



MND Tasmania News

March - April 2008

MND Tasmania
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Patron

Lady Sally 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 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 : 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.

History

One of our members has kindly informed the editor that contrary to the statement in the January-February 2008 MNDTas News, Bill Braithwaite was not the Convenor of the MND National Conference in 1995 in Hobart. The

Conference was actually held in 1996. The Convenor was John Hughes and he was assisted by Vice President Guy Barnett. We apologise for this error.

Donations

We are thankful for donations for research from: friends of Margaret Eldridge, Jane Baker's Line Dancing Group and Bob Minchin, husband of founding member Helen Minchin.

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 has offered to be the ongoing contact person for this group. She may be contacted on 1800 806 632 (message) for information about the next meeting.

MND Tasmania news for members

AGM

The AGM for 2008 was held on Sunday March 30, 2008 at Kings Meadows Health Centre. A summary of the President's Annual Report is enclosed with this newsletter.

Member survey

Thank you to those members who completed the Member Survey which was an outcome of the day of strategic planning held on November 25, 2007. The Report on the results of the survey has been written by Jenene Arnel of MNDVic and is also enclosed.

Renewal of membership form

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

Date to remember

MND Week: May 4 – 10, 2008. Please phone or email us if you are willing to assist with contacting media outlets or collecting donations.

Research

The donations received by MNDTas for research are channeled into the MND Research Institute of Australia Inc (MNDRIA). It is only through research and the discovery of the mechanisms

that produce MND that therapies which slow and stop MND will be available.

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

Dutch study on Chinese stem cell treatment

L. Van Den Berg, a neurologist at the University Medical Centre in Utrecht, the Netherlands, conducted a study of 12 people with MND who went to the Beijing West Hill Hospital and Rehabilitation Centre for treatment with a type of stem cell found in human foetal nasal lining. In his conclusion, he recommends that people not seek stem-cell treatments in Beijing and he reported that the West Hill Centre has since been closed by the Chinese government. (Source: MDA/ALS Newsmagazine Jan.2008, page 4. www.als-mda.org)

Information

PatientsLikeMe is an organization based in the USA which is the only online treatment and outcome sharing community for ALS/MND. Its members believe that treatment outcomes should be shared for everyone's benefit. They invite people who have MND, their families and health professionals to add to the collective knowledge and support by participating in the online forum or adding to the database. Join the site at www.patientslikeme.com

E-network for health professionals

An e-bulletin is sent out every two months. The contact person for joining the network is the Family Support Coordinator at MND NSW ph. 1800 777 175.

Equipment information and assistance

Independent Living Centre Tas: 46 Canning St., Launceston , 7250. Ph. 1300 885 886. www.ilctas.asn.au

Support for carers

CareSearch is an Australian internet resource helping care providers and those receiving palliative care. It is funded by the Australian Government as part of the National Palliative Care Program. It provides information on topics such as how to understand, care and cope, advanced directives, managing medications or starting difficult conversations. It includes

information on local services and resources with specific pages for carers, families and friends, doctors and health professionals.

It is available and free of charge at www.caresearch.com.au

Medicines

Information for consumers about using medicines wisely is available from the National Prescribing Service (NPS). **Consumer Medicine Information** (CMI) leaflets have been written for most prescription and non-prescription medicines. The leaflets explain how the medicine works, how and when to take it, common side effects and potential interactions. Obtain CMI leaflets for your medicine from your pharmacist, Medicines Line (ph. 1300 888 763) or the NPS website (www.nps.org.au/consumers). The Medicines Line also provides a pharmacist with whom you can discuss your prescription and over-the-counter and complementary medicines. It is open Mon.-Fri.9am-6pm.

Palliative care

Palliative care is specialized care and support for someone living with a terminal illness. Its goal is to improve the quality of life for patients, their families and care givers. It aims to help the patient live as well as possible. (Source: What is Palliative Care? Brochure of Palliative Care Australia.)

National Palliative Care Information Line: 1800 660 055.

Website for information and resources: www.pallcare.org.au .

Website for people in the workplace who are either living with, caring for or working with someone who has a terminal illness: www.livingcaringworking.com

Continuity and your newsletter

The Association in Tasmania depends on volunteers. The Committee is grateful for the members who attend Support Group meetings, support MND Awareness Weeks, send in donations and circulate equipment. **Please inform us if we have omitted key points or made errors in any of the information presented in this news sheet. We welcome your ideas, thoughts and questions to MND Tasmania News. Write to us at our email or PO Box address.**