



MND Tasmania News

March - April 2014

MND Tasmania
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Patron

Lady Sallie Ferrall

Board

President: Tim Hynes

Vice-President: Joyce Schuringa

Treasurer: Helen Fleming

Secretary: Michele Newton

Public Officer: John Hughes OAM

Northern Support Group: Mary Erickson

Fundraising Coordinator: Mary Erickson

Libby Cohen

Lisa Batge

Regional Advisor

Leanne Conway: lconway@mnd.asn.au or
telephone 1800 806 632.

Support

Website: Shane Chugg

Membership

MND Tasmania is a member of MND Australia with Tim Hynes serving on the MNDA Board. The MND Research Institute of Australia is part of MND Australia. MND Tasmania is a member of the Neuromuscular Alliance of Tasmania (NMAT).

Support service

The MND Associations of Victoria and Tasmania work together to provide:

- Information and member support by telephone on 1800 806 632, Monday-Friday, 9 am - 5 pm.
- Referral to Tasmanian health & support services.
- Information, support and training for service providers for people with MND in Tasmania.
- Free membership of MND Victoria and MND Tasmania for people living with MND.

- Victorian Newsletter with Tasmanian News insert for members living in Tasmania.
- The Regional Advisor who provides needs-based support and assessment, home visits and refers members to appropriate support services as required.

Freecall 1800 806 632

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

New members

We welcome new members S.Wynne, H.Fleming and L.Batge.

Vale

We extend our sympathy to the family and friends of B.Greenhill, W.Cowell, L.Thomas and T.Williams.

Donations

Donations have been gratefully received from many sources including M.Eldridge, the Wise, Lord and Ferguson Casual Clothes Day, Cathy Clayton's Pianola and Picnic Day supported by Lions, S.Wynne, B.Fitzpatrick, J.Forrester, T.Couzins, M.Elias and B.Pateman. Donations have also been received with thanks in memory of W.Cowel and T.Williams and a bequest has been received from the estate of the late I.A.Weir of Westbury.

MND Week: 4 – 10 May 2014

At this stage we expect that we will conduct our **Charitable Collection Day on Wednesday May 7**

The success of our raising the profile of MND and raising funds in Tasmania associated with the annual Awareness Week depends on a team of volunteers. There are committed people who have faithfully worked hard to contribute to this cause every year. We are looking for volunteers to participate in collections and raising awareness on the streets.

We also have merchandise boxes (with pens, cornflowers, wrist bands) for placement at businesses and workplaces.

If you would like to help or would like to know who will be fundraising in your area, please contact Mary on 0438 523 382.

Bunnings BBQ

Another **Sausage Sizzle Fundraiser** is planned for MND Week.

WHEN: Saturday May 10 from 8.30 a.m.- 4 p.m.

WHERE: Bunnings Launceston at 2/90 Connector Park Drive, Kings Meadows, 7249.

Please come along to support MND Tasmania. Have a good time, cook some snags, meet new people and help raise awareness and funds for MND!

If you would like to help and can spare some time, please contact Mary on 0438 523 382.

Mary Erickson
Fundraising Coordinator

Drink Tea for MND fundraiser

Where: Richmond Wine Centre, 27 Bridge Street, Richmond
Date: Saturday 17th May 2014
Time: 2.00pm - 5.00pm
Cost: \$20 per person (to be paid on arrival)
Includes Afternoon Tea & Fundraising Activities
Limited Tickets Available

RSVP to Anna Macpherson by Friday 2nd May
Email: Annacollins18@hotmail.com
Phone: 0411 161 479

Annual General Meeting: 2 March 2014

The AGM on March 2 was held in Launceston.

The President's Annual Report is below. The office-bearers for 2014 were elected and the new Constitution was adopted. We welcome new members Lisa Batge and Helen Fleming to the Board.

Carol Birks (CEO) and David Ali (President) from MND Australia (MNDA) presented the encouraging outcomes of the MNDA Strategic Plan 2011 - 2014 and sought advice about the content of the next Strategic Plan.

We enjoyed presentations by Jayden Clarke and Rosie Clarke (not related!), two young researchers from the Menzies Centre who have just completed the first year of their Doctorate studies. Their Supervisor Dr Catherine Blizzard and they have received funding from the MND Research Institute of Australia to which MND Tasmania donated \$22,232 during 2013. They described their current

research projects related to MND as well as explaining their motivation and responses to learning about MND and those whose lives are touched by MND.

President's Annual Report

First of all, I would like to welcome all the new members who have joined our Association during 2013. On behalf of our members, I extend our sympathy to those families who have lost someone due to MND during the past year.

Let us take a minute of silence to reflect on the 16 members we have lost to MND during 2013.

The Committee is grateful for those members who continue to faithfully attend Support Group meetings and who participate in MND Awareness Week and fundraising activities. Mary Erickson has been the tireless facilitator and organiser in these valuable networking and awareness building activities.

During 2013 we have received generous donations from fundraisers and supporters, our members, from the families of people who have had MND and from unknown benefactors. As our sole income is from donations, it is difficult to have accurate budgets. The operating deficit for 2012 was \$21,963. It was therefore encouraging to attain an operating surplus of \$8,789 during 2013 due to an unexpected increase in donations. These significant funds enabled us to allocate more to the Regional Advisor position, to equipment for members and to research.

The Committee has continued to steadily turn goals into actions based on our Business Plan. A workshop on Governance which we all attended for a full Saturday taught us important information so that we can conduct the affairs of the Association more effectively and efficiently.

John Hughes drafted a new Constitution based on current advice from the Department of Justice and Michele Newton revised it about 12 times following input from Committee members.

After creating order from the chaos of our financial records 7 years ago, Dora Hugo is resigning from her role of Treasurer. Thank you Dora for looking after our finances so well that we now have a clear 7 year financial history and transparent practices.

We have written an Equipment Policy and during 2013 we have assisted 13 members with payments towards the cost of their equipment to a total of \$14,354.

Since we signed our Memorandum of Understanding (MOU) with MND Victoria in 2007, the staff of MND Victoria has been actively representing us in submissions to and meetings with the relevant levels of State and Australian governments. So far, the National Disability Insurance Scheme (NDIS) has had more impact on people with MND in other States than in Tasmania. There have also been changes in government funding for palliative care which will improve services for our members.

We are grateful to Rod Harris, Jennene Arnel, Julie McConnell, Leanne Conway and the Board of MND Victoria who have supported people with MND in Tasmania with positive and proactive action.

Jennene retired from assisting and supporting people living with MND and their families for a second time. After she retired from working with members in Victoria, we were so very fortunate to have her here in Tasmania for 6 years. Jennene placed MND Tasmania in the forefront of the minds of health and disability workers when they thought about a client with MND. We are really thankful that Leanne Conway has been keen to learn from Jennene and to continue the valuable work of supporting people with MND in our state.

The MND Victoria Fundraising Manager Kathy Nightingale shared her expertise with us again. She knows what to do and does it fast so that more people can do fundraising more effectively. She continued to submit applications for funding and the Trustees of the Winifred D.Booth Charitable Trust in Launceston generously funded a second annual health professionals' forum in October. This was organised by Inez van Polanen and other staff of MND Victoria and was held in the Menzies Centre in Hobart.

Kathy also secured a grant from the Friendly Foundation which contributed \$15,000 to the cost of the Regional Advisor position. MND Victoria Office Manager Peter Allen has continued to process our membership applications and renewals and we continue to have newsletters published by Inez.

Tim Hynes has continued to serve on the Board of MND Australia and we congratulate him on his election to the position of its Vice-President.

I would like to thank my fellow members of the Committee who work hard to implement our goals. We look forward to another year of continuing to provide better services and support for people living with MND in Tasmania.

Joyce Schuringa
President 2013

Regional Advisor's Report

Hello everyone. I can't believe that two months have passed since our last newsletter.

In February, I spent six days in Hobart – three working and three for pleasure. My husband was able to join me for these three days and we spent a wonderful time touring around. This was his first visit to Tasmania and he was duly impressed. The highlight for him was a visit to the Cascade Brewery.

During my (work) stay, I met with five clients, three health professional organisations and provided an information session at a care facility. As always it was a pleasure to meet with everyone.

I am currently preparing for my next visit which will be in May. Please do not hesitate to contact me should you need anything. My telephone number is 1800 806 632 and email is lconway@mnd.asn.au.

Until next time,

Leanne Conway
MND Regional Advisor

Northern Support Group

The contact person for this group is Mary Erickson who may be contacted on 1800 806 632 (message). Meetings are held on the last Monday of each month at 11am – 1pm at the **Ravenswood Community Health Centre, 39 – 41 Lambert Street, Ravenswood** (Launceston).

Dates: April 28, May 26, June 30, July 28, August 25, September 29, October 27 and November 24

Mary Erickson
Northern Support Group Coordinator