



MND Tasmania News

September - October 2010

MND Tasmania
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Patron

Lady Sallie Ferrall

Board

President: Tim Hynes
Vice-President: Joyce Schuringa
Treasurer: Dora Hugo
Secretary: Anna Nicholas
Northern Support Group: Mary Erickson
Kate Barnett
Denis Lyne
Public Officer: John Hughes OAM

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
Fundraising coordinator: Anna Macpherson

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 support services.
- Information kits.
- Free membership of MND Victoria and MND Tasmania for people living with MND.
- MNDVictoria Newsletter with MNDTasmania News insert for members living in Tasmania.
- Telelink 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.

Vale

We extend our sympathy to the family and friends of Shirley Spragg.

HELP Needed

A volunteer is urgently needed to maintain and regularly update the MNDTasmania website. This person would need to have an interest in IT with a moderate level of competency to ensure that the content of the website is kept up to date and is displayed correctly.

The person would receive training, supervision and mentoring from the MNDTasmania Board. We estimate that the time required would be on average up to four hours per month.

If you would be able to assist in this role, or if you know someone who may be suitable, would you please contact Jennene Arnel on 1800 806 632 or email Tim Hynes at info@mndatas.asn.au

Regional Advisor's Report

The previous visit to Tasmania was in July and the next planned visit will be in October. This visit will be combined with the MND Forum for health professionals in Hobart on Wednesday 13 October.

The Forum promises to be a wonderful day which will provide the opportunity for health professionals to network, to discuss, update and learn about motor neurone disease. Speakers will include neurologist Dr. Michael Dreyer, palliative medicine physician, Dr Paul Dunne and Dr. Susan Mathers and her team from the MND Clinic, Calvary Health Care Bethlehem, Melbourne. A further highlight will be Mrs. Doreen Walker and her friend and carer, Margaret Eldridge who will be talking about Living with MND and innovative ways of sharing the care.

Please spread the word about the Health Professionals Forum to members of your care team.

While designed for health professionals, people living with MND and their family and friends are welcome to attend the Forum.

Late registrants should contact Inez van Polanen at info@mnd.asn.au or on FREECALL 1800 806 632.

If you wish to contact me at any time please phone 1800 806 632 (leave a message and I will return your call) or email ra_tasmania@mnd.asn.au

Jennene Arnel

Regional Advisor, Tasmania

Northern Support Group

Meetings are held on the last Monday of each month at 11am at the John Grove Centre, Howick Street. The contact person for this group is Mary Erickson who may be contacted via 1800 806 632 (message). The following dates have been booked: 27 September, 25 October 2010.

Southern afternoon tea

Contact Jennene Arnel on 1800 806 632.

North-west Group

Contact Jennene Arnel on 1800 806 632.

MND Forum

Opportunity, Practice and the Future

Wednesday 13 October 2010

Hobart

The Board of MND Tasmania is very grateful to the staff of MND Victoria who have organized this event for the benefit of people in Tasmania who have MND, their families, friends and health service providers. This is a wonderful opportunity for those who need to update their knowledge and understanding of MND and also to provide a forum for networking and working together to influence and improve the services for people with MND in Tasmania.

The Forum is suitable for people with MND, their relatives and supporters, health professionals, case managers, community care providers, medical specialists and GP's, nurses, palliative care teams and volunteers who work with people with MND.

For information about last minute registrations, please contact 1800 806 632 or email forumtas@mnd.asn.au

Letter to the editor

Tasmania MND Association

Dear Editor,

My name comes up fairly frequently as a donor to MND and I want to let you know that most of the money I sent has been donated by friends who do aquaerobics with me. I have a major fundraiser once a year and my aqua loving friends and others come along to my place for a bring and buy morning tea. It's usually during MND Awareness week but it was early this year as I had to go into hospital. As it happens the week coincides with the

anniversary of the dear friend I helped care for after her diagnosis with MND.

The additional sums of money, which I send specifically for research, come from proceeds donated in return for copies of jingles which I compose for the various celebrations our aqua group has during the year. We have a B----- off lunch when various members head off for warmer weather as winter approaches. Then we have an Ausmas lunch and a Christmas lunch, both at Drysdale Institute which trains hospitality students and we also have occasional one-off gatherings. I write a topical jingle and read it and copies are available for a donation to MND.

My friends are very generous and I have them so well-trained that this July, when I was overseas, someone else in the group read the jingle I had left and I come home to find \$50 in donations when I wasn't even at the function! The group wants me to gather all the jingles and produce them as a book to raise more funds for MND. I'll have to see about that!

Sincerely,

Margaret Eldridge

Fundraising

On Monday 6th September, 33 local Derwent Valley community members attended a Latin-American style group exercise class to raise money for MND Tasmania. The class was held at the Uniting Church Hall in New Norfolk and was organised and instructed by local fitness professional, Stacey Dolliver. \$165 was raised from the event and a lot of fun (and exercise) was had by all the participants!

Spring Raffle 2010

The MND Tasmania Spring raffle is underway! We are delighted that every ticket sold will help raise much needed funds, while increasing awareness of MND and the work of the Association. With your help, we are looking forward to the 2010 raffle being a great fundraising success! As you would be aware, we rely entirely on voluntary donations, so your help in selling and purchasing raffle tickets is greatly appreciated.

A ticket in the MND Tasmania Spring raffle gives you the chance of winning one of the following fantastic prizes:

1st Prize – Painting entitled *ART PILOTS* by North West Tasmania artist Mr Victor Maloney of 'Tiger Creek Art'. It was inspired by his time of study under famous Australian artist Pro Hart who lived in Broken Hill and who was a sufferer of MND. The painting was a finalist

in the 2007 Bald Archy Prize and it depicts Pro Hart with Gough Whitlam. Value \$2500

2nd Prize - Two night's accommodation in a Manor Suite, Country Club Launceston. Includes full breakfast in Link's Restaurant for two persons and \$100 Dining Voucher. Value \$1094

3rd Prize - JBS socket set and a nail gun set (compressor operated 3 Piece Kit including framing nailer, finish nailer and brad nailer) donated by Blackwoods. Value \$600

The closing date for raffle entries is Friday 12th November 2010 and the winners will be drawn at an MND Christmas Party to be held on 29th November 2010 in Newstead.

We will be posting books of 10 tickets so we ask for your support to sell tickets to your network of family, friends and work colleagues. Please contact us at info@mndatas.asn.au or leave a telephone message at 1800 806 632 for Anna Macpherson to return your call if you are able to help by selling or distributing a raffle book or two.

Thank you for your support with our 2010 raffle. We wish you the very best of luck with the draw!

MND Christmas Party - Organised by the MND Northern Support Group

The **MND Christmas Party** is an event held at our Patrons home, Lady Sallie Ferrall.

Date: Monday 29th November 2010

Address: 3 Olive Street, Newstead 7250

Time: 11 - 2 pm

For further information, please contact us via our email address, info@mndatas.asn.au

Resources

Residential respite care

Commonwealth Care and Respite has a website which offers virtual tours of accommodation facilities which offer respite care. Due to the large amount of graphics, access may be limited without Broadband. For further information, see www.residentialrespitetours.com.au or phone 1800 052 222.

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](https://twitter.com/ausstemcell)

or contact the Centre by phone (03) 9271 1180.