

SECOND-HAND EQUIPMENT

The MND Advisors are asked about the donation or sale of equipment and assistive technology that is no longer needed. MND Tasmania does not accept such equipment; however, the State government's equipment scheme – TasEquip – will accept donations of specific equipment. The Independent Living Centre of Tasmania (ILC Tas) provides a service of listing second-hand equipment for sale on its website. We have provided more details on our website, so please visit that for further detail.

HANDY INFORMATION ON HEALTHY AGEING

A new healthy ageing website was launched by the Tasmanian Department of Health in 2019.

It's full of useful information and resources to help those aged over 65 to stay well and also has relevance for people with MND who need information about nutrition and suitable foods.

We recommend you take a moment to explore the website – www.health.tas.gov.au/healthyageing – to get more hot tips on physical activity, recipes, video clips, links to free online training, key contacts and suggestions for support.

For more information email:

community.nutrition@health.tas.gov.au

tas.gov.au

MND ADVISOR AND SUPPORT COORDINATOR SERVICE

CLIENT NUMBERS:

We currently have 29 registered clients in Tasmania

North region—11

North-west—8

South—10

CONTACT DETAILS:

Emma Wilkinson-Reed, (Mon, Wed, Thurs)

email: ewilkinson-reed@mnd.asn.au

or phone: 0456 182 551

Jenny Fuller, (Tues to Thurs)

email: jfuller@mnd.asn.au

or phone: 0412 599 365

Eric Kelly, (Mon to Fri)

email: ekelly@mnd.asn.au

or phone: 0421 323 850

(Eric Kelly is the team leader for all of MND Victoria and MND Tasmania's regional staff including the Tasmanian team)

Emma Wilkinson-Reed (Launceston based, photo top right) and **Jenny Fuller** (Hobart based, photo bottom right) are now familiar with their clients and are working very hard at getting to know the peculiarities of their roles. They are not only familiarising themselves with their clients and families, but also with the many health, disability and community service professionals and agencies who also support their clients.

Emma and Jenny have been working together to support each other, and cover for each other when one of them is on leave.

On January 29th 2020, Eric Kelly, Team Leader MND Advisor & Support Coordinator, spent the day with Emma and Jenny in Launceston office, focusing on staff development with a specific focus on upskilling re NDIS planning and report writing requirements and techniques for people living with MND.

Unfortunately, we had to cancel the Hobart Health Professionals forum that was scheduled for Friday March 27th due to COVID-19.

COVID-19 is impacting communities across the globe and many

people living with MND and their carers may have concerns about this. Our aim, as always, is to provide high quality support services to our clients and families.

The MND Advisor & Support Coordinator service in Tasmania continues to operate and support continues. The main difference is that there are now no face to face meetings with the MND Advisor & Support Coordinator for the immediate future. We can arrange support by phone, email, video or however suits you best. Please discuss with Emma or Jenny your preferred contact method. We will endeavour to update you with changes as they arise.

to appropriate care and support services as required

- Coordination of Supports for NDIS participants
- Assistive technology support
- Information and member support by telephone on 1800 806 632, Monday-Friday, 9am – 5pm
- Information, support and training for service providers for people with MND in Tasmania
- Bi-monthly newsletters from MND Tasmania and MND Victoria for people living with MND in Tasmania.

BOARD

President: Michelle Macpherson

Secretary: Kate Todd

Treasurer: Julie Driessen

Public Officer: Chris Symonds

Fundraising: Michelle Macpherson

Equipment: Libby Cohen

NWSG: Chris Symonds

MND Australia: Joyce Schuringa

MND ADVISORS & NDIS SUPPORT COORDINATORS

Northern Tasmania, Emma Wilkinson-Reed: 0456 182 551, ewilkinson-reed@mnd.asn.au

Southern Tasmania, Jenny Fuller: 0412 599 365, jfuller@mnd.asn.au

SUPPORT SERVICE

MND Tasmania and MND Victoria work together to provide the MND Advisor service which provides State-wide support for members. Services include:

- Needs-based support and assessment, home visits and referrals



MND TASMANIA NEWS | March-April 2020

STOP PRESS!

THE CONTENT OF THIS NEWSLETTER WAS INITIALLY SIGNED OFF FOR PUBLICATION ON 4 MARCH. AND THEN THE WORLD CHANGED. COVID-19 ARRIVED IN TASMANIA.

WE APOLOGISE THAT YOU HAVE RECEIVED YOUR NEWSLETTER LATER THAN USUAL. BUT OUR CARE AND SUPPORT FOR PEOPLE WITH MND AND THEIR FAMILIES IN TASMANIA IS ONGOING.

REFLECTING ON 2019

We have had some great successes over the last couple of months to raise greater awareness and funds to MND and those living with it.

We welcome new members to the MND Tasmania family in 2020. We are here for you and will support you on the journey ahead. Please reach out to us through the Board or our MND Advisors.

Our very own Chris Symonds featured on ABC's Back Roads in his hometown of Wynyard, which highlighted the Yacht Club and how they responded following his diagnosis (and saved him from a role of pure admin!).

In the 2020 Australia Day honour's list, Professor Justin Yerbury was awarded an AM for his contributions to MND research (despite living with MND), which has raised the profile significantly.

We also had a successful turn out for the 2020 Walk D'Feet in Ulverstone, headed up by Junene from the North West Support Group; it raised much needed funds for MND services and research.

The Annual General Meeting was held in Devonport on 15 March. When preparing for an AGM you can't help but reflect on the achievements and learnings from the year.

We're really pleased with what we have achieved in 2019 and feel this year is going to be even better! We'll take this opportunity to thank our broader MND community.

- To those living with MND who show great courage as they face the challenges of this disease –you inspire us every day to do what we do

- To our voluntary board, who give their spare time to guide the efforts of the organisation

- To our incredible advisors – Jen and Emma – who provide much love and support to our members

- To our North-West support group who provide a much-needed forum, fundraising and local support network for those living in these areas

- To the family and friends of our members, who show up to support their loved ones

- And to our financial supporters for digging deep and making it all possible!

The collective efforts of our MND community contribute to the success of MND Tasmania and helping those living with MND.

Thank you to everyone involved. A full report from the AGM will be available in our next newsletter.



FUNDRAISING

A big thank you to all who have generously donated over the last couple of months. MND Tasmania relies on the generosity and efforts of the community to assist us in raising much needed funds and awareness for our specialised care and support services for those living with Motor Neurone Disease.

GIN FOR A CAUSE

Have you got yourself a bottle of MND Gin yet?

With less than 30 bottles left, we recommend you purchase today, to avoid disappointment. We continue to receive great feedback from those who have picked up a bottle on how much they have enjoyed their purchase.

Grab a bottle of Classic Dry Gin (or two) by visiting

www.mchenrydistillery.com.au/shop/mnd-tasmania-gin-for-a-cause

BLUE MOON FUNDRAISING

A huge thank you to Kellie Hills and Grant Wakefield for organising an amazing Blue Moon Raffle that raised over \$1,000 and an online auction. The online auction was our first but won't be our last. With everything from horse racing to football memorabilia, hair care packages, some special gin and household items... there was something for everyone!

Raffle winners:

•1st Prize: a \$2000 landscape voucher - donated by Grant's Landscaping - went to J. Williams;

•2nd Prize: a framed Tasmanian Landscape - donated by Robbie Moles photography - was won by V. Briggs.

•3rd prize: 3 hampers - donated by Belle Parker from Roberts Real Estate - went to D Holloway, Z. Bird and J.Aulich.

We would like to send our heartfelt appreciation to everyone who bought or sold tickets and donated prizes for both the raffle and auction.

CHRISTMAS LIGHTS BRINGS MORE HOPE FOR MND

William Fraser, of Ulverstone, has once again had a Christmas Lights display, during which he was taking donations for MND. He has raised \$920.00. Thank you, William.



PROUD: Bill Fraser works all year towards spreading Christmas cheer in the community at his home in Ulverstone. Picture: Claude Williams

Lights spark Christmas joy for Bill

WHEN the sun sets, the lights sparkle. The Fraser family has become a star of activity with residents, bringing the little town that is the main thing," he said.



USING OUR FEET TO SHARE THE LOVE!

It was a fresh morning in Ulverstone, but it didn't stop over 80 walkers turning up to show their support for those living with MND, by completing a 5km walk.

First up, a big thanks to Geoff Cox and Junene Stephens from the North West Support Group who were a powerhouse of organisation to help bring the event together.



The day was a great opportunity for the broader community to learn more about MND, support those living with it and raise much needed funds for services and research.

The event raised much needed funds on the day. The highest individual fundraiser was awarded to Geoff Cox and the Highest Team Fundraiser was from Stephens family.

Chris and Libby MND Tas board members were on hand on the day to present the awards and say a few words about the work of MND Tasmania and what the funds raised will mean for those living with MND.

Walkers were also rewarded for their kindness with two very Australian institutions... the good old sausage sizzle and ice cream van!!

Well done again to everyone who turned up and supported the day and all those who helped Junene organise the day.



AWARENESS-BUILDING

MND was put front and centre on national television in January, with our very own Chris Symonds (who sits on our board) featuring on ABC program, Back Roads, in January.

The program featured Chris's hometown of Wynyard and the local yacht club which started a Sailability program for those with a disability. You will be amazed at how far across the world this has taken Chris.

The show not only highlighted MND and how it affects a person's mobility; but also showed that you can still keep doing what you love. We're sure you'll all want to go and visit the beautiful Wynyard... and we're sure if you get in contact, Chris will be happy to give you a tour of the yacht club!

You can still catch the program on ABC's iView at

www.iview.abc.net.au/show/back-roads

ONE MAN'S ODYSSEY



Burnie Metro Cinema filmmaker Lochie Hookway has been showcasing the release of his film -

One Man's Odyssey; which highlights Kirk Dickers' fight against MND and Craig Machen's epic paddle around Tasmania to raise awareness and funds for MND.

A preview in late December in Burnie proved a great night with Kirk's family in attendance and Lochie talked about how the film was created and edited. Lachie was keen to show the film around Tasmania and it is also screening on the mainland.

The film is now available and able to be accessed via Lachie's Facebook page:

www.facebook.com/HookwayFilms



RESEARCH

At the AGM we heard from our 2019 Research Grant winners, which allowed them to travel to the Symposium last year and present on MND research from the Menzies Institute's Neurodegenerative Disease and Trauma Group led by Professor Tracey Dickson.

A copy of those presentations will be available on our website shortly; and we intend to outline the key areas of research happening across the community, as there is a lot happening.

Within the broader research community, Professor Justin Yerbury was awarded Member of the Order of Australia (AM) in this year's Australia Day Honour's list.

A Professorial Fellow in Neurodegenerative Disease at



the University of Wollongong and the Illawarra Health and Medical Research Institute, Prof Yerbury is an international leader in Motor Neurone Disease (MND) research. He continues that research, even while he lives with the disease - leaving him paralysed, unable to speak nor breath independently. He communicates using eye-gazing computer technology.

IMPORTANT DATES AND INFORMATION

- 3-9 May MND Week (state-wide)
- 21 June MND Global Day
- 18 October Walk to d'Feet MND (Hobart)

NORTH WEST TASMANIA MND SUPPORT GROUP

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

WHEN: Note that meetings are cancelled until further notice - hopefully we'll be able to meet again soon.

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 Supports).

VALE

We extend our heartfelt condolences to the family and friends of Darren Gale, Leslie Jones and of any other members who have recently passed away. Donations have gratefully been received in the memory of David Greenwood and Wanda Durie.

Thank you to members and other supporters who have sent us donations. As we are dependent on donations to operate as an Association and to provide the MND Advisor service, you enable us to continue to provide care for people living with MND and their families in Tasmania.