



May - June 2019

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*MND Tasmania 1986-2019:
supporting people living with MND in Tasmania for 33 years*



MND Tasmania – Annual General Meeting

The AGM was held on Sunday 17 March 2019 in Bellerive. The President's Report and the audited Financial Statements for 2018 were presented and discussed and the Board for 2019 was elected.

MND Advisor service

Jo Whitehouse, Manager Support Services for MND Victoria & Tasmania was the guest speaker following the AGM. She explained the roles of the MND Advisors and the plans for change in the year ahead.

MND Tasmania and Victoria have a Memorandum of Understanding (MOU) which has ensured that people with MND in Tasmania have had access to the Statewide MND Advisor service since 2008. This service will double from 16 to 32 hours per week in 2019.

Jacqui Holland commenced in the role in

February and is based in Hobart. As Hayley Tristram resigned in January, it is expected that an MND Advisor based in Launceston will be appointed in June.

It is important to note that there is no government funding for the MND Advisor service and it has been funded by fundraising and occasional special grant income from Victoria and Tasmania for over 10 years.

The role now includes that of Coordinator of Supports for NDIS participants who have MND. Some one who is younger than 65 years old and has been diagnosed with MND should contact NDIS and the MND Advisor service immediately and be assessed promptly by a NDIS Planner. The person with MND is entitled to be assisted by a Coordinator of their Support services.

At this stage, it is apparent that the MND

Coordinator of Supports service provides the most expert, appropriate and prompt information and support for people with MND in Tasmania when they need to navigate the processes involved with obtaining funding from NDIS to meet their needs.

Note that NDIS is a funding body. The MND Advisor has the specialist expertise to identify and refer to service providers who are experienced in working with MND and whose services are eligible to be funded by NDIS.

Board elections

Shane Chugg retired after having served on the Board for 2 years. He has also managed our website since 2001. During his time as a director he has provided sensible and wise counsel, calm common sense and excellent editing and support. Chris Symons was elected to the Board as a new member. The other six members were re-elected and their names and offices/portfolios can be seen on page 6.

President's report

by Joyce Schuringa

First of all, we welcome all the new members who have joined our Association during 2018.

We extend our sympathy to those families who have lost a loved one due to MND during the past year.

We are a tiny organisation. At the end of 2018 we had 40 client members and 29 ordinary members. We lost 19 client members during the year.

Of those current client members, 13 were in the North West, 11 in the North and 16 in the South of our state.

Sustainability is a challenge for small not for profit associations and we were very thankful at last year's AGM to elect three excellently qualified new directors following the retirement of Michele Newton, Helen Fleming and William Maguire. Kate Todd as Secretary, Julie Driessen as Treasurer and Andrew Moy have hit the ground running in taking up the reins, improving processes and learning about the Association and MND.

We divide our activities into 5 areas of focus which are -

- the provision of information, care and support
- collaboration and advocacy

- research
- fundraising
- being accountable and improving internal governance.

1. Information, Care and support—The Memorandum of Understanding (MOU) with MND Victoria was renewed in 2018 and we are thankful to MND Victoria for their commitment to assist us for another 3 years in the vital services of providing information and support for our members living with MND and Kennedy's Disease.

Both Associations committed to doubling the MND Advisor service in 2019. Hayley Tristram has been based in Launceston and for 3.5 years she assessed new client members and maintained contact with them to assist them as needed. A second Advisor Jacqui Holland was appointed and commenced in Hobart in February 2019.

However, Hayley resigned in January 2019 so that she could work full time for the Tasmanian Health Service. She will be replaced soon. In the interim, Jacqui will increase her hours and Leanne Conway (the MND Tasmania Advisor prior to Hayley) will assist to fill the gaps.

Our services provided in Tasmania have been funded through donations, bequests and specific purpose philanthropic grants. MND Tasmania has committed to funding the MND Advisor service at \$50,000 per year for another three years with MND Victoria funding the balance. The MND Advisors are also registered as Coordinators of Support with NDIS. Since a proportion of people with MND have become NDIS participants, a percentage of the Advisor service costs will be recouped from NDIS. This, along with the changes in aged care funding, is still a very fluid environment and we are unable to predict the funding outcomes at this stage.

The MND Advisors liaise closely with the Board to ensure that all members have access to the equipment and home and vehicle modifications they require and which are not funded through other means.

In 2018 we supported 13 client members with financial assistance for essential equipment or home

modifications as follows : 3 contributions for 3 members were to partly fund home modifications; 6 contributions to 6 members were to partly fund an item of equipment; 8 contributions to 5 members were to fully fund an item of equipment. (Partly funded means the balance of the cost is met by other service providers and/or the member.)

The Board has contracts with the Independent Living Centre Tasmania (ILC) and the Cure MND Foundation (= Fight MND) to provide the MND Communication Equipment Library to which Fight MND also contributed funds in 2017 and 2018.

The staff of MND Victoria administer our membership processes and client member services, the 1800 telephone information and support service, write and submit funding applications on our behalf and publish our bi-monthly newsletter (which we write). Our 4 page Newsletter grew to 6 pages in March.

In 2015, the MND Tasmania Care Foundation was established after the Association received a number of bequests. Its purpose is to assist in the funding of the MND Care and support service for as long as it is required. Libby Cohen, Julie Driessen and Andrew Moy have worked with our Financial Advisor to ensure that the Foundation Investment account is sustainable, transparent, secure and produces optimal returns.

The North-West Support Group (NWSG) has had a very successful year with a bunch of committed people to learn together and support each other while raising funds for people with MND. They lost a number of significant members to MND during the year as well as some moving into residential care homes.

2. Advocacy & collaboration—Our focus this year has been the ongoing changes for people with MND and their families due to the National Disability Insurance Scheme (NDIS) for those under 65 years old and My Aged Care for people over 65 and the lack of Neurologists in the North and North-West of the state.

The key methods of advocacy are through the MND Advisor service and our active participation in MND Australia (MNDA) and the Neurological Alliance of

Tasmania (NAT). We are continuing to advocate for people living with MND who are missing out due to new bureaucracy and barriers and to educate new service providers.

The appointment by the State government of 3 Neurologists (not all full-time) based in Launceston is a potentially good outcome of over 3 years of meetings with and letters to the Minister for Health and his staff. Through NAT we will continue to insist that all Tasmanians should have equity of access to Neurologists and other essential health professionals irrespective of where they live.

3. Research—MND Tasmania has been receiving donations for research since 1986 and they have been forwarded to the MND Australia Research Institute (MNDRIA).

We have a close working relationship with the MND research team in the Menzies Institute in Hobart to raise the profile of MND in the community and so that their Masters and PhD students learn about the life of people with MND to inform their research choices and their understanding of the human impact of research.

4. Fundraising—Michelle Macpherson has an effective team and networks to raise the profile of MND and to raise funds.

The second **Walk to d'Feet MND** in Tasmania was held in October and it was a great experience as well as adding to our profile and raising funds.

Facebook and mycause online fundraising continue to expand 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 all – it means that we can keep fulfilling the Association's mission and keep the MND Advisor service going.

5. Internal governance—Board members are all volunteers who are united in our motivation to improve the care and support for people living with MND in Tasmania.

I would like to thank each member of the Board for diligently working in their sphere of responsibility, reporting regularly, consulting frequently and holding

each other accountable.

Shane Chugg and **Andrew Moy** have kept our email addresses and website going successfully. Secretary **Kate Todd** has kept the administration of meetings, correspondence, record-keeping and document storage in good order and together with KPMG provided meeting venues and food. Public Officer **Shane Chugg** made sure we fulfilled our statutory requirements with ACNC, the ATO, Australian Business Register and the Department of Justice.

Treasurer **Jules Driessen** has increased our financial capacity to processing credit card income and receipts. **Libby Cohen** has ensured that our client members are supported with donations so that they can have assistive technology and home modifications. **Michelle Macpherson** has ensured that we are networked through social media and fund raising events.

We look forward to another year of continuing to provide better services and support for people living with MND in Tasmania.

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 page 6. 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 family and friends of Kenneth Timms and of any other members who have recently passed away.

Donations

Donations have been gratefully received in memory of Dianne Fuglsang and Tony Dawson and his mother. These funds enable MND Tasmania to continue to provide practical care for people with MND and their families in Tasmania.

Renewal of membership

Thank you to all those who have renewed their membership of MND Tasmania and are therefore continuing to receive this Newsletter. Your support for people living with MND in Tasmania and their families is significant and appreciated.

MND Victoria assists us by providing administrative support which is the reason for your Renewal of Membership form being sent from and needing to be returned to the MND Victoria office.

We value such support from MND Victoria as MND Tasmania has a volunteer Board and lacks the resources to employ staff. Our funding priorities are the MND Advisor service and equipment for members living with MND.

Northwest 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 10.30am

Next meetings: July 2, August 6, September 3.

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

MND Advisors

Leanne Conway has been busy working in the north and north west meeting new members and working through NDIS processes with members and families. Recruitment is underway for an MND Advisor and Support Coordinator for the north and north west.

Jacqui is working in the south and has been busy meeting members and families and working through the transition to the NDIS. Our NDIS pre-planning with members is resulting in good plans and outcomes. Leanne and Jacqui are developing links and connections with the teams at the NDIS offices in Devonport, Launceston and Hobart. With colleagues in Melbourne, Jacqui attended a training day at the end of April to learn more about the role of service coordination which was really helpful. She is settling into the role and enjoying meeting new colleagues in the allied health teams and palliative care teams.

Fund-Raising and Awareness

QUIZ NIGHT



Thank you to everyone (yes, all 200) who attended our quiz night held at the Italian Club in March and helped make it a huge success. Our quiz master Peter Gee had us all entertained during the evening and we were even treated to a skit from the Bawdy Panto gang. With both a “silent” and a “live” auction our generous supporters dug deep to raise an impressive \$10,000. We thank Elizabeth Hammer and Barbara Mitchell for their sensational organisational skills and continued support by bringing another fundraising idea to fruition. If you would like to be part of our organising group for the next fundraiser please get in contact by sending us a message at fundraising@mndatas.asn to register your interest.

HIGH TEA



On Saturday April 13 Jenny Page opened her home to around 65 guests to host a high tea to raise awareness and funds for MND Tasmania. Organised by Jenny Page, Jenny Jarrett and Wendy Roberts the afternoon raised over \$3000 to assist those Tasmanians affected by MND. All three organisers have been deeply affected by MND and generously shared their stories so that others may understand the devastating impact this horrid disease has. MND

Tasmania is extremely grateful to these wonderful, strong women, who despite their own loss continue to fly the flag for MND with the hope that one day we have a cure and others will not have to endure the heart-ache that they have experienced.

GOLF DAY: The Riverside Golf Club Lady Members held their annual Benevolent Day in January with all proceeds from the day coming to MND Tasmania. Over 70 players attended from 8 Northern Golf Clubs. Players competed for \$700 worth of prizes which were donated from local businesses. A very well stocked trade table and a raffle assisted to raise nearly \$2000.

ENTERTAINMENT BOOKS: Do you like to eat out? Would you like to save \$\$ whilst trying some new places or revisiting old favourites. With over \$20,000 worth of savings on offer in one book, the Entertainment Book is a great way to support MND Tasmania whilst doing the things you enjoy. To grab yours visit our FB page or Website to find the link below: <https://www.entertainmentbook.com.au/orderbooks/24004m3>

MERCHANDISE: Have you seen our new hoodies? Super comfy and warm our high quality, fitted MND Tasmania hoodies are perfect for the colder months that are now upon us. Show your support for people with MND wherever you go!



New scarves are available for purchase too. Contact fundraising@mndatas.asn for more information or to place an order today. *(Continued back page)*

GIN FOR A CAUSE: Here we go putting the GIN in GINEROSITY. As most know we can only provide the vital services we do through the generosity of others. We have collaborated with Tasmania's McHenry's Distillery to bring you a bespoke bottling of their high-quality classic gin. Keep an eye on our FB page to grab your bottle as soon as they are released as there are only a limited number of bottles on offer.

MND WEEK: This year MND Australia and state Associations continued the focus on making our Aged Care Fair for people diagnosed with MND aged 65 and over, as they do not have access to the NDIS to cover their disability needs. Instead, they must use Aged Care services, which do not come close to meeting the complex and rapidly progressing disability needs of someone with MND. Aged Care services also have long waiting lists, and some people with MND may die before they get to the top of the list. Together we are seeking six commitments from candidates from all sides of politics in the lead up to the 2019 Federal Election to address the urgent need to improve the lives of people living with motor neurone disease. If you would like further information on this campaign, please visit our website www.mndatas.asn.au

More to come in our next edition regarding our volunteers and the local fundraising that went on during MND Week this year. **#togetherwecan**

MND GLOBAL DAY: June 21 is MND Global day and it's an opportune time to raise awareness in your work place or local community. A morning tea is a great way to bring people together and raise funds to support those Tasmanian's living with MND. Please contact us at fundraising@mndatas.asn if you would like more information regarding a hosting a morning tea or for further fundraising ideas.

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.

MND Tasmania 1986-2019: supporting people living with MND in Tasmania for 33 years

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

NWSG: Chris Symonds



MND Advisors & NDIS Support Coordinators

Phone: 1800 806 632 (message)

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 26 June 2019.