



## MND Tasmania News

### January – February 2010

MND Tasmania  
PO Box 379, SANDY BAY, 7006  
ABN: 21 877 144 292  
Telephone: 1800 806 632 (freecall)  
Email: [info@mndatas.asn.au](mailto:info@mndatas.asn.au)  
Website: [www.mndatas.asn.au](http://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](mailto:ra_tasmania@mnd.asn.au) (note underscore between ra and tasmania) or phone 1800 806 632.

#### 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.

#### Vale

We extend our sympathy to the family and friends of B. Keogh, T. Good and S. White.

#### Donations

Donations have been gratefully received from G.Ashby, P.R. and Friends Inc., S.Lyden and the Sandford Morning Tea Group and M.Eldridge and the Aquarobics Group. Donations have also been received in memory of T.Hickinbotham.

#### Renewal of membership

Would you please complete and return the **enclosed renewal of membership form** so that you will continue to receive this newsletter and to enable us to update our records?

#### HELP Needed

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

- 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 fund raisers by coordinating MND Week activity and to assist people who wish to organize fund raising 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 contact Jennene Arnel or email Tim Hynes at [info@mndatas.asn.au](mailto:info@mndatas.asn.au) ?

#### MND Week May 2010

The success of our raising the profile of MND and raising funds in Tasmania during 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.

However, we are in urgent need of a person who is willing and able to assist the Board in planning for the Week, in the coordination of activities and in the support for people who are raising funds. Please contact us if you can assist in this role.

#### 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 Board 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 – 1pm at the John L.Grove Centre, Howick Street, Launceston. The following dates have been booked: January 25, February 22, March 29, April 26, May 31, June 28, July 26, August 30, September 27, October 25.

### **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.

### **Regional Advisor's Report**

My last trip to Tasmania was to the Southern region in December 2009, when I visited six people living with MND, met with three health professionals and a representative from the committee.

In mid-February, I will be in Tasmania for two weeks and will be travelling around the state to meet with current and new members and a number of new services.

A meeting with the Assistant Secretary of the Department of Health and Human Services has been arranged for February to seek funding for MND Tasmania to provide a Regional Advisor service for people living with MND in Tasmania. The meeting will be attended by the President of MND Tasmania, CEO of MND Victoria and me, as the current Regional Advisor.

The Regional Advisor project, which commenced in October 2008, is funded by a philanthropic trust until September 2010 and the service can only continue if re-current government funding is secured. The need for a Regional Advisor service was initially identified through surveying members.

Over the past 18 months, the project has demonstrated that a Regional Advisor services facilitates many positive outcomes for members both individually and collectively. Significant broad outcomes include better information and support for people living with MND and better education and support for service providers. Most importantly, by working together we have been able to enhance quality of life for people with MND and their carers, enabling people with motor neurone disease to live better for longer.

We will keep you informed on the progress of our discussions with government.

Jennene Arnel,  
Regional Advisor Tasmania

### **Neuromuscular Alliance of Tasmania Getting in Touch**

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

In collaboration with MS Tasmania as the project leader, NMAT has received a grant from the Community Support Levy, Charitable Organisations Grant Program for resources to develop and utilise a survey for obtaining the demographic profile of the population represented by NMAT in Tasmania. This will provide the first set of benchmark information about the prevalence of these complex diseases in Tasmania and the needs of the people who live with them.

The Getting in Touch research project was launched on 30 November 2009. The 2-part survey form is currently being sent to all MND Tasmania members who have been diagnosed with MND or Kennedy's Disease.

If you have received the survey forms, please ensure that you complete and return it to the address provided on the form before **1 March 2010**. If you have been diagnosed with MND and have not received a form, please contact Jennene Arnel.

### **Information**

**The Independent Living Centre (ILC) of Tasmania** provides information and advice on equipment specific to your situation. The October – November 2009 newsletter contained information about electric lift chairs, lounge chairs, lift cushions and on standing up from sitting down. Contact the ILC on phone 1300 885 886 or at [www.ilctas.asn.au](http://www.ilctas.asn.au)

**The Community Palliative Care service in Tasmania** provides information for people with MND on issues such as pain, what to do in an emergency, breathlessness, constipation, fatigue, nausea and vomiting, considerations at the end of life with respect to family, advanced planning and so on. Fact sheets can be viewed at [www.dhhs.tas.gov.au/palliative\\_care/publications2/fact\\_sheets](http://www.dhhs.tas.gov.au/palliative_care/publications2/fact_sheets) or they can be obtained from the Community Palliative Care services at:

Hobart - (03) 6224 2515  
Launceston - (03) 6336 5544  
Burnie - (03) 6440 7111