



MND Tasmania News

January – February 2012

MND Tasmania
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Patron

Lady Sallie Ferrall

Committee

President: Joyce Schuringa
Vice-President: Tim Hynes
Treasurer: Dora Hugo
Secretary: Michele Newton
Public Officer: John Hughes OAM
Northern Support Group: Mary Erickson
Fundraising coordinator: Mary Erickson
Kate Barnett

Regional Advisor

Jennene Arnel: ra_tasmania@mnd.asn.au (note the underscore between ra and tasmania) 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.

Support service

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

- Information and support for members 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.

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 Jennene Arnel, 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 G. Cheeseman (S), D. Wessing (S), R. Hughes (S) and D. Carson (S).

Vale

We extend our sympathy to the family and friends of D. Bell, W. Haymann and H. Butterworth.

Donations

Donations have been gratefully received from M. Haymann, the Tasmanian Retired Teachers Association (N), Freycinet Sports and Community Club, Hands On (Clarence Baptist Fellowship) and M. Eldridge's Aquarobics Group.

Annual General Meeting

The Annual General Meeting is planned for **SUNDAY 4 MARCH 2012**. All members and others who are supportive of people with MND in Tasmania are invited to attend. The Boards of MND Victoria and MND Tasmania are currently planning a new agreement to define our partnership in supporting people with MND in Tasmania. These plans will be discussed at the meeting.

When: Sunday 4 March at 1.30 pm

Where: Joan Marshall Wing, 22 McHugh Street, Kings Meadows, Launceston

Nominations for Committee: The term of office for Committee members is one year. Committee members are nominated and elected at the AGM. If you are unable to attend the AGM and would like to nominate or be nominated for a place on the Committee, please contact Joyce Schuringa at phone 1800 806 632 (message) or at info@mndatas.asn.au

Renewal of membership

Due to the planned changes in our agreement with MND Victoria, the notice for renewal of membership will be sent out later this year rather than with this newsletter.

MND Week: 6 – 12 May 2012

We have received authorization from Tasmania Police to conduct our Charitable Collection Day on **Thursday 3 May 2012**, which is during the week before MND Week.

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. Please look for Mary Erickson's notes in the next MND Tasmania News in April for information on how you can help.

Fundraising

MND Entertainment Book

To order your 2011/12 Entertainment Book go to: www.mndatas.asn.au

Mary Erickson

Fundraising coordinator

Regional Advisor's Report

The new year commenced with a trip to Hobart in early January and was followed by a statewide visit to Tasmania in February. On both visits I undertook home visits, met with health professionals and spent time working with committee members of MND Tasmania.

Over the Christmas break I reflected on the International Symposium I attended in Sydney in November/December 2011. I thought about not only the papers presented but the people I met and the value of having time to connect with people from around the world who share the same commitment to supporting people living with MND.

At the Symposium this year, it was particularly exciting to have time to talk to the ten health professionals from Tasmania – doctors, nurses, therapists, from palliative and the general community sector as well as the President of MND Tasmania. It was wonderful to have such good representation from Tasmania.

Having time to catch up face to face with colleagues from other Australian MND Associations is always beneficial too, exchanging ideas, hearing of new national initiatives and always supporting each other through our highs and lows.

A further highlight for me was having time to meet with health professionals from the UK, hearing how their family support and palliative services have developed since I visited them some years ago. There is always so much we can learn from each other.

Over lunch one day, I met a neurologist and GP from New York and we talked of the challenges of distance when providing services to our members – theirs however was a vertical distance (i.e. people living in high rise building, often without stairs) while for us in Australia the distance is horizontal, as we travel across so many kilometers to provide support to our members.

An underpinning principle of all MND Associations across the world is assisting and supporting less resourced countries to set up services to support people living with MND. We heard at the Symposium a paper presented by two British OTs who have recently helped to establish support services for people living with MND in Turkey. Inspired by this paper a small group from Australia met to discuss how we might be able to support people living with MND in the Asia Pacific region. At that meeting there was a Chinese doctor who, as a sole worker, is trying to set up services for people living with MND in China. What a task! Maybe through the coordination of MND Australia we will be able to make a difference for that worker, and in turn people living with MND in China.

Martine, a former carer from Switzerland 'joined' the Australian ranks at the Symposium and continued to travel in Australia until mid January staying all the way with her new found Australian family in Melbourne, Bendigo, Hobart and Adelaide. She is committed to influencing the development of a Family Support Service in Zurich. She spent many hours visiting services, talking to health professionals, taking notes and she left for home loaded with information and a determination to make a difference in Switzerland.

For me, the papers at the Symposium were stimulating and encouraging and it is reassuring to know there is so much MND research underway across the globe. However, the greatest impact and lasting memory for me is the wonderful people I met. The commitment and drive of so many people

working in the MND area is inspirational and it is only by attending a few days away, such as at the Symposium, that there is time to listen and learn from their knowledge and experience, which in turn enhances and enriches the services we provide to our members.

My thanks go to MND Australia and MND Victoria who made it possible for me to attend the Symposium.

Jennene Arnel
MND Regional Advisor

Northern Support Group

Christmas celebration

The 2011 Christmas party was held at Lady Sally's home on Monday 28 November. Santa arrived with many gifts to share around and to wish a merry Christmas to all.

A raffle was held and the trade table was a huge hit with many items donated and sold on the day.

We would like to thank Lady Sallie Ferrall for opening up her home to the MND Support Group.



Meetings for 2012

We meet on the last Monday of every month at the John L. Grove Center, Howick Street, Launceston.

Time: 11am to 1pm

Dates: February 27, March 26, April 30, May 28, June 25, July 30, August 27, September 24, October 29, November TBC.

Mary Erickson
Northern Support Group

22nd International ALS/MND Symposium

In the first week of December, I had the privilege of representing the members of our Association at the

Symposium in Sydney. I was there for three of the five days and spent the first day in a meeting with the fundraising staff from each Australian MND Association to share ideas and information, plan activities and discuss strategies.

Jennene Arnel and I also had meetings with Rod Harris (CEO, MND Victoria) and Julie McConnell (Manager Family Support Services, MNDVictoria) to discuss plans for a new agreement between our two Associations to take us into the future.

Jennene and I also met with two of the Tasmanian Neurological Support Service (NSS) nurses to discuss our roles in supporting people with MND. The funding for the NSS staff to attend the Symposium was provided by MND Victoria and MND Tasmania, and it was excellent that they were able to participate in this unique event.

The people who were there from Tasmania demonstrate the multidisciplinary nature of this Symposium, which is hosted in a different country every year by the MND Association of the UK. There were five researchers from the Menzies Centre, two palliative care doctors, one palliative care nurse, two speech pathologists, two NSS nurses, Jennene as our staff member, and me as a volunteer. There were also many people who have MND, their families and people who have lost a relative due to MND.

There are other reports about the Symposium in your newsletters but what struck me was the uniqueness of the variety of over 630 people from around the world meeting for a week to focus on MND and the people who are affected by it. The program was multi-streamed so that, for example, a genetic scientist, a psychologist, a respiratory physician and a speech pathologist could be presenting their papers in different rooms at the same time. The level of specialist services for people in different countries varied, for example, between relatively high in Australia to very low in China. Turkey is planning its first support group for people with MND.

I returned home reflecting on how good we have it here compared to many other places, but how much there is still to do to improve the quality of life for our members and their families.

Joyce Schuringa
President