



## MND Tasmania News

### May - June 2013

MND Tasmania  
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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.
- The Regional Advisor who provides needs-based support and assessment, home visits and refers members to appropriate support services as required.

#### **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 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 members**

We welcome our new members M.&P.Hamilton (NW), L.&W.Mitchell (N), B.&K.Pateman (NW) and J.&L.Thomas (S).

#### **Vale**

We extend our sympathy to the family and friends of J. Blizzard and S.McCauley.

#### **Donations**

Donations have been gratefully received in the memory of H.G.Finney and W.Roussakis and from The Catholic Bishop's Samaritan Fund, the Midlands CB Repeater Group, Southern Cross Energy, M.Miell and D.Allen.

#### **MND Week: 5 – 11 May 2013**

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 at our PO Box or deposited into our CBA account at 067-013 2800 5202. Please mark your name and address on the deposit comments or transaction description so that 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.

This year, we received good coverage on SC TV with more frequent screenings of the MND community service advertisement featuring our member Jackie Chugg. *The Advocate* published an article about our member Kerry Upchurch and his

family and *The Mercury* featured Jackie and her family's story later in May. John Hughes did a wonderful job in enlisting the support of local media.

Our **Button Day** was on 8 May. Thank you to all of the volunteers who joined in collections and raising awareness on the streets and in shopping centres on that day and at other times during the week.

The **Launceston Bunnings Sausage Sizzle** was held on 11 May. Thank you to those who supported this venture.

At this stage, I am still collating information on the people who were involved and the monies collected. A full report will be in the July - August MND Tasmania News.

*Mary Erickson*

*Fundraising Coordinator*

### **Governance Training**

The Committee has had a Governance Training Workshop on 1 June to update and improve our knowledge and understanding of the role and management of our Association. We are also in the process of rewriting the Association's Constitution.

As the time of writing is before 1 June, updates will be published in future newsletters.

*Joyce Schuringa*

*President*

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

A short report this time as I prepare for my next visit to Tasmania in June.

This visit will be state-wide and will include home visits to people living with MND, running MND information sessions for health professionals, meeting with individual and teams of health professionals working with people living with MND in both Hobart and Launceston, planning our annual MND Forum for 2013 and meeting with Committee members of MND Tasmania.

I look forward to catching up with many of you during this visit.

A reminder too that part of my role is awareness raising and information. I am always happy to speak to groups when I am in Tasmania. If you know of a group of people who would like to learn more about MND, please pass on my contact details as above.

*Jennene Arnel*

*MND 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 **Ravenswood Community Health Centre, 39 – 41 Lambert Street, Ravenswood** (Launceston).

**Dates for 2013:** 24 June, 29 July, 26 August, 30 September, 28 October and 25 November.

*Mary Erickson*

*Northern Support Group Coordinator*

### **Information**

#### **Independent Living Centre of Tasmania**

The ILC is based at 46 Canning Street, Launceston.

It has a Mobile Outreach Service (MOS) which will be visiting Smithton on 20 June and Ulverstone on 11 July. If you would like to make an appointment or request information about specific equipment, contact the Information Service on 1300 885 886.

In April, ILC Occupational Therapist Chris Bryg visited Calvary Hospital Bethlehem in Melbourne which specialises in services for people with progressive neurological conditions including MND. While there, he attended a product demonstration of the 'Neuro Switch', which has been featured on the ABC on *Australian Story*.

The ILC has recently published a Motorised Mobility Booklet (Scooters and Powered Wheelchairs) with financial assistance from MAIB and HACC.

Further information can be found at their website at

[www.ilctas.asn.au](http://www.ilctas.asn.au) and on Facebook at

[www.facebook.com/ILCTas](http://www.facebook.com/ILCTas)

Source: ILC Tas News

#### **Continence Support Forum**

Despite the fact that 4.8 million Australians experience bladder or bowel control problems, many people are reluctant to discuss these matters, even with their GP. The Continence Foundation of Australia has therefore developed a confidential online chat site for people with continence problems or who are caring for someone with such issues.

The forum is moderated by consumers and health professionals who can answer questions privately.

For more information, go to [www.continence.org.au](http://www.continence.org.au) or telephone the National Continence Helpline on 1800 33 00 66.

Source: Continence Foundation of Australia media release