Days of work: Mon, Wed, Thurs

Jenny Fuller

(photo bottom right)

Email: jfuller@mnd.asn.au

or phone: 0412 599 365

Days of work: Tues, Wed, Fri

Eric Kelly

Team leader for all of MND Victoria and MND Tasmania's regional staff including the Tasmanian team

Email: ekelly@mnd.asn.au

or phone: 0421 323 850

Days of work: Mon to Fri



MND TASMANIA NEWS | May-June 2020

I don't think anyone could have anticipated the last couple of months we have had in Australia, and the world. Our focus at MND has been ensuring our members keep safe during these uncertain times, especially those in the north-west, where an outbreak took hold. We are glad to report that all our members have remained safe; and encourage everyone to stay vigilant over the coming months.

The whole of MND Australia are working online, as are many businesses and organisations across the country. We continue to connect virtually and support members as best we can. Though several events and regular meetings are postponed until further advice from the Government, please feel free to get in touch via our 1800 number, or if you are a member, please contact our Advisors. We are here to help!

On Sunday 15 March at our AGM, we saw a shuffle in the Board, with Michelle Macpherson taking the reins from long-standing President, Joyce Schuringa. Kate Todd took on the role of Vice President and we said goodbye to Public Officer, Andrew Moy. We thank Andrew for his support on the Board over the past two years.

HELLO FROM NEW PRESIDENT, MICHELLE MACPHERSON

Some of you may already know me from some of our fundraising events but I thought this is a great opportunity to introduce myself to our wider community and to share my story of what brought me to where I am today with MND Tasmania.

Although the journey had started much earlier, my moment of 'I have to take action' happened in October 2016 as we were saying our good-bye to Jackie, the much-loved twin of my beautiful sister-in-law Anna.

Jackie was just 25 when she was diagnosed and fought a courageous battle with MND for over 10 years. She always had a smile on her dial, made the most of every moment, managed the MND Tasmania Facebook page through Eye Gaze technology, and anyone who knew her was in awe of her strength and dignity. So, you can probably understand why I always tell people Jackie is my personal inspiration for joining the fight against this beast of a disease. I wanted to continue with the wonderful work that Jackie had started.

Over the past 3 or so years I have met so many people who have been impacted by MND or Kennedy's Disease, each with their own special individual story, and that keeps me motivated to do all that I can to make a difference. I feel extreme pride, somewhat humble, and I would be a liar if I did not say just a tad nervous, in taking this next step in my MND journey. I hope to serve you all well!

I would like to finish with a few words about our previous President, Joyce Schuringa.

As most of you would know, Joyce has spent endless hours so willingly giving for the cause. She brings her wealth of knowledge and experience and a commitment to the Board of over 10 years in ensuring that Tasmanians living with MND or Kennedy's Disease receive the care and support that they need.

Plainly said, Joyce has made a massive contribution to where we find ourselves today, and although Joyce remains on the Board of MND Tasmania to continue her wonderful work, it would be amiss not to take this moment to recognise all that she has achieved.

So, thank you Joyce! On behalf of myself, the Board and all the members you have supported over the years. You are an incredible human and we are blessed to have you in the team.

Michelle Macpherson, President

PLEASE JOIN AUSTRALIA MOVES FOR MND www.am4mnd.org.au



ANNUAL GENERAL MEETING

It seems a lifetime ago, given everything that has happened since, but we held our AGM in Devonport on 15 March at the wonderful library building. We had members attend from the North-West and Hobart, in addition to researchers from the Menzies Centre, who presented on their important work.

To kick off proceedings, the President, Joyce Schuringa, provided a summary of the previous year's activities and achievements and acknowledged the efforts of the voluntary board. Key points are outlined below.



INFORMATION, CARE AND SUPPORT

- At 30 June 2019 we had 40 client members and 26 ordinary members. During the preceding 12 months, 16 people with MND joined and we sadly lost 18 members to MND.
- The MND Tasmania Care Foundation (established in 2015) grew due to the efforts of fundraising and bequests.
- Our Memorandum of Understanding (MOU) with MND Victoria continued for the provision of

administration, and to staff and manage the MND Advisor service.

- Jenny Fuller and Emma Wilkinson-Reed were appointed as Tasmania MND Advisors.
- We continue to advocate for people living with MND and to educate new service providers. The MND Advisor team is actively targeting the private sector with state government no longer providing the care required for those with MND.
- In 2019 we continued to support client members with financial assistance for essential equipment or home modifications when they were unable to obtain such services from government.

ADVOCACY & COLLABORATION

- The main focus of MND Australia's advocacy in 2019 has been improving the services that NDIS should provide for people with MND and their families for those under 65 years of age and "My Aged Care" services for those over 65.
- Our key methods of advocacy are through the MND Advisor service and our active participation in MND Australia and the Neurological Alliance of Tasmania.
- We are a member of Palliative Care Tasmania. Jenny Fuller presented at their November conference. Andrew Moy represented us at the Tas Health Consumers Group and Chris Symonds on the Premier's Disability Advisory Council.
- We work closely with the North-West Tasmania MND Support Group who had a very successful year raising the profile of, and funds for, people with MND; and held their second Walk to D'Feet MND in Ulverstone in March 2020.

RESEARCH

- We have been forwarding donations to MND Research Australia since 1986, and they have a well-respected history of establishing and refining high quality MND research.
- We have a close relationship with the MND research team of the Menzies Institute to raise the profile of MND in the community; so their students better understand the human impact of research.
- We provided travel grants to 3 students to present their research at the 30th International ALS/MND Symposium in Perth WA in December; and Laura Reale won the joint Biomedical Poster Prize.
- Associate Professor, Anna King at the Wicking Centre of UTAS also secured a significant Fight MND grant in September and we shared in the ensuing media coverage.

FUNDRAISING

- Michelle Macpherson (now President) has an effective team and network that raised the profile of MND to raise funds, through innovative and fun events.

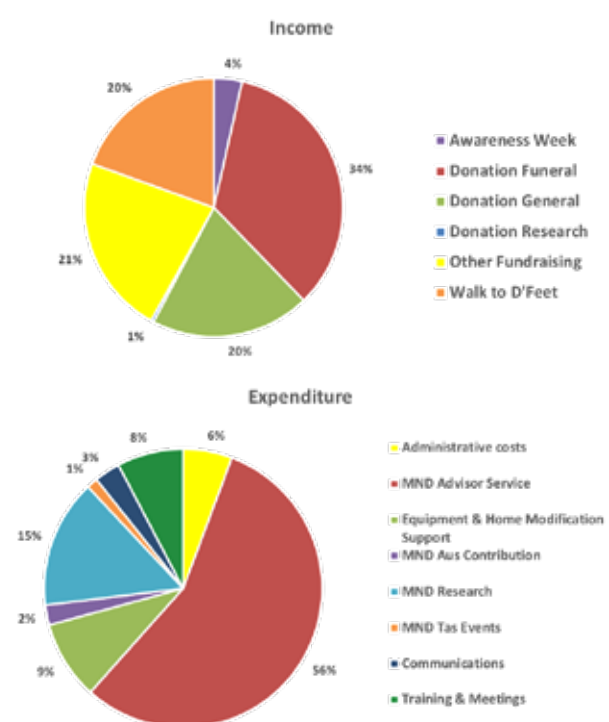
- The third Walk to D'Feet MND in Tasmania was held in October and the first planned in Launceston to align with MND Week in May 2020 (which has subsequently been cancelled due to COVID-19 but will be rescheduled).
- Facebook and online fundraising continue to expand our profile, communications and relationships.
- Many people have organised events and donated time and money for care and support throughout the state. There are also the regular donors who keep giving year in year out.
- Thank you to all the generous and hard-working supporters of MND Tasmania for the wonderful fundraising result where we turned around the budgeted loss for 2019 with a wonderful surplus.

OUR 2019/2020 FINANCIAL POSITION

MND Tasmania is funded entirely by donations with no income from government. We have a volunteer Board and no staff. Our financial year is the calendar year and thanks to the generosity of many donors we were able to:

- continue to support the MND Advisor Service
- help our members navigate the many services they need
- provide funding for our members to purchase equipment, home and car modifications
- fund and maintain an assistive communications library
- support research in the hope that one day we will live in a world without MND.

The pie charts show the origins of the donations that support MND Tasmania and the allocation of these funds.



FUND-RAISING

Fundraising events have come to a grinding halt in recent weeks which means that we have to be more creative in how we raise funds to support the services, equipment and care we provide for those Tasmanians living with MND.

Unfortunately, we had to cancel our first National Walk that was intended to be held in Launceston to coincide with the start of MND Week on Sunday May 3rd. In addition, we have also had to cancel our usual shaking of the tin and selling of merchandise throughout that week.

BUT don't despair, we have a wonderful new virtual campaign that is BIGGER and better, and we say thank you to all those who made this possible and an even BIGGER thank you to all of our supporters who have already signed up.

AUSTRALIA MOVES FOR MND



(#AM4MND)!

We all need a little bit of motivation to stay active during these crazy times. AM4MND is a fun and easy way to do so and support a cause as you stay "socially isolated" due to COVID-19. It's as easy as choosing an activity to do every day or week and asking your friends and family to support you. How about challenging supporters to donate \$10 for every 10 push-ups you do? Or maybe \$10 for every 1000 steps you take? The possibilities are endless, choose the activity that is right for you and stay active your way.

Why get involved?

- You're missing your exercise routine
- You want a reason to stop watching Netflix
- Your dog/ cat / kids / partner is driving you crazy
- You're passionate about raising funds and helping the 2,100 Australians living with MND (This is of course the #1 reason to get involved).

What are you waiting for? Register today – take a photo or video, share it with friends, post it on your social media using #AM4MND and start moving for those who can't!

Register today: www.am4mnd.org.au

AWARENESS-BUILDING

MND GLOBAL AWARENESS DAY - JUNE 21

This a day where people all over the world come together to show their support for the common cause – to raise awareness and funds to support research in the hope of creating a world without MND. Although the world looks a little different this year, there are still many ways you can be involved. Perhaps you could hold a virtual MND morning tea with friends or colleagues to raise some money for the cause.

Make a donation to our Mycause page <https://donate.mycase.com.au/charity/6483>. Share your story on Facebook or email with your network on why you are so passionate to find a cure for MND, or even write a letter to your local government to lobby for more support. The possibilities are endless with the impact immeasurable, so we encourage you to get involved in whatever way you can in the fight against this beast of a disease.

MND, A POEM BY JUNENE STEPHENS

We cannot speak,

Unable to use my hands, our legs are very wobbly or not working at all

Our brains are still running ok, in fact too well, my ears are working as well, and we can still smell

There is enough dribbling going on without drooling over the beautiful food we can smell

Not much joy in being fed through a tube in our stomach

We are very much aware of what is happening around us

We are not just a body in the bed, still yearn for touch, a hug, and "I Love you" to be heard, a touch and a clean body, and my treasured family and friends around us

Trapped in this body that has loved, run, shopped, played sport, made fantastic music, gardened, cuddled our children, so many amazing things and much more, but, now a distant memory.

What is left for us trapped in this body,

A burden we do not want to be

Remember us we are still the father, mother, sister, brother, son, daughter, and partner and friend

Let us pray that a cure is found for this most horrible of diseases, that takes all from us, and our families.

MARRIED AT FIRST SIGHT – BUILDING AWARENESS OF MND



Nationally, MND got some publicity from an unexpected source – Channel 9's Married at First Sight. One of this year's grooms, Josh Pihlak, auctioned his wedding ring with all funds going to MND. Josh lost a young cousin to the disease and turned his 'not so positive' TV marriage experience, into a positive outcome for MND.

RESEARCH

As mentioned in our last edition, our 2019 Research Grant winners presented on MND research from the Menzies Institute's Neurodegenerative Disease and Trauma Group led by Professor Tracey Dickson. Following the AGM we were eager to go to the lab and interview the team in their 'natural habitat', however due to COVID-19 social distancing, we needed to postpone that visit to another day.

The team (Courtney Clark, Laura Reale and Marcus Dyer) spoke about the focus of their research being on how the disease starts, in order to find a cure. Each member of the research team (three energetic researchers, led by Tracey) presented on the different angles they are taking in order to uncover the beginnings of the disease.

Whilst all very scientific, the team were very generous with their time and explained terms in a simple form (so we stood a chance of understanding all the medical mumbo-jumbo!).

Tracey spoke about the international community of MND researchers and the culture of collaboration and sharing that exists. Whilst research can be competitive, she told us that each year, MND researchers come together from all over the globe at the international symposium and they do just that – they share results and findings. This means that, as an international community, we get closer to a cure.



Presentations and an audio recording are available on the MND Tasmania website. Given the team are doing such a great job and drove all the way to Devonport (in the one day) to talk

with us, we gifted them with some MND Gin!



Since the AGM, Courtney Clark (left) and Laura Reale (right), were awarded the MND Australia MNDRIA PhD Top-Up Grants for 2020. These grants provide

a \$5,000 per annum stipend over three years and are awarded to outstanding early career researchers who are studying towards a PhD in MND research.

The latest MND Australia International Research Update is now available to read online and is the best way to keep in touch with MND research happening around the world. Visit www.mndaust.asn.au.