



MND Tasmania News

May - June 2010

MND Tasmania
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Patron

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Board

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Secretary: Anna Nicholas

Northern Support Group: Mary Erickson

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Public Officer: John Hughes OAM

Regional Advisor

Jennene Arnel: ra_tasmania@mnd.asn.au
(note the underscore between ra and tasmania)
or phone 1800 806 632

Support

Correspondence secretary: Michele Newton

Fundraising coordinator: Anna Macpherson

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 by telephone on 1800 806 632, Monday-Friday, 9 am - 5 pm.
- Referral to Tasmanian health & support services.
- Information kits.
- Free membership of MND Victoria and MND Tasmania for people living with MND.
- MND Victoria Newsletter with MND Tasmania News insert for members living in Tasmania.
- Meetings for people with MND, carers and past carers.

New members

We welcome new members C. Clayton (NW), J. & J. Heazlewood (N) and R. & J. Dicker (NW).

Vale

We extend our sympathy to the family and friends of Mick Gleeson and Evaleen Hinds.

Donations

Prior to MND Week activities, donations were gratefully received from R. & J. Dicker, C. Clayton, T. Hanson, The Friendly Circle Club of New Norfolk, M. Eldridge and S. Keogh. Donations have also been received in memory of Mick Gleeson.

MND Week

Sunday 2 May – Saturday 8 May 2010

Thank you to supporters who were busy promoting MND and collecting donations during May. Donations have been gratefully received and receipts are still being processed. Any outstanding funds may be mailed to our Treasurer or deposited into our CBA account at 067-013 2800 5202. Please mark your name on the deposit comments or transaction description so that we can send you a receipt.

Fundraising

To kick off MND Week fundraising, Margaret Eldridge hosted a 'Bring & Buy Morning Tea' where friends and family enjoyed tea and fresh scones with jam and cream. We really appreciate Margaret's fundraising events over the past three years resulting in regular donations via MNDTas to the MND Research Institute of Australia.

On 10 April, Cathy Clayton held a unique event at Weindorfers Restaurant near Sheffield. Sean Roche, Irish singer and entertainer, flew in from Perth, WA, to be the MC and to delight the 40 guests with his unique voice and warm personality as he sang old favourites and his own signature tunes such as Gold & Silver Days. Guests came from across the north and northwest to enjoy good wine and food. We are grateful to Cathy and her friends for the fabulous effort in organizing this special evening.

Anna Macpherson

Fundraising coordinator

Glass Half Full:

Living With Motor Neurone Disease

On Saturday 1 May, over 40 people gathered in the Goulburn Street Gallery for the Tasmanian launch of a documentary which is a rare insight into an inspiring person's life, his family, his support team and his disease.

Tony and his wife Dot live in suburban Brisbane and have worked in the airline industry, travelled the world

and raised a family. Then Tony was diagnosed with motor neurone disease. Although they struggled to come to terms with the diagnosis and prognosis, they chose to 'add life to years', rather 'than years to life'.

Tony and Dot are the parents of our MND Tasmania President, Tim Hynes. Tim and his wife Carolyn organised the launch and this is an excerpt from Tim's speech:

"During MND Awareness Week 2010 the national focus is on the proposed National Disability Insurance Scheme (NDIS). MND associations around Australia are throwing their support behind this proposal for a number of reasons. Firstly, it is time to change the way services for people with disabilities are funded and structured in Australia so that people diagnosed with MND can access disability services based on need no matter where that person lives or how old they are. Secondly, waiting lists are not an option for people with MND and their families. Lastly, a national funding methodology based on need has many benefits for people living with MND and their families to ensure a rapid response to rapidly changing needs."

This DVD is available from MND Australia via a phone call to the MND Victoria office on 1800 806 632.

Freecall 1800 806 632

To assist the volunteer receptionist at the MND Victoria office, please say that you are from Tasmania. If you wish to speak to a specific person, please say so and your call will be returned by that person as soon as possible.

North-west Group

Contact Jennene Arnel on 1800 806 632.

Northern Support Group

The contact person for this group is Mary Erickson who may be contacted via 1800 806 632 (message). Meetings are held on the last Monday of each month at 11am – 1pm at the John L. Grove Centre, Howick Street, Launceston. The following dates have been booked: 31 May, 28 June, 26 July, 30 August, 27 September, 25 October 2010.

Southern afternoon tea

Contact Jennene Arnel on 1800 806 632.

Regional Advisor's Report

During the first week of May, I undertook a Statewide visit to Tasmania, commencing in Hobart, travelling to the North West and finishing in Launceston.

In the course of the week, I visited six people living with MND, including a newly diagnosed person.

I met with eleven health professionals and conducted one training session. I also met with representatives from the committee of MND Tasmania.

A number of our members were away on respite, or about to have a respite break, and it reminded me what a great opportunity respite offers people with MND and their carers to have a break from every day routines, a chance to meet new people and for many people a chance to harness new energy. We often think of respite as providing a break for carers but often it is also a welcome break and change of scene for the person with MND.

The most successful respite breaks occur when the 'new' carer(s) are well briefed about MND, with documented notes about the care needs and preferences of the person with MND. Please contact me if you would like further details about respite opportunities in your area.

Last year, MND Tasmania in conjunction with MND Victoria held a very successful MND Day in Launceston.

We are very pleased to announce:

<p style="text-align: center;">MND Health Professionals Forum Hobart - the Baha'i Centre of Learning Wednesday 13 October</p>
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While designed primarily for health professionals, people living with MND and their families are very welcome to attend. The program and registration details will be available in the next Newsletter.

My next visit will be to the North and North West in June where I will be participating in MND Information Sessions. Next visit to the South will be towards the end of July. In the interim, I can be contacted by phone 1800 806 632 or email (ra_tasmania@mnd.asn.au).

Keep warm as we head into winter.

Jennene Arnel
MND Regional Advisor

Food for thought

'In examining disease, we gain wisdom about anatomy and physiology and biology. In examining the person with disease, we gain wisdom about life.' [From: The Man Who Mistook his Wife for a Hat by Oliver Sacks.]

'As Alice loses her ability..., she is forced to search for answers to questions like "Who am I now?" and "How do I matter?" As the disease worsens and continues to steal pieces of what she'd always thought of as her 'self', we see her discover that she is more than what she can remember.' [From: Still Alice by Lisa Genova.]