



MND Tasmania News

July - August 2008

MND Tasmania
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Patron

Lady Sallie Ferrell

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, 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 new members:

P.Livingstone, J.Plunkett, J.&B.Males, G.&J.Surtees,
W.Roberts and R.Iles.

Vale

Our sympathy is with the family and friends of the following members who have passed away:
M.Scott, A.Williams, S.Death.

Donations

Thank you to the members who sent a donation with their 2008 renewal of membership. Please email us or phone a message through to Dora Hugo 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.

Donations were also gratefully received from ANZ Rosny Park, C.Woodbridge, D.Allen, B. & J.Males Aquaeerobics Group at Hobart Aquatic Centre, R.Iles and J.Plunkett.

MND Week: 4 – 10 May 2008

Thank you to M.Erickson, M.Eldridge, H.&P. Stafford, staff of the Dept of Immigration & Citizenship, A.McPherson, J.Chugg, S.K.&Y. Upchurch, students of Brendan Shaw College, J.Hughes and the Northern Support Group whose monies have been received. Please remember to send us the bank receipt with your name if you deposit funds straight into our bank account.

Local contact with other people with MND

If you would like to be in touch with other people who have MND, please contact Julie McConnell at MND Victoria 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.

Support services for people with MND

A Journey Shared: Margaret Eldridge's personal perspective on the experience of MND was published in the previous issue of *MNDNews*. It elicited warm responses and one of those which contains complementary information is summarised (with permission) below.

"Thank you for the inspirational article contributed by Margaret Eldridge. However, for those people facing their MND journey without access to a large group of willing and able friends and/or family please do not fear that you have to travel this road alone. There is a range of services in Tasmania able to support you and your carers. Community Health Service nurses assist with personal care. Carers from other agencies are also available to supplement the care of community nurses. Occupational and physiotherapists work with you to adapt your home

for safe movement, provide appropriate aids and equipment, and gentle exercise programmes to help maintain some flexibility and strength. Speech pathologists help with communication aids and advice on dietary modifications and swallowing problems. Palliative Care Service nurses, doctors and social workers provide consultancy advice and support as needed, and occasional in-patient respite for a few days at a time may be provided at a Palliative Care Unit. Home Help assist with housework, Hospice Care volunteers, and carer respite workers can give family and friends a break, as well as social support, help with gentle exercise and massage, and other practical care.

This may seem like an overwhelming number of people and confusing range of services, but mostly the services work closely together, and in Tasmania, where we tend to know each other, we can form a coordinated team that will support you, and your family and friends to maintain as good a quality of life, level of independence and dignity as possible.

Professional service providers will do their utmost to ensure that you too are able to achieve your goals, and to stay in your home for as long as possible. Obviously there are limits, and equity issues for services trying to meet a huge range of client needs in the community, and so the more support you can find among friends and family the better, but none of you need to make this journey without the support of community and health services to supplement the care of your family and friends.”

National MND Conference 2008

Nina Buscombe Award: MNDTas Committee members Dora Hugo and Joyce Schuringa were grateful recipients of MND Victoria's Nina Buscombe Award which enabled them to attend the 2008 Australian National MND Conference in Melbourne on 24 June, a day for Family Support workers from each of the MND associations and a day onsite visit to Melbourne's special service for people with MND at Bethlehem Hospital. A report on these meetings will be published in the next issue of MNDTas News.

Jennene Arnel: A significant occurrence of interest to many Tasmanians was the farewell of Jennene Arnel who is retiring from MND Victoria. Jennene has worked with MND Victoria for 11 years and has been a tireless and proactive advocate for people with MND in Tasmania. Jennene has encouraged and assisted us with government advocacy and information and support for people with MND and their families.

Julie McConnell has been appointed to take over the role of Manager, Family Support Services at MND Victoria.

Neuromuscular Alliance of Tasmania

This organization is just over a year old. It 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.

The Alliance has decided to maintain its focus on residential care this year - as this includes people younger than 65 who are inappropriately placed in residential aged care facilities, respite care and the care of carers.

Some snippets reported to the Alliance include:

- a post-basic neurological nursing course for nurses is expected to start in Launceston in 2009
- there was increased funding for respite and home care packages in the Tasmanian State budget although there are about 400 people who still need more care than they are receiving
- a 'big brother' type TV program about the lives of people with neurological conditions is being planned
- Living Artists Week, which raised \$1,000 for each member association in 2007 is being organised by the artists again this year.

March of the Faces Banner

If you would like your friend or relative with MND to be remembered in a worldwide memorial to people with MND, please contact Carol Birks of MND Australia:

(02) 9816 5322 or email carolb@mndaust.asn.au.

For more information, visit: www.mndaust.asn.au

Dr Simon Bower, neurologist from Monash Medical Centre in Melbourne, visits Launceston, currently every two months. Dr Bower 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 Janette McDonald at MND Victoria on 1800 806 632.