



May - June 2018

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MND Tasmania 1986-2018: *supporting people living with MND in Tasmania for 32 years*

Annual General Meeting

The AGM was held in Launceston on March 18. Karen Frost, the Executive Officer of the Independent Living Centre Tasmania (ILC) was our host who presented a summary of the Communication Equipment Library and gave us the opportunity to explore this wonderful facility and the equipment which is specifically for the use of members of MND Tasmania.

AGM - President's report

The Board has benefitted from the increase in size with three new directors following the retirement of Tim Hynes and Mary Erickson in March 2017. We held the Association's first full-day Strategic planning workshop day in October because we have gradually become busier and the external environment is changing faster than ever before in our 32 year history.

What did MND Tasmania do in 2017?

We are a tiny organisation. On February 15 this year we had 37 client members and 70 ordinary members. We were active in -

- the provision of information, care and support
- advocacy
- collaboration with stakeholders and funding research
- fundraising
- being accountable and improving internal governance.

Information, Care and support

1. MOU with MND Victoria

A Memorandum of Understanding (MOU) with MND Victoria provides the management and

underpinning administrative services for the information and support service for our members living with MND and Kennedy's Disease (KD).

Our MND Advisor Hayley Tristram works the equivalent of two days per week and is based in Launceston. She assesses every new client member and maintains contact with them to assist them as needed.

This service is funded through donations, bequests and specific purpose philanthropic grants. In June 2017 MND Victoria was successful in obtaining a grant from Perpetual Philanthropic Services which together with a donation from MND Tasmania will fund the Advisor service for 2017 and 2018.

Hayley liaises 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 2017 we supported 13 client members with financial assistance for essential equipment or home modifications - 3 contributions for 3 members to partly fund home modifications; 6 contributions for 6 members to partly fund an item of equipment; 8 contributions for 5 members 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 staff of MND Victoria administer our membership processes and client member services, provide the 1800 telephone service, write and submit funding applications on our behalf and publish our bi-monthly newsletter (which we write). They have successfully negotiated with DHHS and NDIS to be a service

Equipment update

In collaboration with Fight MND, MND Tasmania has received more funding this year which will be spent to expand the communication equipment library for our client members at the ILC. The \$26,150 from Fight MND will be used to purchase mounting systems for the communication devices managed by the ILC. The five floor and five chair mounting systems will give users more flexibility and stability in communication.

Note that the library has a variety of communication devices which are suitable for all varieties of communication difficulties. The eye-gaze systems are prominent in the current media and news but simpler systems are also available which may be far more practical for particular users. The library works with referring speech pathologists to provide the optimal equipment for each person.

This equipment is available for MND Tasmania members through contact with Hayley Tristram, MND Advisor.

Libby Cohen, Equipment coordinator

Renewal of membership

Thank you to all those who have renewed their membership of MND Tasmania and are therefore continuing to receive this Newsletter as well as other mail from MND Victoria. Your support for people living with MND in Tasmania and their families is significant and appreciated. Members of MND Tasmania are automatically registered as members of MND Victoria due to the Memorandum of Understanding (MOU) between the two Associations. 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.

NWSG = 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 10.30 a.m. The next meetings are planned for 5 June, 3 July and 7 August. (NOTE change of time).

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

The contact person is Junene Stephens who may be

contacted at 1800 806 632 (message) or email info@mndatas.asn.au

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 staff member Hayley Tristram who is the MND Advisor for Tasmania or any member of the MND Tasmania Board. The contact details are in this Newsletter. The MND Advisor service is managed on our behalf by MND Victoria and Hayley is based in Launceston. She travels Statewide as required to support our members on a needs-basis.

Vale

We extend our heartfelt condolences to the families and friends of Gloria Keil, Dennis Conrades, Gary Alexander and of any other members who have recently passed away.

Donations have been gratefully received in the memory of Gary Alexander and of Lynn Blackwood.

Stephen Hawking 8/1/1942 – 14/3/2018 : "It would not be much of a universe if it wasn't home to the people you love." "Without imperfection, you or I would not exist."

HELP NEEDED!

MND Tasmania Newsletter Editor

If you enjoy writing, reading and collating, would you please consider this vital role?

It involves about 3-4 hours every 2 months while being part of a team of people who want to make a difference for people living with MND in Tasmania. Information and contributions are collated and a draft document and attachments are sent to Heidi at the MND Victoria office 6 times a year. Heidi puts it all into Publisher and turns it into this colourful Newsletter which forms an archived history of MND Tasmania on our website. You will be coached, supported and assisted by the current editor and other members of the Board as needed.

If you think you could help in this way, please email Joyce Schuringa at info@mndatas.asn.au

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 June 2018.

MND Tasmania 1986-2018: supporting people living with MND in Tasmania for 32 years

provider for the coordination of supports in NDIS for people in Tasmania who have MND and KD.

In a new collaborative initiative, the Board signed contracts with the ILC and the Cure MND Foundation (= Fight MND) to provide a MND Communication Equipment Library at the ILC.

2. Care Foundation

After the Association received a number of bequests, the MND Tasmania Care Foundation was established in 2015. Its purpose is to assist in the funding of the MND care and support service for as long as it is required. Foundation committee members of Tim Hynes, Helen Fleming, Libby Cohen and William Maguire have worked with our Financial Advisor to ensure that the Foundation investment account is sustainable, transparent, secure and produces optimal returns.

3. Support groups

We were sad to see the last Northern Support Group meeting in September after continuous operation since 1986. Special thanks go to Mary Erickson, Annette Viney and Libby Cohen who have worked with others to keep the Group going in recent years. The support group in Ulverstone (NWSG) attained a higher profile and was more active with the appointment of Geoff Cox as President and Junene Stephens as Secretary. Junene has been proactive in building the relationship and communication with the Board.

Advocacy

The ongoing changes in health, disability and aged care services due to the introduction of the National Disability Insurance Scheme (NDIS) for those under 65 years old and myagedcare for people of 65 and over have consumed ever-increasing time and resources. We are trying to ensure that our client members benefit from the changes rather than be disadvantaged by them.

The lack of access to appropriate specialist neurology and multidisciplinary services and clinics in our health system in Tasmania is continuing and the departure of another Neurologist from Launceston in May has resulted in more gaps in essential diagnostic and clinical service provision for people with MND.

We have made representations to the Tasmanian and Australian governments personally, in writing and via our involvement in MND Australia and the Neurological Alliance of Tasmania (NAT).

Our President's Report at our AGM in 2013 stated: "Key concerns about NDIS for which we have sought clarification include the upper age limit of 65; a potentially cumbersome, expensive and inflexible bureaucracy; raised expectations by people with disabilities about what it will deliver compared to what will actually be delivered." Unfortunately these concerns are now reality and we are continuing to advocate for people living with MND and to educate new service providers. Hayley Tristram, our MND Advisor, provides a Support Coordinator service for client members who are eligible to be NDIS participants.

Fundraising

Michelle Macpherson has been strategic and organised in building an effective team and networks to raise the profile of MND and to raise funds more efficiently and effectively.

We are supported by MND Victoria staff who set up our online mycause donor account and who provide advice and expertise when needed. For example, in February we received emails which we thought were spam until Kathy Nightingale at MND Vic made contact with the sender who was trying to send us a donation of over \$30,000 from the UK! He was a friend of one of our client members with MND and wished to donate to the MND Advisor service.

The inaugural Walk to d'Feet MND in Tasmania was held in October and it was a great time of reunion, sharing of experiences and encouragement for us whose lives have been devastated by MND.

Last year we also enjoyed the brave and daring antics of men such as Craig Machen kayaking around Tassie, Brayden Hayes running from Hobart to Burnie in his undies and Robert Button the Mankini King of the west coast! They put MND onto the front pages of newspapers and the nightly TV News and set social media on fire. They raised lots of money which they donated to provide care and support for people living with MND in our State. Many other people also raised the profile of MND by organising events and donating time and money for care and support. And 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 purpose and keep the MND Advisor care and support service going.

Collaboration and research

Our membership of MND Australia provides the

information sharing and networking to ensure that we are informed about issues affecting MND. Membership of National Disability Services (NDS) and the Neurological Alliance of Tasmania (NAT) provides information and the forum for sharing experiences within the “for purpose” sector in our State.

MND Tasmania has been receiving donations for research since 1986 which have been transferred to the MND Australia Research Institute (MNDRIA).

Funds for research into MND in Australia have recently been boosted by the formation of the Cure for MND Foundation (=Fight MND). It is a new organisation which is separate to the Australian and State MND associations and MNDRIA.

MND associations have been providing care and support for people living with MND for over 30 years and the increased publicity and focus on research by Fight MND has resulted in a welcome higher profile for MND.

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. As a Board we have sought to continuously improve processes and ensure that we are accountable, reliable, transparent and have integrity.

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.

Three directors are retiring -

William Maguire has shone the spotlight on our contracts, documents and processes to improve governance and his wife Iona has faced the media on our behalf with Associate Professor Tracey Dickson from the Menzies Institute to show that the research undertaken by Tracey and her colleagues is of direct relevance and important to people who are living with MND.

Michele Newton as Secretary has spent 7 years keeping the administration of meetings, correspondence, record-keeping and document storage in good order and she produced the Association's first Policies and Procedures manual which was adopted in February 2017. As Public Officer she made sure we fulfilled our statutory requirements with ACNC, the ATO, Australian Business Register and the Department of Justice.

Helen Fleming as Treasurer moved our financial reporting to the Xero financial management system in April. She was elected in 2014 and implemented Commbiz (secure electronic banking).

We now welcome the three new Board members who were elected to fill the vacancies and look forward to another year of continuing to provide better services and support for people living with MND in Tasmania.

Our vision – a world without MND : care to cure.

Joyce Schuringa, President, 18 March 2018

AGM – Invited speaker

The MND Communication Equipment Library was established at the ILC in Launceston in 2017 after a donation of \$50,000 was received from the Cure for MND Foundation/Fight MND for the purchase of equipment. MND Tasmania has committed to donating funds for the ongoing provision of the service.

25 voice amplification devices and 14 communication systems were developed and integrated from the project agreement and are available for trial and loan for client members who have MND or KD. Six items are currently on loan – one in Hobart and 5 in the North-west. Due to the valuable learning and experience we have gained from this collaboration, we have been successful in obtaining a grant from the Tasmanian Community Fund to utilise the processes applied for MND to other groups of people who need complex communication equipment.

We have developed a video of a client member using one of the systems to share with the project partners and place on our website and Facebook page. We used community-developed software provided by a developer in the UK and are collaborating with him in the further development of this project until June. He has used our video on the project website to demonstrate how his software can be used. In addition, we have been interviewed by a freelance journalist on behalf of Energy Australia for a blog about assistive technology.

Karen Frost, Executive Officer ILC Tasmania

March 18 2018

MND Advisor's Report

Hi everyone,

Some people I've met lately haven't been very aware of what a speech pathologist can do for people living with MND—the job title can be misleading I think—so

I thought I'd just write a quick note about it here.

Some people with MND can experience weakness in the tongue, lips, vocal cords and chest, causing speech to become more faint or unclear. For some, this can affect their swallowing. It's a speech



pathologist's role to help in the management of both communication and swallowing problems.

Communication aids range from simple manual systems such as alphabet boards, to voice-synthesising computers that can be operated from a single soft-touch switch. MND Tasmania has a partnership with Independent Living Tasmania to assess and loan out a range of communication devices.

Speech pathologists can assess and advise on different swallowing techniques, food preparation and selection. This may be done in collaboration with a dietitian who can provide dietary and nutritional advice.

If you think a referral to a speech pathologist might be helpful, please get in touch with me or any of your care team.

Best wishes, Hayley

0412599365 / htistram@mnd.asn.au

Fund-Raising and Awareness-Building

Thank you to our generous fund-raisers and awareness-builders including the team from Tasracing whom completed the Gone Nuts run. Decked out in their MND gear they started from The Nut in Stanley and completed 101 km of tracks finishing in Wynyard. Thank you so much we appreciate your help in raising awareness of this devastating disease.

BURNIE HARNESS RACING CLUB



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On the 14th April this wonderful group of people held a function at their Wivenhoe Club Rooms to honour the life of Anne Rawlings who sadly passed away from MND two years ago. A night of live music, supper and raffles saw a massive \$3000 raised with all monies sent to MND Tas to assist us in continuing to provide support and care to those Tasmanians affected by MND today. Thank you for your kindness and support BHR. #CaretoCure

STICK FISHING TRIP

The annual Stick Competition was held on the 2nd June, photos and a full report will be published in our next newsletter.

ENTERTAINMENT BOOKS



Our Early Bird release was a great success and now that the 2017/18 book has expired it is a fantastic time to purchase your new copy to get maximum value. With numerous sensational dining, shopping, travel and activity savings this is a great way support the MND community and save a few dollars doing the things we enjoy. Visit our FB or Website for the link to get yours today: www.entertainmentbook.com.au/orderbooks/24004m3

MND WEEK

This year MND Australia launched a comprehensive campaign which calls on the Government to Make Aged Care Fair for people diagnosed with MND aged 65 and over. Seeking commitment from all sides of politics for:

- Improvements to aged and disability care
- Timely access to a full range of assistive technology
- Development of National MND Guidelines
- A specific commitment to fund specialist MND multidisciplinary clinic nurses
- Increased investment in research

Working with all State Associations to achieve the desired outcomes further information can (to page 6)

be found on our website and Facebook pages.

Also, our regular supporters of this major fundraising activity, along with a big group of new faces, were out and about in Tassie shaking it up for MND and Guy Barnett's continued support saw a motion passed in Parliament on the 3rd of May. More detail to be shared in our next newsletter. **#nevergiveup**

NW Support Group

What a creative and committed group of individuals make up this support group. They got their heads together and came up with a plan to fundraise through placing collection boxes in local businesses in the area with all monies they raise going back into their local community to help those affected by MND with household tasks such as gardening. MND Tas is proud to have been able to support this enterprise by purchasing the collection boxes for the NW Support Group and we wish them all the success with their initiative.

Launceston Event

During April a group of people came together for a fundraiser luncheon and auction at Peppers Seaport Hotel in Launceston. It was hosted by Jackson Volkswagen, in conjunction with Grain of the Silos and Spicer Thoroughbreds. As it was incorrectly reported in the media that the funds raised would go to MND Tasmania, we contacted the organisers who reported that the funds were actually raised for research and that all funds would be donated at the Fight MND Website.

Walk to D'feet MND

Save the date: Sunday 21st October, 2018

The wonderful Elizabeth Hammer has already been working tirelessly to make our raffle this year AMAZING!! If you know a business that may be interested in supporting our day either by donating a prize or becoming a Corporate Sponsor for Walk to dFeet please get in touch by dropping me a line at fundraising@mndatas.asn.au

Once again, a big THANKYOU to all our generous fund-raisers and awareness-builders, it is only through your work that we can continue to provide specialised care and support to the Tasmanian community. **#togetherwecan**

*Michelle Macpherson,
Fundraising coordinator*

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. It is a member of MND Australia and of the Neurological Alliance of Tasmania.

Board

President: Joyce Schuringa

Vice-President: Libby Cohen

Secretary: Kate Todd

Treasurer: Julie Driessen

Public Officer: Shane Chugg

Fundraising: Michelle Macpherson

Logistics: Dr Andrew Moy

Ex-officio support: Chris Symonds

MND Advisor

Hayley Tristram

phone 0412 599 365

Email: htristram@mnd.asn.au

Support Service

MND Tasmania and MND Victoria work together to provide the MND Advisor service which is based in Launceston and 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

> 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

> free membership and 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 the MND Advisor, you will be asked for your contact details and your call will be returned by that person as soon as possible.

