



MND Tasmania News

November-December 2007

MND Tasmania
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State Committee

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Secretary: Denis Lyne

Public Officer: John Hughes

Northern Support Group: Bill Braithwaite

Care Advisor: Anna Nicholas

Kate Barnett

Lyle Sydes

This broadsheet is produced by the MND Associations of Victoria and Tasmania. These two associations are working together to improve support for people with MND.

Support service

- Access to information and support, by telephone (1800 806 632), Monday to Friday.
- 9 am – 5 pm.
- Referral to Tasmanian support services.
- Information kits for:
 - people living with MND, family and friends;
 - general practitioners;
 - health professionals.
- Free membership of MND Victoria and MND Tasmania for people living with MND.
- Victorian Newsletter with Tasmanian News insert for members living in Tasmania.

New Members

We welcome the following new members:

Mr & Mrs Gordon and Irene Dunsby, Mr & Mrs Bevan and Beth Gleeson, Mrs Eve Hinds.

Vale

Our sympathy is with the family and friends of the following people with MND who have passed away:

Mr Charles Henry; Mr Bill Rasmussen; Mr Brian Wright.

Donations

Memorial donations have been received in memory of Mrs Marjorie Williamson whose husband had MND.

Northern Support Group

Bill Braithwaite organises the monthly meetings in Launceston. He may be contacted on 6326 7788 for information about the next meeting.

Local contact with other people with MND

A few members have asked to be given details of other members for contact and support. If you would like to be in touch with other people who have MND, please contact Jennene Arnel at MNDVictoria on 1800 806 632.

State Committee

A day of strategic planning is booked for Sunday November 25 in Launceston. Watch this space for the outcomes of the first face-to-face meeting since the AGM.

Carer support

The Carers Association of Tasmania Inc. promotes the role and interests of carers in Tasmania to enhance their quality of life.

Carer Support Groups are held in Beaconsfield, Bellerive, Burnie, Deloraine, Devonport, Mornington, Glenorchy, Hobart, King Island, Sorell, St Helens, Ulverstone and Wynyard. They would like to hear from carers who are interested in forming a writers' group.

Carers Tasmania also has five counsellors who are available to visit. They are Ian Snare (NW&N), Geoff Divall (N), Shirley Catchpole and Clare Voss (S).

Telephone Carers Tasmania on 1800 242 636 to enquire about these services.

Equipment: Lightwriter and Scanner

The Lightwriter is a communication device supplied by Zygo Australia. It has a keyboard, a display screen and a voice output. MND Tas has four of these machines available for loan.

The Association also has two scanner modules which enable a person to communicate without typing onto the keyboard. A scanner is a small triangular grey plastic box with an illuminated screen which displays words.

One of our scanners is missing. It was loaned with a Lightwriter which was returned.

If you have our scanner or have accidentally returned it to a health service, would you please contact us on our 1800 number.

Research news

Dutch researchers from the University Medical Centre in Utrecht found that eating a high amount of polyunsaturated fats and vitamin E may halve the risk of developing MND. Polyunsaturated fats include omega 3 in fish and leafy vegetables and omega 6 in cereals and whole grain bread. The research team found that a daily intake of more than 32g of these fats was associated with a 60% lower risk of developing MND compared with a daily intake of less than 25g. (From BBC NEWS:

<http://news.bbc.co.uk/go/pr/fr/-/2/hi/health/4946396.stm>)

MNDRIA

The donations received by MNDTas for research are channeled into the MND Research Institute of Australia Inc. Prof. James Vickers from the University of Tasmania and the Menzies Centre is on the Medical/Scientific Committee of the Institute and Tim Hynes is the Tasmanian Delegate. 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-mda.org/research/news

Neuro-Muscular Alliance Tasmania (NMAT)

The Alliance submitted a paper for the Tasmanian Government 2008-09 budget process which highlighted the following urgent needs for people who have chronic progressive muscular or neurological conditions:

- Preventative care: Cough-assist machines; special dietary supplementation; appropriate equipment to support living at home.
- Individual Support Program: More care packages to enable people to live at home and reduce the need for hospitalisation.
- Young People in Residential Aged Care (YPIRAC): This Federal/State initiative needs to be extended to those who are aged 50-65 years old.
- Community Equipment Scheme: Chronically under-funded.
- Respite care: Currently inadequate.
- Forward planning: Disability Services to recognise and provide timely service for the relatively predictable pattern of the needs of our members.

- Carers: Specific funding is required to assist the people who support our members at home.
- Rapid response: Timely and appropriate services are required for many of our members during the relatively short time of life following diagnosis.
- Medical services: Specialist neuromuscular medical services are required in Tasmania.
- Commonwealth State and Territories Disability Agreement: The State Government is urged to resume dialogue with the Australian Government to immediately resolve the impasse on this Agreement.
- DHHS funding shift to hospitals: The overwhelming focus on the acute hospitals seems to be starving community and other health services which are intended to support people outside the hospitals.

NMAT Art exhibition and auction

This new venture during Living Artists' Week raised the profile and \$1,000 for each member association. We are thankful for the work done in particular by artist David Hopkins and Robert McNabb of the Saddlers Court Gallery, Richmond, Anne Ashford of Muscular Dystrophy Association of Tasmania Inc., Joyce Abblitt of Australian Huntington's Disease Association (Tas) Inc. and Harry Wilsdon of Multiple Sclerosis Society of Tasmania Inc.

The Alliance plans to hold a similar event during the 2008 Living Artists' Week.

Continuity and your newsletter

The Association in Tasmania depends on volunteers to make things happen. The Committee is grateful for those members who continue to faithfully attend Support Group meetings, to support MND Awareness Weeks, to send in donations and to circulate equipment. We also appreciate the new members who have joined and who are willing to continue the work of supporting people who have MND and of increasing the knowledge and awareness of MND in our communities and among health service providers.

Please let us know 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 to MND Tasmania News. Write to us at our email or PO Box address.