



MND Tasmania News

January – February 2009

MND Tasmania
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Patron

Lady Sallie Ferrell

State Committee

President: Tim Hynes

Vice-President: Joyce Schuringa

Treasurer: Dora Hugo

Secretary: Denis Lyne

Public Officer: John Hughes OAM

Northern Support Group: Mary Erickson

Care Advisor: Anna Nicholas

Lyle Sydes

Kate Barnett

Regional Advisor

Jenene Arnel

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 : Mon.-Fri., 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.

Renewal of membership form

Would you please return the enclosed Renewal of membership form so that we can update our records?

New Members

We welcome new members:

S.Eriksen (NW); W.& M.Gurr (N); D.Billing (NW); F.Oakley (S); F.&F.Walker (NW); R.Dobner (S).

Vale

Our sympathy is with the family and friends of our member Gordon Dunsby.

Regional Advisor's Report

In October 2008 I commenced in the role of Regional Advisor for Tasmania. Since that time I have contacted 25 people living with MND who are registered with MND Tasmania.

In November I visited Tasmania and undertook home visits and meetings across the state. I visited 20 people living with MND and their families in their homes, met with 10 key service providers and talked with two groups of health professionals. Through the visit a number of newly diagnosed people were referred to services and a number of resources have been sent to people as a follow up to the visit.

The November visit provided a wonderful opportunity to familiarize myself with MND in Tasmania and to start to understand the issues and needs of members and service providers. Generally people are well supported and receiving the supports they need. Throughout Tasmania, professional staff are keen to learn more about MND and there will be opportunities for running information sessions in the future.

Some people with MND and their families are keen to meet others in a similar situation and in 2009 I hope there will be opportunities for people to meet together, particularly in the South and North West where there is no Support Group currently. Newly diagnosed people especially benefit from Regional Advisor visits. A home visit provides the opportunity to discuss MND, current and future needs and to make links to local services.

The next visit to the North and North West will be in February and a visit to the South is planned for March. During these visits I will continue to meet people with MND and health providers. In between visits I can be contacted by email at ra_tasmania@mnd.asn.au (note the underscore

between ra and Tasmania) or by phone on 1800 806 632. Please contact me at any time.

Thank you all for the warm welcome. I look forward to working together in 2009.

Jennene Arnel

Regional Advisor, Tasmania

Donations

Donations have been gratefully received in memory of A.Williams and G.Dunsby, from Kemp & Denning, R.Minchin and M.Eldridge's Aquaerobics Group.

Local contact with other people with MND

If you would like to be in touch with other people with MND in Tasmania and who live near you, please contact Jenene Arnel at MNDVic on 1800 806 632.

Northern Support Group

Mary Erickson is the contact person for this group. She 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 St., Launceston.

Neuromuscular Alliance of Tasmania

This organization consists of MND Tasmania, Alzheimer's Australia (Tas.), Australian Huntington's Disease Association (Tas.), Multiple Sclerosis Society of Tas., Muscular Dystrophy Association of Tas., Parkinson's Tas. and Spina Bifida Association of Tas.

The Alliance is continuing to maintain its focus on residential care, particularly for people younger than 65 who are inappropriately placed in residential aged care facilities, as well as respite care and the care of carers.

The Tasmanian Department of Health and Human Services has been restructured and Disability Services will undergo significant changes. The new model of service is being monitored by NMAT.

Despite the best efforts of artist David Hopkins, NMAT will not be receiving support during Living Artists Week this year.

History of MND Tasmania

John Hughes has provided a copy of his Chairman's Annual Report of March 17 1996 which summarises the history of MNDTas. up to that time. It mentions people whose names are

familiar to readers of this Newsletter over 10 years later. We will publish excerpts in order to preserve our history and to encourage us as we read of those who have travelled this journey before us.

It gives me great pleasure to present this tenth annual report for the Association.

As this is my last report as Chairman, I would like to take the opportunity to reminisce over the past 13 years I have been associated with motor neurone disease.

At the 31st Lions Multiple District Convention in April 1983, we were asked to pledge our support for patients with MND. Lion Ken Blackmore of Victoria had set up the Lions MND Fund the previous year and I quote: "You may ask how I became involved with MND. Peter Buscombe (Nina Buscombe's brother), a friend and MND sufferer, spoke to me about his condition. He asked if I would talk to my fellow Lions and endeavour to interest them in this relatively unknown disease."

Lion Ken also visited the Founder President of the Victorian MN Society, Andy Kaszonyi, who was then unable to move his arms or legs and had lost the power of speech.

As incoming District Governor for Tasmania, I was moved by the address Lion Ken gave and as there were only three Societies formed at that time, Victoria, W.A. and Qld, with an ALS Society in NSW, I was determined somehow to set up a Society here in Tasmania.

Trevor McIntyre of Lindisfarne, a MND patient, had tried to set up a Society in conjunction with Lion John Piggitt, Hobart Town Lions Club, with little success. The first money raised by Tasmania for the Lions MND Fund was \$122 by the Order of Ladies Glades (Marjorie Wilson) who were supporting Al Steen at that time.

Then out of the blue, I received a letter from Nina Buscombe of the MN Society of Victoria mid-1985 with the news that John Barnett of Quamby had passed away from MND and that his wife Sallie asked for donations to be made to the Victorian Society and that the money received be earmarked for Tasmanian members. The money was put aside by Nina and would be used as an initial fund for the running of the Society if it was formed.

In October 1985, I contacted Rosemary Stobart of Hagley and Sallie Barnett with the proposal that we form a Society and the meeting was held at

Quamby on 15 October 1985 with great success. Later Geoffrey Wall of Launceston was invited to be on the steering committee and after many informal meetings we decided to launch the Society.” (To be continued.)