



MND Tasmania News
May - June 2008

MND Tasmania
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Patron

Lady Sallie Ferrall

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

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 Brendan Barry, Christine Everett and Margaret Nolan.

Membership renewal

Thank you to those members who sent in their Renewal of Membership forms and subscriptions. If you have not yet renewed your membership for 2008 or would like to be removed from our mailing list, would you please send us the Renewal of Membership form that was inserted into the March-April 2008 of *MNDNews*.

Donations

Thank you to the members who sent a donation with their 2008 renewal of membership. Please accept this statement of appreciation instead of an individual letter of thanks. Please email us or phone a message through to Dora via the helpline if you did not receive a receipt although you enclosed your contact details. Those who made bank direct deposits will be sent a receipt after their deposit shows on the monthly bank statement. A donation was also gratefully received from Lyn Sell and Sue Lyden of the Sandford Morning Tea Group.

MND Week: May 4 – 10, 2008

Many volunteers were mobilized to increase awareness of MND and the first donations from collectors have arrived. Thank you to all those supporters who spread information about MND and organized fund raising activities.

Thank you to Alice Hanson, Margaret Eldridge and John Hughes whose monies have been received.

We expect that by the time you receive this newsletter many more donations will have been received. Please remember to send us the bank receipt with your name if you deposit funds straight into our bank account.

Annual General Meeting

The AGM which was held on March 30, 2008 in Launceston was well attended by members from all regions in Tasmania. Reports were received from Tim Hynes (President) on the activities of MNDTas during 2008, from Dora Hugo (Treasurer) on finance and from Jennene Arnel (MNDVic) on the MNDTas Needs Survey results.

Australian MND DNA Bank

A number of people came to the donor drive following the AGM to donate blood samples and to complete a questionnaire to assess possible exposure to environmental agents that could play a part in MND. Assoc. Professor Roger Pamphlett of the Faculty of Medicine at The University of Sydney received a NHMRC Grant to set up the Australian MND DNA Bank in 2000 to look for genetic susceptibility to all forms of MND. The aim of the Bank is to provide a resource to researchers undertaking studies into the causes of MND.

**Memorandum of Understanding between
MNDTas and MNDVic**

This commenced in April 2007 and has been reviewed and renewed for the three years 2008 – 2011. The new Memorandum includes an undertaking to apply to philanthropic organisations for a grant which will provide funding for an MND

Family Support worker in Tasmania. This is an exciting initiative which is already well underway. We are grateful to Tim Hynes for the thought and work that he has been putting into this issue for a number of years.

Local contact with other people with MND

If you would like to be in touch with other people who have MND, please contact Jennene 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 Street, Launceston. The meetings planned for 2008 are on June 30, July 28, August 25, September 29, and October 27. The venue for the meeting on November 24 is the home of Lady Sallie Ferrall and there is no meeting scheduled for December.

Research

The donations received by MNDTas for research are channeled into the MND Research Institute of Australia Inc (MNDRIA).

Further information about the Institute can be obtained by telephone: 02 8877 0990 or from the website: www.mndresearch.asn.au

More news on the latest research can also be found at the following website:

www.als-mds.org/research/news

Information

A Journey Shared: Margaret Eldridge has written her personal perspective for us on sharing the experience of MND with a close friend. As we felt that her account should be shared with a broader community than MNDTas, it has been published in the *MNDNews* which accompanies this news sheet.

Margaret wrote *A Journey Shared* in response to a request from the MNDTas newsletter editor. MND is rarely seen by health professionals. At the AGM, Jennene Arnel reported that on average a GP would see only one person with MND during their professional life. An implication of this is that people with MND and their families are often researching and seeking information which is only available all over the place and from a huge range of sources. They gain a level of specialized knowledge which is difficult to share and may not be passed on. This knowledge covers a huge range of issues from medical diagnostic tests to wheelchair accessible vehicles, from the design of home refurbishment to counselling young relatives.

We would love you to write down your perspective of your experience and submit it to the newsletter editor at our PO Box.

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

This publication has been published by MND Australia and is available via our telephone information service. It is a comprehensive document with sections titled:

- What is motor neurone disease?
- Settling into residential care.
- The importance of multidisciplinary care for people with MND.
- Managing MND in residential care.
- Managing secondary symptoms of MND in residential care.
- End of life care for people with MND.

The information is practical and authoritative and may also be of benefit to people who live in their own home.

Equipment information and assistance

Independent Living Centre Tasmania
46 Canning Street, Launceston, 7250. Telephone:
1300 885 886, Website: www.ilctas.asn.au

Entertainment Book 2008-2009

Help to raise funds for MND while enjoying great deals. Contact Tim Hynes for a copy. The books make a great present for friends and family (please see enclosed flyer). Phone: (03) 6233 5978, email: tim.hynes@dhhs.tas.gov.au.

Dr Simon Bower, neurologist from Monash Medical Centre in Melbourne, visits Launceston, currently every two months. He runs a neurology clinic at Launceston General Hospital on a Friday, and at private rooms on Thursday afternoons. Dr Bower is interested in MND and the ongoing care and management of people living with the disease. Appointments can be made by phoning LGH, Jenny Inglis, on (03) 6348 7465, or by contacting the clinic at 16 Lyttleton Street on (03) 6334 4188.

For further information, contact Jennene Arnel at MND Victoria on 1800 806 632.

Continuity and your newsletter

The Association in Tasmania depends on volunteers. Please inform us if we have omitted key points or made errors in any of the information presented in this newsheet. We welcome your ideas, thoughts and questions. Write to us at MNDTas News via our email or PO Box address.