



MND Tasmania News

September - October 2008

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
Care Advisor: Anna Nicholas
Lyle Sydes
Kate Barnett
Public Officer: John Hughes OAM
Northern Support Group: Mary Erickson

Support service

The MND Associations of Victoria and Tasmania work together to improve support for people with MND.

- Information and support by telephone 1800 806 632, Monday-Friday 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.

New Members

We welcome new members:
J.Conlan, W.Roberts, E.Peattie, L.Murray-Williams, P.&S.Fraser.

Vale

Our sympathy is with the family and friends of our member Eva Borzak.

Baby News

Our volunteer Care Advisor Anna's ability to contact new members of MND Tas was gradually curtailed this year due to the imminent arrival of Baby Nicholas. We received THE email and we rejoice with Anna and Richard as they share their lives with their son Samuel.

Donations

Donations have been gratefully received from staff of Aurora Energy, Margaret Eldridge, June Robinson and Allison Connell.

June and Allison live in Wollongong, NSW and are related to Alan Peattie who lived in Tasmania and had MND. They and their families organized a concert in Wollongong on July 26 to raise funds to assist with the purchase of equipment for people with MND in Tasmania.

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 Julie McConnell 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 Street, Launceston.

National MND Conference 2008

Nina Buscombe Award

MND Tas Treasurer Dora Hugo and Vice-president Joyce Schuringa were grateful recipients of the Nina Buscombe Award from MND Victoria. This enabled them to attend the annual meeting of Family Support Services workers from each of the MND associations and the Australian National MND Conference in Melbourne in June as well as a day site visit to Melbourne's specialist service for people with MND based at Calvary Health Care Bethlehem. Their report follows.

1. Family Support Services meeting:

Attending the Family Support Services day gave us the opportunity to present the State Report for Tasmania and to answer questions about:

- the services we provide without the benefit of employed staff,
- the Memorandum of Understanding with MNDVictoria and
- our plans for the future.

In addition, we were able to present the Report on the outcomes of the Tasmanian MND Survey conducted in 2007 by MNDVic. in collaboration with MNDTas. Jennene Arnel had presented this Report at the AGM of MNDTas in March 2008 and it was a pleasure for us to present it at this forum and to answer the questions that it generated.

It was helpful to meet staff from Victoria with whom we liaise regularly and whom we knew by name but had not met. There was sufficient time and opportunity to meet many of the 30 staff from the other MND Associations and to discuss issues of common concern. The benefit of this contact was already felt soon after when Joyce was approached by a person in NSW who wished to assist MNDTas. As Joyce now knew Gina Svolos at the MNDNSW office, she immediately phoned Gina to discuss the issue.

The day also gave us the opportunity to thank Jennene Arnel for her long relationship with people with MND in Tasmania and for her proactive support.

2. National MND Conference:

The presentations had a significant impact on the 280 people at the conference and increased our knowledge about MND and the impact the disease has on the lives of people who have it and those who surround them.

There was a wealth of sound and updated information about many aspects of MND which will assist us to improve our communication about MND when we talk with people who contact our Association. As one speaker observed, the Conference had moved from discussions at the cellular and aetiological level to the issues around the quality of life with MND.

There were an encouraging number of health professionals from Tasmania at the conference. They included staff from the Whittle Ward which is the palliative care unit at the Repatriation Hospital site in Hobart, Margaret Barlow (physiotherapist, LGH, Northern Community Services), Julie Simpson (occupational therapist,

LGH), Linda Murray-Williams (RN, Community Palliative Care North), Helen Fourez (occupational therapist, Community services South) and three RN's from Community Palliative Care South including Jane Jupe and Jane Plunkett.

3. Visit to Bethlehem Hospital:

This hospital provides specialist consultancy services for people with progressive neurological conditions. People with MND in Tasmania may visit this team for assessment and advice and health professionals are also provided with education and information.

We visited this site and there were three aspects to this day – the lectures, the visits to each clinical area and the opportunity to network with people from other services.

It was helpful to see the clinical sites so that we are better informed on the benefits of visiting this service from Tasmania when we discuss it with both health professionals and people living with MND. In addition, it gave us a view of best practice in various aspects of care related to MND. The lectures were a valuable adjunct to the Conference and provided additional information. Joyce has already been able to share some of this information with a local occupational therapist and speech pathologists about specific issues related to their clients with MND who are members of our Association.

Talking with Young People about MND

These new packs for parents are now available and have been sent to some members with young families, the Independent Living Centre and to a selection of health professional in our state.

They are designed to strengthen communication with children who have a parent recently diagnosed with MND. There are six booklets for parents, 8-12 year olds, teenagers, friends, schools and health professionals.

The pack is available via our helpline number and they can also be downloaded from the MND Australia website at

<http://www.mndaust.asn.au/just-been-diagnosed/>

Motor Neurone Disease: aspects of Care for staff of residential facilities

This publication is also available via our helpline service. The information is practical and authoritative and may also be of benefit to people who live in their own home.