



MND TASMANIA NEWS | January-February 2020

ANNUAL GENERAL MEETING AND MND RESEARCH UPDATE

SUNDAY, 15 MARCH 2020. 10.30 AM

PARANAPLE CONVENTION CENTRE –
QUOIBA ROOM, LEVEL 1

145 ROOKE ST DEVONPORT

THE CENTRE HAS ACCESSIBLE FACILITIES
WITH ACCESSIBLE PARKING IN THE
PARKING STATION NEXT DOOR

Guest Speakers

At 11 am there will be a presentation by Neuroscientists from the MND research team, Menzies Institute, University of Tasmania who presented their research at the International ALS/MND Symposium in Perth in December 2019.

All friends of MND Tasmania are warmly invited.

Nominations for the Board

The term of office for Directors of MND Tasmania is one year. The election of nominated members of MND Tasmania to the positions of Directors is conducted at the AGM.

If you are a member who is unable to attend the AGM and would like to be nominated for a place on the Board and/or would like a proxy voting form, please contact Secretary Kate Todd via email at info@mndatas.asn.au

FUNDRAISING & AWARENESS BUILDING

WUSS IN BOOTS – BAWDY PANTO

The Bawdy Panto's Wuss in Boots was an absolute riot providing plenty of opportunities for laughter over the four nights. Such a fun loving, creative and generous group who come together every year to pull apart a fairy tale and put their own twist on it. Each night in the middle of the performance, they stopped the show and had a meat tray raffle with all proceeds going to MND Tasmania. The night I was there, the meat tray raised \$1050 – I know... right! Some seriously generous people. At the end of the show the cast came out and shook tins and collected donations for us which resulted in a grand total of \$6,672.40. Thank you, Bawdy Panto, and thank you to all those who donated. We can't do what we do without you all.



GIN FOR A CAUSE

Have you got yourself a bottle yet?

With only 100 bottles available you should get in quick, so you are not disappointed. We have been so happy to hear from those who have picked themselves up a bottle as to how much they have enjoyed their purchase. Now that summer has seemed to finally arrive, it is a great time of year to enjoy a refreshing gin

700ml Classic Dry Gin – citrus peel is present and balanced with a small amount of star anise, coriander



seeds, cardamom and orris root all beautifully balanced with the juniper. Grab a bottle or two now by visiting

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

HASH HOUSE HARRIERS

They have done it again!

Long-time supporters of MND Tasmania, Hash House Harriers, again generously donated monies to the cause. On a Thursday night in November they set to the streets for another epic run enjoying a BBQ and well-earned beer at the end of the night. Thank you for your continued support, your donations make a difference.

HILLIARD ADVENTIST SCHOOL



Thank you to the students and staff of Hilliard Adventist School who collected donations just prior to Christmas for those Tasmanian's affected by MND. We are very appreciative of all their efforts and we were extremely sorry to hear that their community has been affected by this horrid disease.

HOLY ROSARY PRIMARY SCHOOL

Each year at Christmas time the staff at Holy Rosary Primary School select a charity to raise funds for. It was so lovely to receive the call to let us know that this year MND Tasmania was their chosen charity. We thank each and every person who donated.

IMPACT 100

We say THANK YOU to the Board of Impact 100 for generously donating during December. It is heartening to know that our work is being recognised and valued by so many. Donations are integral to being able to provide the care and assistance that is required by those living with MND.

BLUE MOON DINNER

We are so fortunate to have so many generous supporters. Late last year we were approached by a family we have got to know well as they are always one of the first to sign up for an event or buy a raffle ticket. Kellie and Grant wanted to hold a night where people could come together, enjoy some good food, and have some fun whilst raising funds for the cause....and there came the idea for a blue moon dinner and dance which will be held at the Brighton Bowls Club. They are really working hard to bring all of this together and we would love you to show your support by coming along. It is guaranteed to be a great night. Please use the following link to reserve your tickets <https://www.trybooking.com/BH NJH> or contact us at fundraising@mndatasn.au

SAVE THE DATES IN 2020

- **February 29: Blue Moon Dinner (South)**
- **Sunday March 1: Walk to D'Feet MND, Ulverstone**
- **Sunday 15 March: MND Tasmania AGM, Paranal Convention Centre, Devonport**
- **Friday 27 March: MND Tasmania Health Professional Forum, Blundstone Arena, Bellerive**

Tell your health professionals, support workers and volunteers about the Forum and encourage them to join the email list for updates : info@mnd.asn.au

- **Sunday May 3: Walk to D'Feet MND, Launceston**
- **May 3 to 9: MND Week, State-wide**
- **Sunday June 21: MND Global Day**
- **Monday October 19: Walk to D'Feet MND, Hobart**

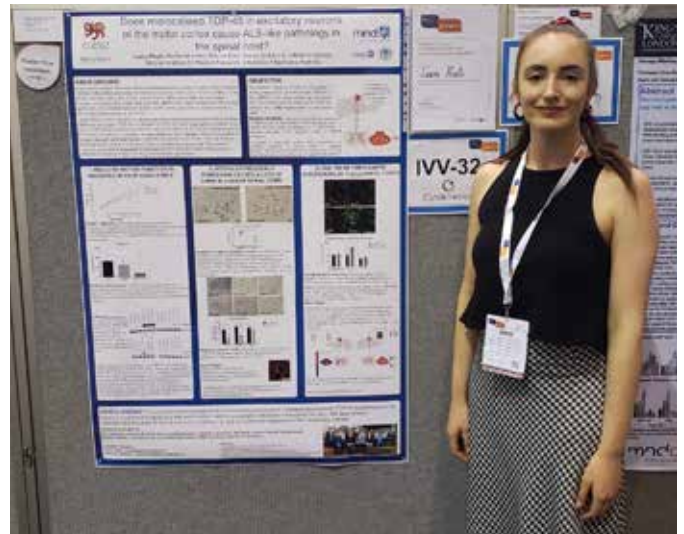
Thank you to all who have generously donated over the last couple of months. MND Tasmania relies heavily on the generosity and efforts of the community to assist us in raising much needed funds and awareness for our specialised care and support services for those living with Motor Neurone Disease. THANK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

RESEARCH

30TH INTERNATIONAL SYMPOSIUM ON ALS/MND, 4-6 DECEMBER 2019, PERTH, WA

MND Tasmania awarded MND Research Travel Grants to 3 Tasmanian researchers from the Menzies Institute, UTAS to assist them to present their research at the Symposium. We congratulate Laura Reale who won the

joint Biomedical Poster Prize selected from almost 500 abstracts. She will be progressing her research in her PhD study this year.



Kate Todd, Jules Driessen and Joyce Schuringa from our MND Tasmania board attended 3 days of meetings before the Symposium, and their report follows.

The **International Alliance meetings** on December 1&2 (before the Symposium) commenced with the Annual General Meeting of the International Alliance of ALS/MND Associations. There were a number of sessions throughout the day to discuss contemporary ALS/MND management such as major changes towards best practice in the Netherlands as well as other advances in programs and care from other parts of the world. A number of representatives also spoke about their success with various fundraising initiatives and using online/video conferencing forums to provide support networks to People Living with ALS (PALS) and Carers of People Living with ALS (CALs). PALS and CALs Advisory Councils have been established in the Alliance for over a year and will become an important influence in the projects and policy of the Alliance.

A strategic workshop was held to identify the information needed by the ALS/MND community (Alliance members, health professionals, PALS and CALs) and how the Alliance can assist in information sharing. The groups considered different stakeholder needs and how these could be met or facilitated by the Alliance. If you have any suggestions, feel free to let them know on their website: www.alsmndalliance.org

A highlight was the 2 hour **Connect (Ask the Experts)** forum which provided the latest information about research on MND. It was a brilliant overview of the causes of MND and the future of MND research. It included insightful questions from the audience and is well worth

watching. It was streamed live and people could send in questions from around the country. It can be viewed on the MND Australia facebook page at

www.facebook.com/mndaustralia/videos/948216232245973

The **17th International Allied Professionals Forum** was held on 3 December. It was a platform for Allied Health and Social Care professionals to share their experiences, knowledge and strategies for caring for people with ALS/MND to an international audience. The opening address came from the International Alliance of ALS/MND Associations with their clear focus being on Community and Capability and what they do to build capacity.

There were a number of local and international guest speakers who presented throughout the day, with an array of topics being covered - including Care, Community, Research and Technology. Each presentation promoted better outcomes for people living with ALS/MND.

Topics covered included -

- Occupational therapy – adapting and adjusting to rapidly changing function
- Management of neck weakness
- Improving recruitment to clinical trials
- Interdisciplinary model for cough secretion management
- End of life and challenges in voluntary assisted dying
- Eye gaze technology
- The acceptance and use of assistive technology and life prolonging interventions
- Voice bank and communication technology.

The **Inaugural Global Walk to D'Feet MND** was held in Perth along the Swan River on the evening of 4 December with many colourful ALS/MND t-shirts from around the world on display.



NEW MEMBERS

We welcome new members living with MND and their families to the MND Tasmania community, network and services. Please feel free to contact our MND Advisors for Tasmania who are also our NDIS Coordinators of Supports. Board members may also be contacted. The contact details are on the back page. The MND Advisor service is managed on our behalf by MND Victoria with MND Advisors who travel Statewide as required to support our members on a needs-basis.

VALE

We extend our heartfelt condolences to the families and friends of Andrew Neilson, Margaret Woolley and any other members who have recently passed away. Donations have been gratefully received in the memory of David Greenwood.

DONATIONS

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 MND Tasmania to continue to provide practical care for people with MND and their families in Tasmania.

ADVOCACY AND INFLUENCING

PALLIATIVE CARE WORKFORCE DEVELOPMENT

Palliative Care Tasmania has worked with the Tasmanian Department of Health to develop the Strengthening Communities of Care Strategy in Palliative Care (2018-2021). A number of MND Tasmania members and supporters including Geoff Cox, Rob & Sally Bonde, Libby Cohen, Joyce Schuringa, Chris Symonds and Dr John Saul contributed to this in December through telephone interviews & workshop attendance.

Tasmanian Palliative Care Conference 14-15

November 2019: Jenny Fuller (MND Advisor) presented a paper on behalf of the MND Advisor service at this conference. Emma Wilkinson-Reed (MND Advisor) and Libby Cohen (board member) also attended.

Libby's report is as follows -

This excellent conference was held at Wrest Point with presenters from Tasmania as well as national and international speakers. Michael Hebb's presentation "Facing Mortality" was a highlight as he spoke of how conversations about death can bring healing. He founded 'Death over Dinner' and shared his journey on bringing a topic of taboo into the mainstream. Peter Morgan-Jones is a distinguished chef who changed direction to become the executive chef for Hammond Care & Dementia Centre. He has created foods suitable for people with dysphagia and for those who are losing chewing and swallowing functions. He has written several very useful books including Lobster for Josino.

Little Haven Palliative Care is an NGO started in Gympie, Qld. It is a great example of a service evolving with community input and it has online resources which are useful for others. Di Carter's presentation on the Bereavement Care Network described the community's capacity to support people who are bereaved and how the Network is a resource for referral and support services such as our MND Advisors. Rob Hill was in his mid-twenties when he cared for both of his parents before their deaths. He described the challenges he had faced with society's expectations of him and the difficulty of managing his own self-care.

Jenny, Emma and I benefitted from this local opportunity to network with people from a broad range of backgrounds who came together because they are committed to palliative care in Tasmania.

NORTH WEST TASMANIA MND SUPPORT GROUP

The NWSG in Ulverstone invites all MND Tasmania members and supporters to its monthly meetings -
WHEN: The first Tuesday in every month at 10.30 a.m.

Next meetings: February 4; March 3; April 7; May 5.

WHERE: Ulverstone Returned Serviceman's Club,
21 King Edward St., Ulverstone.

The contact person is Junene Stephens at 1800 806 632 (message) or email info@mndatas.asn.au

WALK TO D'FEET MND ON 1 MARCH IN ULVERSTONE AND 3 MAY IN LAUNCESTON!

NEVER
GIVE
UP

NEVER
GIVE
UP

NEVER
GIVE
UP

MND ADVISOR AND SUPPORT COORDINATOR SERVICE

Emma Wilkinson-Reed (Launceston based, *photo top right*) and **Jenny Fuller** (Hobart based, *photo bottom right*) have been spending time getting to know clients in the region and networking with key organisations over the last few months. Between Emma and Jenny, all days of the working week are covered and they can support each other's clients if required.

The Tasmanian duo both attended the ALS/MND International Allied Health Professional Forum in Perth in early December, grasping the opportunity to learn about recent updates in MND management and research.

CLIENT NUMBERS:

We currently have 31 registered clients in Tasmania with MND or Kennedy's disease –

North region—11

North-west—10

South—10

CONTACT DETAILS:

Emma, (Mon, Wed, Thurs) email: ewilkinson-reed@mnd.asn.au
or phone: 0456 182 551

Jenny, (Tues to Thurs) email: jfuller@mnd.asn.au
or phone: 0412 599 365

Eric, (Mon to Fri)
email: ekelly@mnd.asn.au
or phone: 0421 323 850

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

ALLIED HEALTH PROFESSIONAL FORUM —SAVE THE DATE!!

Allied Health Professional Forum
- 27th March at the Blundstone Arena, Hobart.

We are thrilled to announce that Neurologist, Helen Castley will be our keynote speaker.

Jo Whitehouse
Manager Support Services
Ph: 0402 183 140



MND TASMANIA

PO Box 379, SANDY BAY, 7006

Charity ABN 21877144292

Telephone: 1800 806 632 (MND Victoria office so leave a message)

Email: info@mndatas.asn.au

Website: www.mndatas.asn.au

MND Tasmania has a volunteer Board and no paid staff.

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



BOARD

President: Joyce Schuringa
Vice-President: Michelle Macpherson
Secretary: Kate Todd
Treasurer: Julie Driessen
Public Officer: Andrew Moy
Fundraising: Michelle Macpherson
Equipment: Libby Cohen
NWSG: Chris Symonds

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

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.

FREECALL 1800 806 632

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

MND TASMANIA NEWS

Please tell us your stories! Send them to the Editor at our postal or email address.

The deadline for the next issue is 25 February 2020.