



MND Tasmania News

November - December 2009

MND Tasmania
PO Box 379, SANDY BAY, 7006
ABN: 21 877 144 292
Phone: 1800 806 632
Email: info@mndatas.asn.au
Website: www.mndatas.asn.au

Patron

Lady Sallie Ferrall

Board

President: Tim Hynes
Vice-President: Joyce Schuringa
Treasurer: Dora Hugo
Secretary: Anna Nicholas
Public Officer: John Hughes OAM
Northern Support Group: Mary Erickson
Southern Group: Anna Nicholas
Lyle Sydes
Kate Barnett
Denis Lyne

Regional Advisor

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

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 support services.
- Information kits.
- Free membership of MND Victoria and MND Tasmania for people living with MND.
- Victorian Newsletter with Tasmanian News insert for members living in Tasmania.
- Telelink meetings for people with MND, carers and past carers.

New Members

We welcome new member L.White.

Vale

We extend our sympathy to the family and friends of A.Sullivan, J.Conlan, Tom Hickinbotham and K.Scott.

Donations

Donations have been gratefully received from R.Minchin and in memory of K.McPherson, S.Eriksen and J.Conlan. Paula Horton and other supporters raised a considerable amount of funds with a wonderful community event and publicity for MND in Burnie. MND Tasmania has also received a grant from the Tasmanian Community Fund to supplement the funding for the Regional Advisor position.

HELP Needed

The Board is seeking to invite members or prospective members to join the Board in order to assist people in Tasmania with two specific tasks:

- A person to assist with sending letters to members and donors and to write the minutes of meetings. This would take on average up to approximately six hours per month.
- A person to provide support to fundraisers by coordinating MND Week activities and to assist people who wish to organize fundraising events for people with MND in Tasmania. This would take on average approximately four hours a month.

If you would be able to assist in these roles, or if you know someone who may be suitable, would you please either email Tim Hynes at info@mndatas.asn.au or leave a phone message on 1800 806 632 for Joyce Schuringa with your contact details.

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 Jennene Arnel, please say so and you will be asked for your contact details. Your call will be returned by that person as soon as possible.

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 at the John Grove Centre, Howick Street.

Southern afternoon tea

Anna Nicholas is the contact person for this group. She may be contacted on 1800 806 632 (message).

North-west Group

Contact Jennene Arnel on 1800 806 632.

Advocacy

MND Tasmania Forum – 23 October

In October MND Victoria and MND Tasmania held a very successful MND Forum at the Tram Shed in Launceston. The venue was lovely, the food was good and the program was a groundbreaking networking,

bonding and educational event for people involved with MND in Tasmania. There were ten speakers and MNDV staff from Victoria and over 80 Tasmanian health professionals and workers from all of the public and private residential, care management and health care sectors.

MNDTas President Tim Hynes opened the day with a welcome on behalf of MND Tasmania and Victoria. He outlined the history of MNDTas with a focus on the opportunities presented since 2007 when we commenced a formal collaborative relationship with MNDV.

The program was chaired by Rod Harris (CEO, MNDVic.). A description of MND from the perspectives of neurology and palliative care were presented by Dr Michael Dreyer, Director of Neurology at RHH and Dr Paul Dunne AM, Senior Palliative Care Physician of the Palliative Care Service in Hobart.

Ms Ingrid Ganley, the Manager of Disability Reform in DHHS, spoke about the potential opportunities in the support of people with MND in Tasmania. This was followed by presentations by Dr Susan Mathers, Clinical Director of Neurology at Calvary Health Care Bethlehem (CHCB) Victoria and Chris Bryg from ILC Tas Technology Access Service in Launceston. I was pleased to have the opportunity to talk about the MND Regional Advisor service in Tasmania.

Lunchtime presented the opportunity to network and look at resources and materials.

After lunch overview presentations were made by the Chief Speech Pathologist and Clinical Nurse Consultant from CHCB and Eric Kelly, Regional Advisor from MNDVic on therapy services, residential care and community care respectively.

A breakout session of three groups was held in the afternoon with a representative from MNDTas in each group. Jennene Arnel joined the community care group, Kate Barnett joined the health professionals' group and Joyce Schuringa joined the residential care group. The latter was by far the smallest group but it demonstrates the cross-sectoral nature of the day. It was chaired by a Registered Nurse from Melbourne and the three other participants were a Disability Services Coordinator from the North, a Palliative Care Nurse from the Northwest and a Physiotherapist from the South. The Palliative Care Nurse had also attended the first National MND Symposium held in Tasmania in 1996.

The Forum provided a valuable opportunity for people to network, put faces to names, learn more about MND and to discuss their common interest – caring for people living with MND. It was very pleasing to see so many health professionals with a keen interest in developing skills and knowledge that in turn will enhance the quality of life of people living with MND in Tasmania.

Feedback from those attending the Forum was very positive and we look forward to having similar sessions about MND in the future.

I extended my visit to Launceston by four days and visited eleven members living in the North and North East. My next visit will be to Hobart in early December. Regular eight-weekly visits to Tasmania will resume in February 2010.

If you wish to contact me at any time please phone 1800 806 632 (leave a message and I will return your call) or email ra_tasmania@mnd.asn.au

With best wishes to all members for happy festive season.

Jennene Arnel
MND Regional Advisor

Finding good information on the internet

Searching for health information on the internet can be overwhelming. To make it easier for people to find health information, several organizations have set up websites that provide a pathway to good quality health information.

Some examples of websites which have passed rigorous quality tests to ensure that information is accurate, balanced and up to date are:

- A Victorian Government site Better Health Channel at www.betterhealth.vic.gov.au
- MyDr health information by CMP Medica at www.mydr.com.au
- The USA Government site Medline Plus at www.medlineplus.gov

Websites that display the HEALTHInsite or Health on the Net Foundation (HON) logo have been judged as being of good quality and suitable for consumers. (Source: Medicines Talk Spring 2009 at www.nps.org.au/consumers)