



## MND Tasmania News

July – August 2009

MND Tasmania  
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### Patron

Lady Sallie Ferrall

### State Committee

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 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, 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 members: D. & E. Ellis (N), P.Curtis (N) and K. & J. Scott (S).

### Regional Advisor's Report

In May, I visited people living with MND and health professionals in the North West, North, North East and South of Tasmania. Eleven people with MND were visited at home and this included meeting with two new families. People who are newly diagnosed are always most appreciative of these visits and value the opportunity to talk about the experience of being diagnosed with MND and their future hopes and aspirations.

In Launceston I met with a representative from the Department of Health and Human Services and an occupational therapist to discuss ways in which we might be able to establish a clear pathway into appropriate support services for people newly diagnosed with MND who live in the Northern region.

We also discussed the possibility of holding a Statewide Forum on MND. It was agreed to organise a MND Forum on Friday 23 October 2009 at the Tram Shed in Launceston. The program is now being planned and we will provide more details in the next newsletter. While intended for health professionals, families living with MND will be most welcome to attend the day.

From 6 – 15 July I was in Launceston and Hobart where I met with a number of people with MND, health professionals, and participated in a Study Day on Neurology, organized by the Tasmanian Association for Hospice and Palliative Care.

A group of people with MND in the North West continue to meet every couple of months, rotating the venue between members' homes. In Hobart a group of people met in March and planned the next meeting for May. Unfortunately, this meeting was cancelled as a number of people were unable to attend. In Launceston there is a long established Support Group, which meets regularly. If you are interested in meeting with other families living with MND please let me know. All the groups warmly welcome new people.

The next visit will be in September 2009.

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](mailto:ra_tasmania@mnd.asn.au)

*Jennene Arnel*

*Regional Advisor, Tasmania*

### **Freecall 1800 806 632**

Calls to this number go directly to the MND Victoria office. To assist the volunteer receptionist, please identify at the outset that you are calling from Tasmania. If you wish to speak to a specific person such as 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.

### **MND Week**

Thank you to supporters who were busy promoting MND and collecting donations during the first week of May. Donations have been gratefully received and receipts are still being processed.

### **Donations**

Donations have gratefully received in the memory of J.Males, W.Parcell and M.Shipp.

Thank you for the donations which have been sent with membership renewals. Other donations were received from the Sandford Morning Tea Group.

### **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.

### **Resources**

#### **Glass Half Full: Living With Motor Neurone Disease (MND)**

A new DVD is available from MND Australia via a phone call to the MND Vic office on 1800 806 632. An excerpt from the cover of the DVD follows -

“This documentary is a rare insight into an inspiring person’s life, his family, his support team and his disease. He openly invites you into his home and shares his journey, with honesty and humour. Tony and Dot’s story is about experiencing life with a positive approach, no matter what comes your way. Tony and his wife Dot live in suburban Brisbane, Australia and spent their time working in the airline industry, travelling the world and raising a family. Then Tony was diagnosed with Motor Neurone Disease (MND)... Although initially they struggled

to come to terms with the diagnosis and palliative prognosis, they chose to ‘add life to years’, rather ‘than years to life’ ”.

Tim and Dot are the parents of our MND Tasmania President, Tim Hynes. Tim gave a speech at the launch of this DVD in Brisbane on May 11. The following words are an excerpt from Tim’s speech:

*“Dad developed a ‘glass half full’ approach prior to his diagnosis of MND to get through tough periods... Over the last 5 years since diagnosis, Dad has managed to retain some of his key strengths that people are drawn to: his clever wit and enduring sense of humour... I think for Dad, drawing on these strengths assists as both a coping mechanism and a way to say death is coming, but I am living not dying.*

*Seeing both Mum and Dad navigate through their challenges every day together, really illustrates what is possible with a positive mindset... Due to his attitude I personally have been able to achieve things I never thought possible, and will never look at the glass as being half-empty ever again.*

*With my hat on as a board member at MND Tasmania and MND Australia, I feel this documentary contributes significant value to those people living with MND, service providers, bureaucrats and health professionals. ...my role in MND Tasmania has involved assessing what people with MND really want and need how it should be delivered by NGOs, Government and our Tasmanian association.”*

### **Residential respite care**

Commonwealth Care and Respite has set up a new website which offers virtual tours of accommodation facilities which offer respite care. The site will expand as it is only showing places in southern Tasmania at this stage. Due to the large amount of graphics, access may be limited without Broadband. For further information, phone Craig at 1800 052 222 or visit [www.residentialrespitetours.com.au](http://www.residentialrespitetours.com.au)

### **Walk to d’Feet MND**

Tim Hynes represented our members at a walk along Lake Burley-Griffin in Canberra on June 21. Organised by MND NSW, this wonderful community event promoted the cause of MND. MND NSW registered the walk with ‘Everyday Hero’ where ‘hero’ pages can be created at: [www.everydayhero.com.au/event/globalday](http://www.everydayhero.com.au/event/globalday)