



## MND Tasmania News

March - April 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

Northern Support Group: Mary Erickson  
Kate Barnett

Denis Lyne

Public Officer: John Hughes OAM

### Regional Advisor

Jennene Arnel: [ra\\_tasmania@mnd.asn.au](mailto:ra_tasmania@mnd.asn.au)  
(please note the underscore between ra and tasmania) or phone 1800 806 632.

### Support

Correspondence secretary: Michele Newton

Fundraising coordinator: Anna Macpherson

### 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.
- MND Victoria Newsletter with MND Tasmania News insert for members living in Tasmania.
- Telelink meetings for people with MND, carers and past carers.

### New members

We welcome new members: G & D. Short (S), N. Turner (S), Q. & S. Brown (NE), M. Howell and (S) and D. Walker (S).

### Vale

We extend our sympathy to the family and friends of B. Barry, S. McMurtrie and F. Oakley.

### Donations

Donations have been gratefully received from D. Walker, D. & S. Couzins, J. Higgins, S. Bower, B. Males, M. Eldridge, L. Willis, the Archbishop of Hobart's Charitable Foundation and the Mowbray Cricket Club. Donations have also been received in the memory of B. Barry, B. Keogh and T. Good.

### Renewal of membership

Thank you to the members who have sent in their **renewal of membership form**. If you would like to continue your support and to receive this newsletter, please ensure that you complete and send us the form that was enclosed with the January-February 2010 *MND Tasmania News*. If you have misplaced the form, please contact us via email or the 1800 telephone number.

### HELP received

It was encouraging to receive offers of assistance following our call for help in the previous two newsletters.

### Fundraising

I am excited to take on the role of volunteer Fundraising Coordinator for MND Tasmania. I will be coordinating activities and providing support for people who are raising funds during MND week, or for those who wish to organise fund raising events.

Thank you to all who support us so generously. Each year our fundraising efforts get better, however, we know there is more we can do!! Your support is valuable in assisting us to raise funds for the care and support of people in Tasmania with MND and for MND research.

*Anna Macpherson*  
Fundraising coordinator

## **MND Week**

### **Sunday 2 May – Saturday 8 May 2010**

MND week is coming up in May, so please give some thought as to what you may be able to do to assist with fundraising activities. Will you shake a tin, organise a morning tea or an event, wear a blue cornflower or wrist band?

If you would like to assist in any way, Anna Macpherson would be happy to help you get started and support you where she can. If you would like information on how to actively participate this year, please contact Anna via our email address [info@mndatas.asn.au](mailto:info@mndatas.asn.au) or telephone 1800 806 632 (leave a message for her to phone you).

A BBQ to raise awareness will be held at Bunnings in Launceston on 7 May 2010. The coordinator is Kate Barnett.

### **Annual General Meeting**

The AGM was held in Launceston on 14 March. Members and supporters heard Dr Tracey Dickson, NHMRC Senior Research Fellow, present an encouraging summary of research being undertaken at the Menzies Research Institute in Tasmania. She described various studies and explained how they may impact on the body of knowledge and understanding of MND.

The 2009 Board members were re-elected. It was heartening to have some of our longstanding members with us at the meeting, including Lyle Sydes after a long break and Life Member John Hughes.

### **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 specific MND Tas 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.

### **North-west Group**

Contact Jennene Arnel on 1800 806 632.

### **Southern afternoon tea**

Contact Jennene Arnel on 1800 806 632.

## **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: 26 April, 31 May, 28 June, 26 July, 30 August, 27 September and 25 October.

## **Regional Advisor's Report**

My visit to Tasmania in February included visits to 19 people living with MND, discussions and information sessions with five groups of health professionals and a meeting with the Assistant Secretary of the Department of Health and Human Services to discuss recurrent funding for the Regional Advisor service in Tasmania. Rod Harris, CEO of MND Victoria and Tim Hynes, President of MND Tasmania also attended that meeting.

At the suggestion of the Assistant Secretary, further meetings with the Director of the Reform Implementation Unit and managers from the Gateway programs (to commence 1 July 2010) have since taken place. A new proposal for recurrent funding of the Regional Advisor service which incorporates the Regional Advisor service with the Gateway model will be submitted to the Tasmanian Department of Health and Human Services and we will await a response. We will keep you informed.

During my February visit, the glorious late summer weather turned many discussions with people living with MND to leisure, recreation and holidays. This reminded me of all the great information and ideas we gather from personal experience and how useful this information can be to others. For example, who has the best information about holiday accommodation suitable for people living with MND? People with motor neurone disease who have used the accommodation, of course!

So, I am starting to gather information about accommodation that you have found to be excellent. The accommodation can be anywhere in Australia. I will compile this information and record the contact details of the person providing the information. The resource information will be retained by me and anyone can obtain a copy by contacting me.

There are a number of travel books available commercially which focus on accommodation with disability access. If you use these books, always check with the manager before making a booking to ensure that their 'disability access' meets your requirements.

If you have access to the internet you will find a number of accommodation resources by googling "Holiday Accommodation Disability Access 2007", and there is a most comprehensive document about accessing Melbourne at:

<http://www.melbourne.vic.gov.au/AboutCouncil/PlansandPublications/Pages/AccessibleMelbournepublications.aspx>.

Please send me any hints, ideas and details of good accommodation you have found in your travels. Mail to MND Victoria, PO Box 23, Canterbury, Victoria 3126 (marked to my attention) or email to [ra\\_tasmania@mnd.asn.au](mailto:ra_tasmania@mnd.asn.au). (please note the underscore between ra and Tasmania).

I look forward to hearing from you and to my next visit to Tasmania in early May.

*Jennene Arnel*  
*MND Regional Advisor*

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

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

In collaboration with MS Tasmania as the project leader, NMAT received a grant from the Community Support Levy, Charitable Organisations Grant Program 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 two-part survey form

was sent between 1 January and 31 March to the current 32 members of MND Tasmania who have been diagnosed with MND or Kennedy's Disease.

We have been told that the response rate from our members was excellent. Thank you! We hope that the results of the survey will be available for the next edition of this newsletter.

### **Research**

The donations received by MND Tasmania for research are sent to the MND Research Institute of Australia. Further information about the Institute can be obtained by telephone at (02) 8877 0990 or at the website [www.mndresearch.asn.au](http://www.mndresearch.asn.au)