

MND Tasmania News



May – June 2007

MND Tasmania

PO Box 379

Sandy Bay, TAS 7006

ABN: 21 877 144 292

Phone: 1800 80 6632

(1800 80 MND A)

Email: info@mndatas.asn.au

Website: www.mndatas.asn.au

Patron

Lady Ferrall

State Committee

President: Tim Hynes

Vice-President: Joyce Schuringa

Treasurer: Dora Hugo

Secretary: Denis Lyne

Public Officer: John Hughes

Bill Braithwaite

Kate Barnett

Lyle Sydes

Anna Nicholas



Welcome to the first edition of MND Tasmania News.

New initiative

This broadsheet is the result of a new initiative by the MND Associations of Victoria and Tasmania. In addition to this News, a Motor Neurone Disease Information and Telephone Support Service for people living in Tasmania became available on the first of April 2007. We are grateful to the staff of the Victorian office who will be sharing their knowledge and expertise with people in Tasmania who have MND and their families, friends and medical and health professionals.

MND Victoria and MND Tasmania will be working more closely together to improve support for people with MND in our state.

The support service will be free of charge and can be accessed by phoning 1800 806 632.

It will include:

- Access to initial information and support, by telephone, Monday to Friday, 9am – 5pm.
- Referral to Tasmanian support services.
- On-going telephone support.
- 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.

Annual General Meeting

The Annual General Meeting for 2007 was held in Hobart on March 18. This was the first time in many years that the meeting was held in Hobart rather than Launceston or Campbelltown. New office-bearers were elected.

Carol Birks, Executive Director of MND Australia, presented a paper on the Key Objectives of MND Australia for 2006-2011. She outlined the advances in care achieved for people with MND, including detail on the key areas of diagnosis, multidisciplinary care, managing saliva, PEG-RIG insertion (for nutrition), communication, cognition, respiratory support and carers' issues.

Life Members

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 and that person shall not be required to pay an annual subscription." The Meeting unanimously agreed that Life Membership should be awarded to Kevin Anderson and Bill Braithwaite.

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 the Convenor of the MND Conference in 1995 in Hobart. This event was a milestone for a number of reasons. A significant one was that Dr Paul Dunne led a renewed focus by the Palliative Care services in Tasmania onto people with MND. Bill is still serving as the Convenor of the Tamar Support Group. As Immediate Past President, he is the source of much knowledge for the State Committee and has recently handed over the telephone support and information service to MND Victoria when Telstra discontinued the 0500 number on 12 April 2007.

Kevin Anderson was diagnosed with MND in the 1990's. Since joining the Association in 1998, he has served as President, Secretary, Treasurer, Newsletter Editor and as statewide visitor to people with MND. He has served as the Tasmanian delegate on the Board of MND Australia and the MND Research Institute and as the Treasurer of MND Australia. Kevin was Convenor of the MND National Conference held in Hobart in 2001. He has moved to the warmer northern island but rumour has it that he is currently teaching English in Russia.

The Association's other Life Members are John Hughes OAM of Devonport, Anne Steer and Geoff Wall of Launceston and Rosemary Stobart of Hagley.

MND DNA Bank

Following the AGM, Lorel Adams presented information about the Australian MND DNA Bank and the current knowledge about the possible causes of MND. Lorel is the Manager of the Bank. Assoc.Prof. Roger Pamphlett of the Faculty of Medicine at The University of Sydney received a NHMRC Grant to set up the 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. A number of people came to the

donor drive following the AGM to donate their blood samples and to complete a questionnaire to assess possible exposure to environmental agents that could play a part in MND.

Neuro-Muscular Alliance Tasmania

MND Tasmania has participated in the formation of a new organization in the state with the aim of improving the lives of people who have progressive muscular or neurological conditions. The current membership consists of MND Tasmania, Alzheimer's Australia (Tas.), Australian Huntington's Disease Association (Tas.), Multiple Sclerosis Society of Tas., Muscular Dystrophy Association of Tas., Parkinson's Tas. and Spina Bifida Association of Tas.

Initial meetings have been held to develop the terms of reference and subsequently to examine the issue of accommodation for people who have these conditions and who may be unable to continue living at home.

Continuity and your newsletter

Kevin Anderson produced the final issue of the MND Tasmania Newsletter in 2001. The Committee apologises for the lack of publications since that time. The Association depends on volunteers to make things happen. The characteristics of MND tend to make it difficult to have good continuity and a large base of volunteers.

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. In particular, we acknowledge the work of the Palliative Care and Hospice services who have continued to inform and educate about MND when the Association has been undermanned.

Please contribute your ideas, thoughts and questions to MND Tasmania News by writing to us at our email or PO Box address.