



MND Tasmania News

July - August 2011

MND Tasmania
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Website: www.mndatas.asn.au

Patron

Lady Sallie Ferrall

Board

President: Joyce Schuringa

Vice-President: Tim Hynes

Treasurer: Dora Hugo

Secretary: vacant

Northern Support Group: Mary Erickson

Fundraising coordinator: Anna Macpherson

Public Officer: John Hughes OAM

Kate Barnett

Regional Advisor

Jennene Arnel: ra_tasmania@mnd.asn.au

(note the underscore between ra and tasmania) or
phone 1800 806 632.

Support

Correspondence secretary: Michele Newton

Website: Shane Chugg

Membership

MND Tasmania is a member of MND Australia with Tim Hynes serving on the MNDA Board. The MND Research Institute of Australia is part of MND Australia.

Support service

The MND Associations of Victoria and Tasmania work together to provide:

- Information and support by telephone on 1800 806 632, Monday-Friday, 9 am - 5 pm.
- Referral to Tasmanian health & support services.
- Information kits.
- Free membership of MND Victoria and MND Tasmania for people living with MND.

- MND Victoria Newsletter with MND Tasmania News insert for members living in Tasmania.
- Meetings for people with MND, carers and past carers.

Freecall 1800 806 632

To assist the volunteer receptionist at the MND Victoria office, please say that you are from Tasmania. If you wish to speak to a specific person, please say so and your call will be returned by that person as soon as possible.

New members

We welcome new members H. Butterworth and D. Kelly.

Vale

We extend our sympathy to the family and friends of B. Boys.

Donations

As well as the funds still coming in from MND Week, donations were gratefully received from A. Warren, the Aurora Ground Services Subs North Team, I. Preston, DJ Allen and the Centrelink Tasmania Staff Community Fund. Donations have also been received in the memory of Q. Brown and B. Boys.

MND Australia Ambassador

MND Australia was very pleased to announce the appointment of retiring Senator Guy Barnett as the MND Australia Ambassador at an event held in Canberra in his honour on 19 June. His appointment is the first under a new Ambassador Program that has been established by MND Australia.

Prior to and during his term as Senator for Tasmania, Guy has been a clear and persistent advocate for people living with MND. His mother Lady Sallie Ferrall was a founding member of MND Tasmania in 1986.

For further information contact Carol Birks, MND Australia on 0408 461 932 or visit the MND Australia website at www.mndaust.asn.au

Northern Support Group

The contact person for this group is Mary Erickson who may be contacted via 1800 806 632 (message). Meetings are held on the last Monday of each month

at 11am – 1pm at the John L.Grove Centre, Howick Street, Launceston. The following dates have been booked: 30 August, 27 September, 25 October.

Fundraising

MND Entertainment Book

To order your 2011/2012 Entertainment Book go to:
www.mndatas.asn.au

Anna Macpherson
Fundraising coordinator

Regional Advisor's Report

Most of my planned home visits and information sessions in May were cancelled due to a respiratory infection that developed when I was in Hobart. Ongoing respiratory problems subsequently forced me to cancel the proposed visit in July. My next visit is now planned for September.

In lieu of home visits, I have been communicating with people living with MND, their families and health professionals by phone or email and this has enabled us to keep in touch and make referrals over recent weeks. Please remember that I can be contacted through MND Victoria on Freecall 1800 806 632. Just leave a message for me and I will return your call as soon as possible.

Having no voice for 10 days was a good reminder to me of the communication difficulties many people with MND face each day: the frustration of miscommunication, the exhaustion of trying to make yourself understood, the often inappropriate response of 'the public', and the ease (and sometimes relief) I experienced of slipping into isolation and avoiding communication altogether. I happened to have a few MND cards with me which read: "I experience difficulties with my speech. Thank you for your patience" and I found these were helpful on several occasions. Through the experience I have an increased empathy for people with ongoing speech difficulties and a heightened awareness of the issues which arise when a person suffers loss of speech. I am fortunate – my voice has now returned and I have a new respect for it and the role it plays in communicating with the world.

I look forward to catching up with everyone in September.

Jennene Arnel
MND Regional Advisor Tasmania

Finding good information on the internet

Searching for health information on the internet can be overwhelming. To make it easier for people to find health information, several organizations have set up websites that provide a pathway to good quality health information.

Some examples of websites which have passed rigorous quality tests to ensure that information is accurate, balanced and up to date are:

- A Victorian Government site 'Better Health Channel' at www.betterhealth.vic.gov.au
- 'MyDr' health information by CMP Medica at www.mydr.com.au
- The USA Government site 'Medline Plus' at www.medlineplus.gov

Websites that display the HEALTHInsite or Health on the Net Foundation (HON) logo have been judged as being of good quality and suitable for consumers. (Source: Medicines Talk Spring 2009 at www.nps.org.au/consumers)

Overseas stem cell therapies

Are stem cell therapies safe? How do I know which ones to consider? What are the risks of stem cell treatments?

In response to increasing concerns about the marketing of unregulated and unproven stem cell therapies overseas, the Australian Stem Cell Centre (ASCC) has published a Patient Information Handbook.

Further information may be seen at:

- www.stemcellcentre.edu.au
- www.stemcellchannel.com.au
- www.twitter.com/ausstemcell

Telephone (03) 9271 1180.



22nd International ALS/MND Symposium

For more information and to register, visit:
<http://www.mndaust.asn.au/sydney-2011/>