



## MND Tasmania News July – August 2013

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.

- 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 C.Peardon (N), D.Foster (NW), M.&C.Jacklyn (NW), M.Richardson (N), S.&G.Rowbottom (N), E.&J.Jarrett (S), S.Donnell (S), W.Cowell (N) and K.&G.Atherton (N).

In the President's Annual Report published in the March-April 2012 News, we noted that the number of members with MND had dropped to 18. Demographically we would expect there to be about 30 people with MND or Kennedy's Disease in Tasmania at any one time. During the past 12 months, we have been saddened to note that there has been a steep increase in the numbers of referrals received by our Regional Advisor and on 1 July this year we had 36 members with MND.

There does not seem to be anything untoward about this fluctuation. Since we commenced our partnership with MND Victoria in providing the Regional Advisor (RA) service in 2007, we have been collecting such data. We are confident that our links and networks are sufficiently established to ensure that people who wish to seek our support and membership are referred to our regional advisor service.

### Regional Advisor's Report

In June I had a busy statewide visit to Tasmania, which extended over two weeks. Included in this visit was a morning tea at the Menzies Institute in Hobart. As a representative of MND Tasmania, I met with young researchers working on MND research projects as well as representatives from other groups and the researchers working on their projects. Also in attendance were representatives from philanthropic organisations and families who make the research work possible through their fundraising and donations. A gathering like this brings the research world into 'real life' and it was a particular pleasure to meet the enthusiastic young researchers striving to find a breakthrough in MND research.

In August, I will be making a further statewide visit over a two week period. On this trip, I will be visiting newly diagnosed people and those people who have complex and rapidly changing needs, and a number of health professionals.

This visit will be my last visit to Tasmania as MND Regional Advisor. I have resigned from the position to pursue my personal interests, and to spend more time with friends and family. The last six years have been rewarding and fulfilling. Working in Tasmania with people living with MND, their families and health professionals has been a great privilege. Travelling through your beautiful state has been an added bonus.

Thank you all for your support and friendship. I will think of you often.

With best wishes  
**Jennene Arnel**  
**MND Regional Advisor**

**Jennene Arnel**  
**Regional Advisor**

In 2007, a new initiative changed the quality of care for people with MND in Tasmania and their families. Following the adoption of a cooperative partnership between MND Tasmania and MND Victoria, Jennene Arnel was appointed to the inaugural position of MND Regional Advisor for Tasmania.

For the past six years, Jennene has provided our members and their families who live with MND personal, practical and emotional support, relevant and correct information, helpful advice, referral to and advocacy with service providers and training and education for members' health professionals.

Jennene has established formal training and professional development about MND for service providers in the fields of disability services, palliative care, community health, primary health, residential and respite care and she has facilitated the formation of links between researchers, clinicians and the Association's members. She has pioneered a new and excellent service model of individualised and comprehensive care in Tasmania. Jennene has recently announced her plan to retire from this role.

Others will follow in her footsteps, and the support for people with MND will continue.

However, our members and their families, the Committee, service providers and health professionals will miss Jennene's wisdom, experience and compassionate support and understanding. We wish her well as she embarks on this next phase of retirement planning.

**Joyce Schuringa**  
**President**

**Hobart, 30 October 2013**  
**Partnerships – Supporting People**  
**Living with MND**

At the time of writing this newsletter, we are finalising the program for the MND Forum to be held in Hobart at the Menzies Research Institute Tasmania on Wednesday 30 October 2013

We are very pleased to be able to offer this MND Forum for health professionals, once again, with the support of The Winifred D Booth Charitable Trust.

This year, the MND Forum is particularly exciting because we are working together with the Tasmanian Association for Hospice & Palliative Care Inc. In addition, the majority of presenters are Tasmanian. This is indicative of the knowledge, skills and expertise of health professionals working with people living with MND in Tasmania. Health professionals from across the State are very dedicated and keen to provide the best possible services to our members, and the MND Forum will provide a wonderful opportunity to showcase and share their work and expertise.

While the day is designed for health professionals, people living with MND and their families and friends are welcome to attend. For catering purposes it is essential to register prior to attending.

We will be circulating information about the day across Tasmania, but if you are in contact with health professionals, please draw their attention to the day. It is important for health professionals to be kept up to date about MND care and management issues. Our aim is to have well informed and well supported health professionals who, in turn, enhance and support quality of life for people living with motor neurone disease.

Details of the MND Forum are as follows:

**MND Forum: 'Partnerships – Supporting People Living with MND'**

**Menzies Research Institute Tasmania,**  
**17 Liverpool Street, Hobart**

**Wednesday 30 October 2013**  
**9.00 am – 4.00 pm**

**Registration cost: \$66 (including GST)**  
**Enquiries: [info@mnd.asn.au](mailto:info@mnd.asn.au)**

**Supported by an educational grant from**  
**The Winifred D Booth Charitable Trust**

### **Donations**

Donations have been gratefully received in the memory of J. Conlan, S.McCauley and E.Pearce; from T.Tasker in the memory of her friend Liz; from M.Bramich in the memory of her sister; from the Hobart Friendly Society Foundation, Southern Green Energy and St Leonards Primary School.

Thank you to supporters who were busy promoting MND and collecting donations during MND Week in May. Donations have been gratefully received from collectors and organizers of MND Week events including M.Erickson, A.Macpherson, A.Butterworth, V.Evans, M.Miell, T.Miles, J.Chalmers, R.Betts, M.Eldridge, M.Collins, L.Goodsell, M.Vinney, J.Hughes, P.Harris, Y.&S.Upchurch, B.Pateman, the staff and students of St Brendan Shaw College, the Lions Clubs of the City of Devonport and Latrobe.

### **Fundraising**

The **MND Week Launceston Bunnings Sausage Sizzle** was held on 11 May. Thank you to those who supported this successful venture, including the Batge family, A.Viney, A.Steer, A.Erickson, K.Barnett, C.Cohen, B.Wolf, H.Stafford and our patron Lady S.Ferrall.



**MND Week in 2014** is planned for 4 – 10 May, with the Bunnings BBQ on Saturday 10 May.

### **St Leonards Primary School fundraiser**

Thank you to the St Leonards Primary school community for inviting us to attend a fundraising event for MND. The students were dressed in blue and were innovatively carrying blue food and drinks! It was a fantastic effort!

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

### **Governance Training**

The Committee had a Governance Training Workshop on Saturday 1 June to update and improve our knowledge and understanding of the role and management of our Association. It resulted in a list of tasks for us to work through.

It also informed the current process of rewriting the Association's Constitution, which we plan to bring before the members at the Annual General Meeting in March 2014.

**Joyce Schuringa**  
**President**

### **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:**

26 August, 30 September, 28 October, 25 November.

### **Christmas Party Invitation**

The Northern Support Group would like to invite you, your family and friends to our Annual Christmas Party to be held at the Ravenswood Community centre on:

**Monday November 25 at 11.00am – 2.00pm**

Look for the MND car. Drinks will be supplied and please bring a small plate of food to share. Also please bring a small gift to share marked M (male), F (female) or C (child). Best of all, SANTA will be coming along with his supply of presents!!

**Mary Erickson**  
**Northern Support Group Coordinator**