



## MND Tasmania News

### July - August 2012

MND Tasmania  
PO Box 379, SANDY BAY, 7006  
ABN: 21 877 144 292; Incorporation.No.: 01323C  
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#### **Patron**

Lady Sallie Ferrall

#### **Committee**

President: Joyce Schuringa

Vice-President: Tim Hynes

Treasurer: Dora Hugo

Secretary: Michele Newton

Public Officer: John Hughes OAM

Northern Support Group: Mary Erickson

Fundraising coordinator: Mary Erickson

Libby Cohen

#### **Regional Advisor**

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

#### **Support**

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. MND Tasmania is a member of the Neuromuscular Alliance of Tasmania (NMAT).

#### **Support service**

The MND Associations of Victoria and Tasmania work together to provide:

- Information and member support by telephone on 1800 806 632, Monday-Friday, 9 am - 5 pm.
- Referral to Tasmanian health & support services.
- Information, support and training for service providers for people with MND in Tasmania.

- Free membership of MND Victoria and MND Tasmania for people living with MND.
- Victorian Newsletter with Tasmanian News insert for members living in Tasmania.

Please note that the Regional Advisor provides needs-based support and refers members to appropriate support services as required.

#### **Freecall 1800 806 632**

This number is at the MND Victoria office in Canterbury. To assist the volunteer receptionist, please say that you are from Tasmania. If you wish to speak to a Committee member or to Jennene Arnel, you will be asked for your contact details. Your call will be returned by that person as soon as possible.

#### **New member**

We welcome new members K. Ellerton and C. Symonds.

#### **Vale**

We extend our sympathy to the family and friends of D. Wessing.

#### **Donations**

Donations have been gratefully received in memory of B. Clay and R.M. Durant. We have also received donations from Aurora Energy, ACL Cricket Club, J. Preston, DJ Allen, W and J Fischer, M. Viney, the Northern Support Group Bunnings BBQ and from the many MND Week collectors including S and J Chugg, A. Macpherson, Mrs Scott, M. Collins, T. Stephenson, M. Eldridge, Y. Upchurch, K and S Upchurch, P. Harris, the City of Devonport Lions Club, students of St Brendan-Shaw College and J. Hughes.

#### **MND Week: 6 - 12 May 2012**

Thank you to everyone who collected donations during MND Week. People from all over the State volunteered their time towards this great cause and it was a great effort this year.

John Hughes and Josie Emery coordinated two groups of students from St Brendan-Shaw College who raised \$835 in under three hours in Devonport.

The Northern Support Group held their MND Week Bunnings BBQ at Connector Park. This was the

third one we have held and it was so worthwhile, I think there will be many more to come! I would particularly like to thank Kate Barnett, Harry Stafford, Maree Gurr, Tammy and Greg Batge and a special thank you to Queechy High School students Ashleigh, Shantel and Taylor who did a great job of collecting money and selling MND merchandise.



The Northern support groups' BBQ at Bunnings.

Margaret Eldridge hosted another Morning Tea for MND Week. Her Aqua Group also donates funds regularly for research. Margaret often writes poems for these events and below is a short excerpt from her Christmas ditty which earned \$80! She accepts a

donation from her fellow Aqua Group members in exchange for an individual copy of the jingle!

*I thought I'd take this Christmas off  
And wouldn't write a ditty,  
But Helen said, "You can't do that,  
It would be such a pity!"*

*And then I thought of MND  
And how the ditties help them.  
I thought of all the cheques I write  
And all the cash you've paid them!*

*I realized then I had to write  
A Christmas rhyme this season,  
To celebrate the Aqua year  
There is no better reason!*

*If anyone is feeling down  
When to the pool they come,  
Laughs and friendship cheer them up;  
For sure there's always some.*

*We benefit in many ways  
As in the pool we frolic.  
We move in rhythms right and left;  
The movements are bucolic.*

*The interaction we enjoy,  
It keeps us bright and happy.  
We're multi-skilled, two things at once!  
We're nothing if not snappy.*

**Mary Erickson**  
**Fundraising Coordinator**

### Regional Advisor

*"Life is a gift, and it offers us the privilege, opportunity, and responsibility to give something back by becoming more."*

Anthony Robbins, Motivational Speaker

Earlier this year our Association was privileged to get to know Lynn Blackwood and her family when Lynn was diagnosed with MND.

After her death in February, Lynn's husband, David, and her son Stephen, encouraged us to apply to The Winifred D Booth Charitable Trust for funding to support the education of health professionals and Tasmanians living with MND. The Blackwood family was familiar with the Trustees who also knew

Guy Barnett, the recently appointed Ambassador for MND Australia.

As a result of this contact, MND Victoria submitted an application to The Winifred D Booth Charitable Trust to financially support our proposed Tasmanian project: **“Getting it Right: Supporting people living with MND”**.

We were delighted to receive a very quick response from the Trustees who have agreed to fund this project over two years, commencing with a \$10,000 grant in July 2012. A second amount of \$10,000 will be provided in July 2013. The project will run over two years and will enhance the quality of life for Tasmanians living with MND.

Both MND Victoria and MND Tasmania are very grateful to the Blackwood family for their encouragement and introduction to the Trustees of The Winifred D Booth Charitable Trust and, of course, to The Winifred D Booth Charitable Trust for recognising the needs within the Tasmanian MND Community.

*Jennene Arnel*  
*Regional Advisor*

### **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 : June 25, July 30, August 27, September 24, October 29, November TBC.

*Mary Erickson*  
*Northern Support Group Coordinator*

### **Events**

**6<sup>th</sup> National MND Conference** – Adelaide  
Monday September 10, 2012.

**Tasmanian MND Forum** – Launceston  
Wednesday October 24, 2012.

### **Information**

The Australian Government has launched the **Essential Medical Equipment Payment** for people with medical conditions including MND.

It provides up to \$140 annually towards the energy costs of running medical equipment in the home such as nebulisers and electric wheelchairs and includes heating and cooling.

To qualify for assistance, a medical practitioner’s certification is required. The claim can be processed through Centrelink, online or by contacting the Australian Government Department of Human Services on 13 24 68 for a form.

A film about an Australian family’s experience with **familial MND** was shown on ABC News24 on The Health Quarter on June 19 2012. This can be seen online at:

[www.abc.net.au/health/video/healthquarter](http://www.abc.net.au/health/video/healthquarter).

### **No Interest Loan Scheme**

From 30 June 2012, the Tasmanian Government expanded its partnership with the No Interest Loan Scheme (NILS) to enable the purchase of energy efficient white goods and heating.

The NILS loan limit has been increased from \$1500 to approximately \$2520, providing a 30% subsidy off the purchase price of energy efficient appliances.

The aim is to support those hit the hardest during the Tasmanian winter. The subsidy is available for Pension Concession and Health Care Card holders who are seniors, living with a disability or have medical heating and cooling needs including those with neuromuscular conditions.

Enquiries can be made to the NILS Network of Tasmania at [coordinator@nilstasmania.org.au](mailto:coordinator@nilstasmania.org.au) or telephone 1300 301 650 or 6224 6597.