



# MND Tasmania News

March - April 2009

MND Tasmania  
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## Patron

Lady Sallie Ferrall

## State Committee

President: Tim Hynes

Vice-President: Joyce Schuringa

Treasurer: Dora Hugo

Secretary: Denis Lyne

Public Officer: John Hughes OAM

Northern Support Group: Mary Erickson

Care Advisor: Anna Nicholas

Lyle Sydes

Kate Barnett

## Regional Advisor

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

(note the underscore between ra and tasmania)

## Support service

The MND Associations of Victoria and Tasmania work together to improve support for people with MND. The service includes:

- Information and support by telephone on 1800 806 632, Mon.- Fri. 9am - 5pm.
- 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.

## Renewal of membership form

We apologise that the membership renewal form was inadvertently not enclosed with the previous newsletter. Would you please return the enclosed Renewal of Membership form?

## New Members

We welcome new members:

T. & D. Hickinbotham (North), L. Sharman (NW), Cron (N), P & M Carney (NW).

## Vale

Our sympathy is with the family and friends of our member Maureen Lane. Maureen had MND for over 15 years.

## Personal story

Stephen Death was a member of MND Tas who passed away in May 2008. His wife Carlene has written a moving account of their experience which is published on page 9 of the MND Vic newsletter.

## Regional Advisor's Report

As I write this report, I am on the eve of departing for my March visit to the South where I will be meeting with the committee of MND Tasmania, attending the AGM, visiting people living with MND and their carers and catching up with many of the health professionals who so ably support our members in Hobart and surrounding areas.

In February, I spent five very busy days in the North and North West visiting 10 members and meeting with six separate groups of health professionals (a total of more than 60 people) to talk about MND. I was impressed by the commitment of these people and their interest in learning more about MND and care and management issues.

During my recent visits to Tasmania a number of people have expressed an interest in meeting with others living with MND. So, in February I arranged an afternoon tea in Ulverstone for people interested in meeting together. Eight people attended and within minutes people were making connections and chatting about their common experiences in life. It was an enjoyable afternoon and participants agreed they would like to meet again. Jenny, a family carer, kindly offered her home in Devonport for the next meeting which will be in April. Anyone interested in joining the group should contact me (1800 806 632) regarding the next meeting.

In Hobart, a similar meeting will take place in March. All people living with MND and their carers have been invited and I am sure it will be an equally successful afternoon.

The first step to meet others on a similar life experience is a big one, and often takes some courage. Those who take the step say through meeting with others they gain strength, support and confidence and of course many new friendships.

Having enjoyed the summer fruits of Tasmania (what wonderful raspberries you grow) I now look forward to experiencing some winter delights. My next visits will be in May and July.

If you wish to contact me at any time please do so on 1800 806 632.

*Jennene Arnel*  
Regional Advisor, Tasmania

### Donations

Donations have been gratefully received in memory of M. Lane and from J & K Harris, F. Oakley and F & E Hinds.

Lightwriters have kindly been donated by G.Lane and MNDVictoria.

### Local contact with other people with MND

If you would like to be in touch with other people with MND in Tasmania and who live near you, please contact Jennene Arnel at MNDVic on 1800 806 632.

### Northern Support Group

Mary Erickson is the contact person for this group. She 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, Launceston.

### Diary dates

Monday 27 April, 11am:

Northern Support Group meeting, John Grove Centre

Wednesday 29 April:

Deadline for May-June newsletter. Material to Editor, MNDTas at PO Box 379, SANDY BAY 7006 or email to [info@mnd.asn.au](mailto:info@mnd.asn.au)

May 3 – 9: MND Week

Thursday 7 May: MNDTas Committee meeting

Monday 25 May, 11am:

Northern Support Group meeting, John Grove Centre

Thursday 18 June: Global MND/ALS Awareness Day

Tuesday 23 June: MND National Conference, Sydney.

### News from others

**Physical Disability Australia** is the broadest cross-sectorial organization for people with a physical disability in Australia. They are promoting the concept of a National Disability Insurance Scheme and information about this can be found at [www.natdis.com.au](http://www.natdis.com.au) Their new website is at [www.pda.org.au](http://www.pda.org.au) and they welcome input from people with physical disability.

**MedicinesTalk** is published quarterly free of charge on paper and online. It is published by the National Prescribing Service (NPS) and is available at

[www.nps.org.au/consumers](http://www.nps.org.au/consumers) or via the NPS Medicines Line at 1300 888 763.

**www.healthinsite.gov.au** is the Australian Government website that links you to hundreds of reputable health information websites providing information about medicines, medical conditions and staying healthy.

[www.wheelies.net.au](http://www.wheelies.net.au) is a new website for **wheelchair users** who find it difficult to have holidays because of cost or the lack of suitable accommodation. It is sponsored by the MS Society of Tasmania and funded by the Tasmanian Community Fund.

### History of MND Tasmania

John Hughes provided a copy of his Chairman's Annual Report of 17 March 1996 which summarises the history of MNDTas up to that time. We are publishing excerpts in order to preserve our history and to encourage us as we read of those who have travelled this journey before us. This is the second instalment.

*Nina Buscombe (of the MND Society of Victoria) was most supportive and gave us much encouragement and advice.*

*In October 1985, we received our first money from the Lions MN Fund for a patient, Helen Minchin. We held a special meeting on December 6 where we finalised the Constitution and the management was vested in myself as Chairman/Public Officer, Vice Chairman John Piggin, Secretary Geoff Wall, Treasurer Rosemary Stobart, Fundraising/Publicity Officer Sallie Barnett, Medical Liaison Officer Dr MacLaine Cross and a Committee of Margaret Robinson, Beryl Howie, Mary Peypers, Carl Bullock and Helen Minchin.*

*We were incorporated on 9 December 1986. The first general meeting was held at Quamby on 5 April 1986 with 29 people in attendance. We ended that meeting with a lot of optimism for the future for our patients, carers and friends. At the end of April that year we had 19 patients listed and 64 members statewide.*

*Since then we have come a long way. Unfortunately, we have lost a great number of loved ones and friends but that is the nature of this terrible disease. We have seen the growth of the society to an Association with many members and large amounts of money raised to aid patients. There have been many marvellous workers who have given extraordinary service to the Association over the years. We have seen the growth of our National body, the MNDAA, and the International Association with our very own International President in Mavis Gallienne. The MND Research Institute has been given a new lease of life with a new Committee and membership of the MNDAA.*

(to be continued)