



MND Tasmania News

January-February 2008

MND Tasmania
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Patron

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State Committee

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Secretary: Denis Lyne

Care Advisor: Anna Nicholas

Lyle Sydes

Kate Barnett

Public Officer: John Hughes

Northern Support Group: Mary Erickson

This broadsheet is produced by the MND Associations of Victoria and Tasmania who work 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:
Shane Sause, Darren Pendrey, David Trotter.

Vale

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

Helen McLeod; Bill Braithwaite; David Baker.



Bill Braithwaite

A section of the Constitution of MND Tasmania Inc. states: "Life membership may be awarded by the Association to a member who has rendered meritorious service to the Association." Bill Braithwaite, Life Member of MNDTas, passed away on January 15.

Bill was diagnosed with MND in 1994. This diagnosis was revised and changed to Inclusion Body Myositis in 1997. Since joining the Association, Bill has served as President, Secretary and Treasurer at various times. He has also served as the Tasmanian delegate on the Board of MND Australia and the MND Research Institute of Australia. Bill was Convenor of the MND National Conference in 1995 in Hobart. After Kevin Anderson moved interstate, Bill kept the Association and the 0500 telephone service going. His wife Sue's assistance as Treasurer and as support for Bill's work in keeping the Association going has been invaluable. His niece Mary has also been a wonderful support in housing equipment and attending the Northern Support Group meetings. "Bill has contributed a huge amount to the MND Association of Tas. and has provided great input and commitment to MND in our State." (Tim Hynes 22/1/08)

Donations

Memorial donations have been received in memory of David Baker and Bill Braithwaite. We are also thankful for donations from: (1) Margaret Eldridge (friend of Dr Kate McPherson) celebrated her 70th birthday and she received gifts which came to a total of \$700 for the MND Research Institute of Australia; (2) The Wesley Friendship Circle; (3) Living Artists' Week raised the profile of MND and artists' donations of their work raised \$1,000 for the association.

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 who is Bill Braithwaite's niece, 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.

E-network for health professionals

A network based in NSW was established following the 2005 National MND Conference. An e-bulletin is sent out every two months and annual MND Workshops are held for health professionals. The contact person for joining the network is Jane Barrett, Family Support Coordinator at MND NSW ph. 1800 777 175.

State Committee

A day of strategic planning was held in Launceston on Sunday November 25. The enclosed Member Survey was one of the outcomes of this day as we consider a long term memorandum of understanding with MNDVic. The outcomes of the day will be presented at the 2008 AGM (see time and venue below).

Member survey

Please take time to complete the enclosed survey and return it to us. The information will assist us in developing a long term strategy for seeking increased support for people with MND and their families.

Planning ahead

AGM : Sunday March 30, 2008 at 2pm: Kings Meadows Health Centre, Launceston.

Renewal of membership form: March/April issue of newsletter

MND Week: May 4 – 10, 2008

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. MNDTas 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.

Books

Losing my Voice by B.F. Williams describes a journey of discovery about the world around her when she had MND. Barbara Williams of Auckland, NZ commenced this journey in 2004 and her book can be purchased online via www.losingmyvoice.com

MNDRIA

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.

During 2007 the Institute awarded a record total of \$705,000 for new grants commencing in 2008.

Anna King, of the University of Tasmania and who spoke at our AGM a few years ago, has been awarded a MNDRIA scholarship to travel to the 19th International ALS/MND Symposium in the UK in October 2008. Anna's paper *Unravelling the cellular pathology underlying neuronal degeneration in MND* was presented at the MNDRIA 2007 Scientific Meeting in Sydney in October.

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

Workplace Modification Scheme

This scheme helps employers cover the costs of purchasing special equipment and modifying the workplace for employees with a disability. Information is available from www.jobaccess.gov.au or JobAccess at 1800 464 800.

Neuro-Muscular Alliance Tasmania (NMAT)

The Alliance is writing a response to the Tasmanian Government's review of the Community Equipment Scheme.

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. 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 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.**