



MND Tasmania News

November - December 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
telephone 1800 806 632.

Support

Correspondence secretary: Michele Newton

Fundraising coordinator: Anna Macpherson

Website: vacant

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.
- Victorian Newsletter with Tasmanian News insert for members living in Tasmania.

New Members

We welcome new members W. & M. Haymann (South Tas.).

Vale

We extend our sympathy to the family and friends of N. Gatehouse and P. Carney.

Donations

Donations have been gratefully received from R. Minchin and in the memory of N Turner.

Renewal of membership

Please complete and return the **enclosed renewal of membership form** so that you will continue to receive this newsletter and to enable us to update our records.

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, please contact Jennene Arnel on 1800 806 632 or email Tim Hynes at info@mndatas.asn.au

Freecall 1800 806 632

This number is at the MND Victoria office. To assist the volunteer receptionist, please say that you are from Tasmania. If you wish to speak to a Board member or Jennene Arnel, please say so and you will be asked for your contact details. Your call will be returned by that person as soon as possible.

MND Forum

Opportunity, Practice and the Future

Wednesday 13 October 2010

Hobart

The Board of MNDTasmania is very grateful to the staff of MNDVictoria who organized this event for the benefit of people in Tasmania who have MND, their families, friends and health service providers. This was 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.

It was very pleasing to see so many health professionals (from across the State) with a keen interest in developing skills and knowledge that in turn will enhance the quality

of life of people living with MND in Tasmania. We were also pleased to welcome a number of people living with MND and their families to the Forum.

MND Tas President Tim Hynes opened the day with a welcome on behalf of MND Tasmania and Victoria.

The program was chaired by Rod Harris, CEO MND Victoria. Keynote speakers were Dr Michael Dreyer, Director of Neurology at RHH and Dr Paul Dunne, Senior Palliative Medicine Physician from the Palliative Care Service in Hobart. They provided an excellent overview of MND and the role of palliative care in the care of people living with MND.

Doreen Walker, a member of MND Tasmania, gave an inspirational talk about her life and living with MND. Her friend Margaret Eldridge talked about Sharing the Care, an innovative model of care provided by friends and family.

Two further models of care were described by Baptcare (Gateways) and Megan Hanley from the SNACS team in Hobart.

Lunchtime presented the opportunity to network and look at resources and materials.

After lunch, Dr Susan Mathers, Clinical Director of Neurology from Calvary Health Care Bethlehem Victoria talked about their MND Clinic and integrated care. This was followed by breakout groups led by allied health professionals from Calvary Health Care Bethlehem and Jennene Arnel.

Feedback from those attending the Forum was very positive and we look forward to having similar sessions about MND in the future.

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.

With best wishes to all members for a happy festive season.

Jennene Arnel, MND Regional Advisor

Fundraising

Spring Raffle 2010

The MND Tasmania Spring raffle was drawn at the MND Christmas party held on 29th November 2010 and the lucky winners have been notified. We would like to thank the many people who assisted in selling raffle tickets and also those who purchased a raffle ticket, supporting such a worthy cause. A special thank you to: Vic Maloney for donating the 1st prize, a painting entitled 'ART PILOTS', Ben Cooper (Aurora) for arranging the 2nd and 3rd prizes and Red Jelly, Geon

Print and Communication Solutions for printing the raffle books and for donating their time and expenses. Every ticket sold has helped raise much needed funds, while increasing awareness of MND and the work of the Association. Thank you for your support with our 2010 raffle.

Anna Macpherson, Fundraising coordinator

Northern Cricket Match

On 9 October, Launceston's ACL Cricket club held a cricket match to honour the memory of two long serving club members Brendan Barry and Leon Skeggs. The game was held at Brooks High School Oval in Launceston.

It was a sunny day on a good pitch. I met Kerry Henye the coordinator of the day along with LCCA Rob Soward and many others.



As I set up the table with corn flowers, wrist bands, raffle tickets and information on MND they got ready to give out their team shirts - Team Crash (in Blue) and Team Skeggs (in black).

As the game started, I caught up with Brendan's family and the friends and families of both teams who shared their stories about MND.

My daughter Ashleigh ran around giving all the kids MND stickers and selling raffle tickets. We were sitting watching the teams hit it out when one ball went flying through the air and SMASH into one of the car windows!

Kate and Guy Barnett, Ben and Alice also arrived to help.

As the day went on donations kept coming in.

Team Skeggs won on the day with 185, Team (Brendan) Crash 157. At the end of the game photos were taken and I was presented with cheques for MND Tas from Kerry Henye and Chris Barry who is Brendan's brother.

Donations were also received from:

- ACL receivers and managers of \$ 500
- Giraffe Excavations, Chris Barry of \$ 500
- Raffle tickets sold \$ 150
- Bucket donations \$ 206
- Total for the day \$1,356



Thank you to everyone who joined in, especially Kerry Heyne for inviting MND to attend the game. It was great to see everyone pull together and be so passionate about the MND cause. Thanks also go to Kate and Guy Barnett with Ben and Alice and Ashleigh Erickson who was with me 10am - 5pm on the day.

Mary Erickson, Northern Support Group

Hospice Care Association of Tasmania

Jenny Fuller has been leading this organisation in Hobart for over 16 years. During this time she has trained and managed an army of volunteers who support people in their homes. She has been a proactive advocate for people with MND and many of our members and their families have been grateful for the HCA volunteers who have assisted them with massage, exercise, emotional support and other activities.

Jenny is leaving HCA to work in a Goals of Care project. Paul Connor-Kearns will take over at HCA.

Neuromuscular Alliance of Tasmania (NMAT)

The Neuromuscular Alliance of Tasmania (NMAT) celebrated its third birthday in October. It consists of MND Tasmania, Alzheimer's Australia (Tas), Aust. Huntington's Disease Assoc. (Tas), Multiple Sclerosis Tas., Muscular Dystrophy Assoc. of Tas., Parkinson's Tas. and the Spina Bifida Assoc. of Tas.

Getting in Touch

In collaboration with MS Tasmania as the project leader, NMAT received a grant from the Community Support Levy, Charitable Organisations Grant Program in 2009 for resources to develop and utilise a survey for obtaining the demographic profile of the population represented by NMAT in Tasmania. The results will provide the first set of benchmark information about the prevalence of these complex diseases in Tasmania and the needs of the people who live with them.

The results of the survey will be released early next year and the Executive Summary will be printed in our January/February 2011 MND Tasmania News. The preliminary results have been used on behalf of NMAT by MS Tasmania in discussions with the Office of the Minister for Human Services to reinforce the urgent need to fill the vacancy for a neurologist in the North and North-west of the State and to press for a new neurological clinic to serve the North and Northwest regions.

Parkinson's Tasmania Nurses

Parkinson's Tasmania has received funding from the State Department of Health for neurological nurses to support people with Parkinson's Disease in Tasmania. This is the culmination of many years of submissions to government by the volunteer Board of this Association where they could utilise the evidence of the value of such positions demonstrated in other states.

MND Regional Advisor

Although the number of people with Parkinsons Disease far exceeds those with MND, this milestone complements the work done by MNDVictoria and MNDTasmania in establishing the Regional Advisor position. As we go to press, we are awaiting a response from the Office of the Minister for Human Services on ongoing funding to take over when the 3 years of philanthropic funding comes to an end.

National Neurological Alliance (NAA)

This new national organization has presented a submission to the Productivity Commission into the proposed National Disability Insurance Scheme. Current member organizations are Muscular Dystrophy Australia, MNDAustralia, MS Australia, Huntington's Australia, Alzheimer's Australia and Parkinson's Australia.

