



November - December 2017

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MND Tasmania 1986-2017: supporting people living with MND in Tasmania for 31 years



Where to start! What a morning! What an outcome! What a success!

We had almost perfect weather for our inaugural Walk to D'feet, with just over 200 participants across all age groups converging on the Queens Domain in Hobart to take part in the day. We were so lucky to have Peter Gee as our M.C. for the morning and it was great to hear from Associate Professor Tracey Dickson and her team from the Menzies Institute for Medical Research about the promising work they are undertaking. Brayden "Undie boy" Hayes was there to lead our walk, this time fully clothed donning an MND shirt and cap. Some ran the distance, some walked, some of us were pushed around the track and some of us got carried – whatever the method, whatever the distance we were united in working towards a World without MND. We have been overwhelmed by the fundraising organised by enterants and are thrilled to announce that our combined efforts has seen us raise a grand total in excess of \$22,000. MND Tasmania will use this money to provide support and care for those currently impacted by MND. We cannot THANK everyone enough for all their effort to make this a hugely successful event. **#togetherwecan**

We would like to acknowledge again the very generous support of the following businesses that also contributed to the days success:

Blundstone Australia, Skyline Roofing, Elite Appliances, Routley Menswear, Woolstore Accommodation, Frank Restaurant, Calvery Hospital, Daci & Daci, Lipscombe Larder, Shiploads, The Hair Lounge, Yeltour, Clarendon Arms Hotel, Taste.Walk.Talk. tours, Chandlers Nursery, Rebel Sports, Fullers Bookshop, Savoy Baths, Anytime Fitness, I'm back catering, Banjo's Bakery Lindisfarne, Running Edge.

A lot of preparation goes on behind the scenes for the day to run smoothly and it was through the very careful and efficient planning of Robin Barnes and Elizabeth Hammer, with an amazing group of volunteers assisting on the day that the event ran like clock- work. We are already planning to be back bigger and better next year, we are going to need more people to make this happen, so if you would like



to be a part of the organising committee or have suggestions for the Walk next year, please drop me a line at fundraising@mndatas.asn.au

MANKINI KING: In the last newsletter I reported that Robert Button had raised in excess of \$8000 running from Rosebery to Boat Harbour in a mankini to raise funds for MND Tasmania. A little correction needed here, he did raise over \$8000 and in fact the final tally was \$13,300! Mighty effort with every cent staying in Tasmania to assist those impacted by MND. **#togetherwecan**

HOBART SUNSET INNER WHEEL: You might also remember I wrote about how we had received a donation from the Hobart Innerwheel Club. In October I had the opportunity to attend one of their meetings and provide some information on MND and personally thank them for their generosity. What a lovely group of women, who were so welcoming and interested to learn more about MND and how the Association provides support. They were extremely surprised to learn that the Board are all volunteers! I took some of our cornflowers as a small gesture of thanks, but they insisted on doing a whip around and I left with another donation for the cause! The kindness of groups like this one is truly impressive.



BIG FREEZE BALL AND SLIDE: You may have seen or heard that Fight MND held their annual Freezing for MND events in Launceston during early October. Neale Daniher and his team continue their good work to raise awareness for MND.

MORNING TEA: Brooke Dobson has been working towards her Queen's Guide Award and needed to undertake some kind of community service as part of her pursuit. Brooke chose to organise a fundraiser in honour of her grandfather and selected MND Tasmania to be the recipient of monies raised. Morning tea was baked for around 40 people and from all accounts Brooke was kept



very busy on the day, but she did manage to snap a couple of pictures before the fun and rush began. Thankyou Brooke for raising over \$700 for the cause, we really appreciate the hard work that went into making your event such a triumph and we wish you well on your completing the Queen's Guide Award.

Michelle Macpherson, Fundraising Coordinator

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 on page 4 of 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 Mrs Jean Pearce and of our other members who have recently passed away.

Communication Equipment Library

MND Tas Communication Equipment Library is ready for our members to access. The Independent Living Centre Tasmania (ILC Tas) has assisted with the purchase, assembling and integration of this 'Assistive Technology' for communication. ILC Tas will administer this specialised service. New Equipment available includes voice amplifiers and 'high end' communication systems with different mouse controls such as eye control, head control and switch accessible.

Members whose communication would be enhanced by such assistive technology will be referred to ILC Tas by their Speech Pathologist. They will work together to assess needs, trial communication systems and organise a loan from the library. Loans will be at no cost to members. The main office of ILC Tas is in Launceston and the service is provided statewide.

The new equipment is already in use. Have a look at the video clip on the MND Tas website.

If you need to know more contact Hayley Tristram our MND Advisor. This new service has been made possible with a donation of \$50,000 from Fight MND.

Libby Cohen, Equipment Coordinator

MND Advisor Report

Hi everyone, It's been a long wait but from next year NDIS packages will start to become more available to

people with MND as the age group eligibility widens. In Tasmania, NDIS has become available, according to age cohorts. It's currently available to people under 35. From 1 July 2018, the NDIS will be available for those aged 35 to 49. From 1 January 2019, the NDIS will be available for adults, aged 50 to 64.



The NDIS aims to provide eligible people under 65 years old assessed as having a disability with a flexible, support package. If you currently receive disability services and are eligible to enter the NDIS, you will be contacted when you become eligible for NDIS. If you are currently not receiving support, you may still be able to access the NDIS.

If you'd like more information, feel free to get in touch, or if there's anything else you might need assistance with. Best wishes, Hayley 0412599365/ htistram@mnd.asn.au

Donations

Donations have been gratefully received in the memory of Mrs Elizabeth Wadley.

In addition to the donors mentioned in the Fundraising report, we were grateful to receive donations from the staff of Aurora Energy.

Advocacy

State-wide Neurology Services: MND Tasmania is a member of the Neurological Alliance of Tasmania (NAT) which has been proactively in contact with the Ministers for Health for many years about the lack of continuous and Statewide Neurology services. The President of MND Tasmania and five representatives from other member associations of NAT met with the Minister for Health Michael Ferguson MHA and his Health Advisor Catherine Schofield in Hobart on Monday 23 October. The purpose of the meeting was to discuss matters of mutual interest concerning policy affecting, services and programs, for Tasmanians living with neurological or progressive neuromuscular conditions. The agenda of the meeting included -

- the current situation and future plans for Neurology services in Tasmania
- priority issues affecting Tasmanians living with neurological or progressive neuromuscular conditions including but not limited to -
- the current longstanding inequities in Neurology services across Tasmania

- preventable hospital admissions
- the value of community services as frontline and essential service providers
- early intervention as best practice.

Legislative Council Inquiry into acute health services in Tasmania

NAT submitted a paper to this Inquiry and MND Tasmania has contributed case studies to illustrate how the issues affect people living with MND requiring hospital services. Details may not be released until after the Inquiry so watch this space ...

Vital Statistics

Annual data from the State and Territory MND associations is collected by MND Australia.

This data collected from MND Tasmania during July 1 2016 – June 30 2017 revealed the following information -

39 members of the Association had MND as at 30 June 2017.

19 new members with MND joined the Association during the year and there were 15 deaths.

458 hours of service (0.42 FTE) were undertaken by the MND Advisor Hayley Tristram.

11 MND information packs were sent from the MND Victoria office to people and organisations in Tasmania (excluding new members who have MND).

13 items of equipment were partially or fully funded by MND Tasmania for 12 members.

15 members have equipment funded by the Association as at 30 June.

\$151,756.00 was received in donations and grants which was an exceptionally high amount. Thank you fundraisers and donors!

In addition -

100% of funds donated to MND Tasmania which are specified by the donors to be for research are sent to the MND Research Institute of Australia (MNDRIA). The Institute has been funding Australian research (including the Menzies Centre in Tasmania) into MND since 1984. It is an entity of MND Australia.

100% of funds donated to MND Tasmania which are not allocated to research are utilised to support people living with MND in Tasmania.

The Association's financial year is January 1 – December 31 and the annual audited financial Statement is presented at the AGM in March every year. Copies can

be requested from the Board Secretary at email info@mndatas.asn.au or phone 1800 806 632 (message).

The next MND Tasmania AGM is scheduled to be held in Launceston on Sunday 4 March.

HELP Wanted!

MND Tasmania Newsletter Editor

If you enjoy writing, reading, collating, just fiddling about with letters and words on your screen, would you please consider this useful task?

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

If you think you might be able to help us in this way, please email Joyce Schuringa at info@mndatas.asn.au

Northern Support Group

This Group is currently in recess until further notice.

The contact person is Libby Cohen who may be contacted at 1800 806 632 (message) or email info@mndatas.asn.au.

NWSG = Northwest Support Group

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

WHEN: The first Tuesday in every month at 10a.m. The next meetings are planned for 5 December and 6 February with no meeting on January 2018.

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

MND News Tasmania

Please tell us your stories! Send them to the Editor at our postal or email address. The deadline for the next issue is 5 January 2018.

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: Michele Newton

Treasurer: Helen Fleming

Fundraising: Michelle Macpherson

Equipment: Libby Cohen

IT support: Shane Chugg

Governance: William Maguire

Ex-officio wisdom: John Hughes OAM

MND Advisor

Hayley Tristram, 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.

