



## MND Tasmania News

### March - April 2013

MND Tasmania  
PO Box 379, SANDY BAY, 7006  
ABN: 21 877 144 292; Incorporation.No.: 01323C  
Phone: 1800 806 632  
Email: [info@mndatas.asn.au](mailto:info@mndatas.asn.au)  
Website: [www.mndatas.asn.au](http://www.mndatas.asn.au)

#### **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

Libby Cohen

#### **Regional Advisor**

Jennene Arnel: [ra\\_tasmania@mnd.asn.au](mailto: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. 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.

Please note that the Regional Advisor provides needs-based support 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 Jennene Arnel, you will be asked for your contact details. Your call will be returned by that person as soon as possible.

#### **New member**

We welcome J.Blizzard (N).

#### **Vale**

We extend our sympathy to the family and friends of W.Roussakis.

#### **Donations**

Donations have been gratefully received in the memory of G.Cooper and K.Ellerton and from J.Nickolls and M.Viney.

#### **MND Week: 5 – 11 May 2013**

MND Week is celebrated nationally in the first full week of May every year. MND Associations work together during this week to raise awareness of MND to realise our Vision of a World Free from MND.

#### **Button Day**

We have received authorization from Tasmania Police to conduct our Charitable Collection Day on:

#### **Wednesday 8 May 2013**

We are looking for volunteers to participate in collections and raising awareness on the streets. We have merchandise boxes (with pens, cornflowers, wrist bands) for placement at businesses and workplaces. If you would like to assist, please contact Mary Erickson via our email address [info@mndatas.asn.au](mailto:info@mndatas.asn.au) or telephone 1800 806 632 (leave a message for Mary to phone you).

#### **Bunnings Sausage Sizzle Fundraiser**

**Saturday 11 May from 8 am – 4.30 pm.**

#### **Helpers are needed!**

Please come and support us at Bunnings on Connector Road, Kings Meadows 7249

*Mary Erickson*

*Fundraising Coordinator*

#### **Annual General Meeting**

The Annual General Meeting was held in Hobart on Sunday 3 March.

#### **Committee**

The 2012 office bearers were re-elected.

## **President's Annual Report**

First of all, I would like to welcome all the new members who have joined our Association during 2012. On behalf of our members, I would also extend our sympathy to those families who have lost someone due to MND during the past year.

The Committee has continued to steadily turn goals into actions since we signed our Memorandum of Understanding (MOU) with MND Victoria in 2008. During 2012 we have received generous donations from fundraisers, our members and from the families of people who have had MND. However, our income was less than it was during 2010 and 2011 as we received three large unsolicited donations during those two years. These significant funds have enabled us to allocate more to the Regional Advisor position and for better administrative support.

The National Disability Insurance Scheme (NDIS) has been prominent in the news during the year. We have been involved in representations to the Tasmanian and Australian governments via our membership of the Neuromuscular Alliance of Tasmania (NMAT) and the Neurological Alliance of Australia (NAA). 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.

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. I would like to thank some people in particular while being mindful that there are many others who continue to generously support us. Jackie Chugg who agreed to be filmed for MND Awareness Week and therefore continues to be seen in Southern Cross Community Awareness advertisements and on our website; Margaret Eldridge who has been sending regular cheques since 2007 when she commenced fundraising when one of her colleagues had MND; John Hughes, our Public Officer, who has spent at least six months working through issues with the Taxation Office and then prepared a draft rewritten Constitution for the Committee.

During 2012, we have benefitted from an expansion of shared services with MND Victoria. We are grateful to Rod Harris, Jennene Arnel and the Board of MND Victoria who have supported people with MND in Tasmania with positive and proactive action.

The MND Victoria Fundraising Manager Kathy Nightingale has shared her expertise with us, and she knows what to do and does it fast so that more people can do fundraising more effectively without the Committee needing to spend time as volunteers trying to manage people's projects.

She also submitted applications for funding to assist in the education of health professionals in Tasmania. In response, the Trustees of the Winifred D.Booth Charitable Trust in Launceston generously committed funding for two years. This Trust funded October's health professionals' forum, which was organised by the staff of MND Victoria.

MND Victoria Office Manager Peter Allen commenced processing our membership applications and renewals last year, and we continue to have newsletters published by Inez van Polanen. The Regional Advisor service has built up networks within all sectors of the health and community services in the three health regions of Tasmania. Thus during the past 12 months, Jennene Arnel conducted 12 information sessions in Tasmania attended by 209 health workers. She is a wonderful support and advocate for people who have MND and their families. Her wisdom and advice is invaluable to all of us.

I would like to thank the 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**

## **Regional Advisor's Report**

My most recent visit to Tasmania, in February, started in the North West and concluded in the far South, taking me through the fire ravaged areas around Dunally. It was sad to see the twisted remnants of people's lives and amazing to see the new growth of the gum trees already pushing through the blackened trunks. I was reminded of the resilience of human beings on seeing tents, caravans and other temporary accommodation where families are re-establishing their lives next to charred remains. Along the roadside were frequent signs thanking volunteers for their support and aid through the fires.

A few days after this trip through Dunally, I had the pleasure of running an information session on MND for palliative care volunteers in Hobart.

Volunteers at palliative care, as in the fire areas, perform a valuable and unique role providing help as needed and friendship - and sometimes friendship is the most significant element. A new face and new conversation is

often a breath of fresh air for people experiencing shock and trauma or confined or restricted in their activity.

Palliative care volunteers are carefully selected, trained and supervised in their role. After a person requests a volunteer, the coordinator visits the client, assesses the needs and then introduces the volunteer who has been selected as the 'best' match. This may be because of their experience, skills, similar interests, location etc.

There are many stories of the difference volunteers make in all walks of life. I have witnessed on many occasions the difference volunteers have made to the lives of people living with MND.

So there are two things I want to say:

1. If you living with MND there may be ways in which a volunteer could become meaningfully involved in your life. Think about it. You are welcome to discuss your thoughts with me.
2. Thank you volunteers for the gift of your time and the difference you make in your volunteer role, whatever that might be. And an especially big thank you if you are supporting people living with MND. Your contribution is valued and appreciated by all of us.

My next visit to Tasmania will be May/June

**Jennene Arnel**  
**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 29, May 27, June 24, July 29, August 26, September 30, October 28, November 25.

**Mary Erickson**  
**Northern Support Group Coordinator**

### **Neuromuscular Alliance of Tasmania (NMAT)**

NMAT consists of MND Tasmania, Alzheimer's Australia (Tas), Australian Huntington's Disease Assoc. (Tas), Multiple Sclerosis Tasmania, Muscular Dystrophy Assoc. of Tasmania, Parkinson's Tasmania and the Spina Bifida Assoc. of Tasmania.

During 2012, NMAT conducted the Keeping Cool Campaign to lobby for comparable electricity concession assistance as offered by other State governments to people with heat and cold intolerance.

On 5 May 2013, Premier Lara Giddings announced that the Tasmanian Government will fund a new **Medical Cooling Rebate** for eligible electricity concessions customers of \$135 per annum in the coming State Budget. This will be available from 1 July 2013 and is a very welcome announcement.

**Joyce Schuringa**  
**NMAT**