



## MND Tasmania News

### May - June 2011

MND Tasmania  
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#### Patron

Lady Sallie Ferrall

#### Board

President: Joyce Schuringa  
Vice-President: Tim Hynes  
Treasurer: Dora Hugo  
Secretary: vacant  
Northern Support Group: Mary Erickson  
Fundraising coordinator: Anna Macpherson  
Public Officer: John Hughes OAM  
Kate Barnett

#### Regional Advisor

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

#### Support

Correspondence secretary: Michele Newton  
Website: Shane Chugg

#### Membership

MND Tasmania is a member of MND Australia with Tim Hynes serving on the MNDA Board. The MND Research Institute of Australia is part of MND Australia.

#### 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 health & 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.
- Meetings for people with MND, carers and past carers.

#### Vale

We extend our sympathy to the family and friends of Rosalie Svennsen and Que Brown.

#### Donations

As well as the funds raised during MND Week, donations were gratefully received from W.Parsons, M.Gurr, the estate of P.N.Wiseman and the Independent Order of Oddfellows in Launceston. Donations have also been received in the memory of R.Svennsen and M.J.Whenn.

#### MND Week

##### Sunday 1 May – Saturday 7 May 2011

Thank you to supporters who were busy promoting MND and collecting donations during May. Donations have been gratefully received and receipts are still being processed. Any outstanding funds may be mailed to our Treasurer or deposited into our CBA account at 067-013 2800 5202. Please mark your name on the deposit comments or transaction description so we can send you a receipt.

MND Week is celebrated nationally to raise awareness of the needs of people living with MND and their families. It is a time to acknowledge the MND community and people living with MND and to remember those who have passed away.

#### Tuesdays with Morrie

The launch of MND Week by the MND Association of Tasmania coincided with the opening of the tender and uplifting two-man show about a life-altering friendship in *Tuesdays with Morrie* at the Theatre Royal. Although the second night was cancelled at the last minute due to one of the actors needing emergency surgery, the first night received good reviews and many people learned more about the impact that MND has on people's lives.

#### Community advertisement: SCTV

John Hughes, Jackie and Shane Chugg, Anna Macpherson and Adam Widdison (of Southern Cross TV Tasmania) have been a fantastic team in organizing and creating an advertisement about MND for MND Week. We expect that the film clip will continue to be shown by SCTV as part of their Community Service Announcements.

#### Fundraising

##### Bring and Buy Morning Tea

On 30 April 2011, Margaret Eldridge again hosted her "Bring and Buy Morning Tea" where friends and family enjoyed tea and fresh scones with jam and cream. We appreciate Margaret's fundraising efforts resulting in regular donations via MND Tasmania to the MND Research Institute of Australia.

## **Davo's Run**

Tasmanian long-distance runner David Brelsford has recently run across the State and donated the funds to MND Tasmania for research. Thank you Davo!

The 68-year-old runner from Legana completed a run from Launceston to Hobart and then a run from Strahan to Bicheno. Here is a report from Davo of his amazing journey:



*My first leg was from Launceston to Hobart - and the first day was the worst! I ran 66 km to Campbell Town but it was too warm for me. After that I disciplined myself to running for 70 seconds, walking for 50 seconds and I kept that up for the rest of the project. It meant constant glancing at the watch, and my wife in particular kept admonishing me to "look at the scenery!"*

*I reached Hobart after just over three days and was glad to head back to Lonnie for a day's rest before meeting Vlastik Skvaril, who was to crew for me for the West to East leg, starting at Strahan.*

*However, after three days Vlastik's van played up. That meant that I had to finish the double crossing over the next two weekends, with my friend Paul Wright crewing*

*for me to Ross, and then the next weekend my wife Anne crewing for me from Ross to Bicheno.*

*The crewing is absolutely essential. No-one can run those distances without the occasional break for a drink or a meal, or even a short siesta!*

*Vlastik is an old hand at fundraising, Paul proved to be quite the salesman, but Anne and I are not very good at asking for donations from complete strangers, although I think we did improve as time went on. After I had finished and we were having coffee at Bicheno, a very nice old couple came up to us and said they'd seen me on the road, and donated \$20. It is gestures like that which restore one's faith in humanity.*

*My sister is the president of the Mossman Senior Citizens in North Queensland, and they had a collection which raised over \$100. I was very touched with that, as we all know that pensioners do it hard. (I speak from personal experience here!)*

*But all in all it was a great experience. I'd love to do something similar again, but I think the hardest part will be finding willing crew members to accompany me. Vlastik runs many of these sort of things himself, Anne and Paul both have full time jobs and little time to spare, so if anyone has a couple of weeks free ... .let's talk!*

## **Bunnings Sausage Sizzle - Kings Meadows**

A sausage sizzle was held at Bunnings, Kings Meadows on Saturday 30 April 2011. The famous Bunnings Sausage Sizzle is enjoyed by thousands of Bunnings customers every weekend of the year. The day provided a valuable fundraising opportunity for MND Tasmania. Thank you to those people who organised and worked hard at this fundraiser!

## **Button Day**

On Thursday 5 May 2011, many volunteers were out and about on Tasmanian streets to 'Shake the tin' and raise awareness of MND. In the lead up to MND week, a special advertisement on Southern Cross was aired to promote button day and MND awareness. We are grateful to all involved in organising the advertisement, and to those volunteers who assisted with 'Shaking the tin' on button day.

## **MND Entertainment Book**

To order your 2011/12 Entertainment Book go to: [www.mndatas.asn.au](http://www.mndatas.asn.au)

***Anna Macpherson***  
***Fundraising coordinator***

## **HELP Found**

### **Website**

We are grateful to Shane Chugg who has volunteered to maintain and update the MND Tasmania website.

### **Support staff**

As described in the last edition of MND Tasmania News, we have been working with MND Victoria on the neurological nurses project initiated by Parkinson's Disease Tasmania and funded by the State Government. We are seeking to ensure the inclusion of people with MND into this new service and a smooth transition from the Regional Advisor to the regional neurological nurses. We are pleased to advise that the MND Victoria State Council has confirmed an extension of the funding of Jennene Arnel's position into March 2012, giving us an extra six months from the cessation of the philanthropic funding - great news!

In addition, Dr Jane Tolman has informed us that the nurse project has been named the 'Neurological Support Service'.

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

In October 2008, MND Tasmania in partnership with MND Victoria, commenced the MND Regional Advisor program with the aim of enhancing services for people living with MND in Tasmania. The program was funded through a three year grant provided by a Victorian Trust. By demonstrating the benefits to people living with MND of an effective Regional Advisor service, we hoped to obtain a commitment from the Tasmanian government for re-current funding to enable the continuation of the service beyond September 2011.

In the last 12 months, written and verbal submissions have been made to government and many members sent excellent letters to politicians outlining the need of people living with MND for specialist services and supporting our submissions. All our submissions were unsuccessful and the Council of MND Victoria and Board of MND Tasmania have been concerned for the ongoing and continuing support of people living with MND in Tasmania beyond September 2011.

In the last Newsletter, I briefly reported on a newly funded statewide program in Tasmania recently established to provide support for people with Parkinson's disease and other neurological conditions. In recent weeks, we have had fruitful discussions with program staff from the Neurological Support Service regarding the needs of people living with MND and the capacity of the new program to support our members.

As a consequence, MND Victoria State Council has approved the extension of the MND Regional Advisor program to 31 March 2012 with the aim of integrating the role of the nurses of the Neurological Support Service and the MND Regional Advisor and to identify and resolve gaps in service delivery and responsibilities.

The newly integrated program will develop slowly over coming months. It will be monitored and evaluated in consultation with members, health providers, MND Associations, program staff and other stakeholders. We believe that through integration and by working together people living with MND in Tasmania will continue to receive relevant and appropriate support services.

As a first step, in mid-May, I will be participating in a formal orientation program for the newly appointed nurses and this will be the start of an ongoing working relationship together. I look forward to developing our work together and further enhancing services for people living with MND in Tasmania.

During May, I will be visiting many members in Tasmania and look forward to talking with you about the new directions of the Regional Advisor service. Alternatively, at any time, you can contact me by phoning 1800 806 632 and leaving a message and I will return your call.

*Jennene Arnel*  
*MND Regional Advisor*

### **Northern Support Group**

The contact person for this group is Mary Erickson who may be contacted via 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:

- 28 June
- 26 July
- 30 August
- 27 September
- 25 October

### **Freecall 1800 806 632**

To assist the volunteer receptionist at the MND Victoria office, please say that you are from Tasmania. If you wish to speak to a specific person, please say so and your call will be returned by that person as soon as possible.