



**MND Tasmania News
November - December 2013**

MND Tasmania
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Patron

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Committee

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Secretary: Michele Newton

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Northern Support Group: Mary Erickson

Fundraising coordinator: Mary Erickson

Libby Cohen

Regional Advisor

Leanne Conway: lconway@mnd.asn.au or
telephone 1800 806 632.

Support

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. MND Tasmania is a member of the Neuromuscular Alliance of Tasmania (NMAT).

Support service

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

- Information and member support by telephone on 1800 806 632, Monday-Friday, 9 am - 5 pm.
- Referral to Tasmanian health & support services.
- Information, support and training for service providers for people with MND in Tasmania.
- Free membership of MND Victoria and MND Tasmania for people living with MND.
- Victorian Newsletter with Tasmanian News insert for members living in Tasmania.

- The Regional Advisor who provides needs-based support and assessment, home visits and refers members to appropriate support services as required.

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 Committee member or to Leanne Conway, you will be asked for your contact details. Your call will be returned by that person as soon as possible.

New members

We welcome our new member D.Brelsford (N).

Vale

We extend our sympathy to the family and friends of M.Coggan, G.Cheeseman, L.Sydes, T.Hansson and E.Jarrett.

Lyle Sydes passed away on October 6 after having been a member of MND Tasmania for 17 years. He served on the Committee until he moved into The Manor residential accommodation and he was an active participant of the Northern Support Group. Lyle was a gentleman who was a "great advocate for MND" (John Hughes).

Regional Advisor's Report

Hello everyone,

In October, I visited your beautiful state and attended the Health Professional day held at the Menzies Research Institute. This day was presented by the Tasmanian Association for Hospice and Palliative Care (TAHPC) in conjunction with MND Tasmania and MND Victoria.

The day was about 'Partnerships – Supporting People Living with MND' with many health professionals from around the state (and the ACT) attending. A number of keynote speakers presented, including Associate Professor Tracey Dickson who outlined current research into MND that was being done at the Institute. Feedback from attendees was very positive.

The day was also a great opportunity for me to meet with some of the health professionals who provide services to our clients.



Forum attendees network during lunch

Unfortunately, due to ill health I was unable to make my planned visit in November. My next visit will be early next year so I look forward to catching up with our clients then.

I would like to thank everyone for making me feel so welcome and for being so patient with me as I 'learn the ropes'. I have big shoes to fill and hope to provide the same quality of service Jennene did.

Please do not hesitate to contact me should you need anything. My telephone number is 1800 806 632 and email is lconway@mnd.asn.au.

Until next time,
Leanne Conway
MND Tasmania Regional Advisor

**Tasmanian MND Forum
30 October 2013
'Supporting People Living with MND'**

On Wednesday 30 October, sixty one participants attended the annual seminar: 'Partnerships - Supporting People Living with MND'. This year it was held at the Menzies Research Institute Tasmania – an excellent choice of venue as this enabled attendees to visit the science labs where some of the research into motor neurone disease and other degenerative neurological conditions is being conducted.

The program covered many topics ranging from advances in research, aspects of care and support to end of life decisions.

Dr Christine Edwards spoke about MND and its variations in her presentation – upper motor neurone, lower motor neurone and generally a mix of both of these. She discussed the relentless progression of the disease. The aims of palliative care are to improve the quality of life for the person

living with MND and their family by the careful multidisciplinary assessment of the problems that are experienced: physical, psychological and spiritual. Christine stated that the mainstay of care is palliative from the time of diagnosis. The emphasis is that the holistic approach is crucial from the outset to support the patient and their family and friends.

A/Prof Tracey Dickson of the Menzies Research Institute of Tasmania presented some of the recent research into neurodegenerative conditions. Current research is investigating why upper motor neurones and lower motor neurones die. Understanding cellular mechanisms is critical for the development of treatments and cures.

Dr Fiona Fisher, Clinical Neuropsychologist with Calvary Health Care Bethlehem, discussed the incidence of Fronto-Temporal Syndrome (FTS) in some people living with MND. Appropriate assessment and referral to a neuropsychologist will assist both the client and their family.



During lunchtime, attendees visited the labs - researcher Rosie Clark explains some of the work that she is doing on MND

Margaret Hickman discussed the practicalities of the PEG tube. The realistic benefits of the PEG tube are in maintaining nutrition and hydration. Good care and maintenance of the PEG is essential for the prevention of complications such as infection, ulceration, hypergranulation and for the avoidance of wear and perishing of tube. Margot shared her knowledge, experience and skill with us in her presentation.

The fascinating developments in assistive technology have presented new opportunities of assisting people living with MND. Katie Greatbatch and Peter Hockley of St Giles Services discussed the developments in speech generating devices and the variety of access options. Basic eye gaze is one new option that was demonstrated.

This is an area of rapid change with new technologies becoming more available. Katie reported what a hard job it is to keep up to date.

Jenny Fuller discussed the vital part that advance care planning and end of life decision making play in the care of a person living with a life limiting condition. This is not just about end of life but is necessary for every stage of disease progression with a focus on quality of life, values and beliefs, goals and preferences of care. It is important to check with the client every point of the way.

General discussion with Rod Harris CEO, MND Victoria raised some local problems in Tasmania:

- Access to funding for communication equipment
- Access to funding for electric wheelchairs
- Need for suitable accommodation for the younger client
- Availability of 'appropriate' respite for people living with MND

Rod discussed the need for MND Associations to keep their 'eye on the ball' with regard to the NDIS trials and roll out and to have 'input' at every opportunity.

The film 'I am Breathing' was shown in the evening. This is the story of Neil Platt, a young man of 33 when he was diagnosed with MND. The film was made to fulfill Neil's wish was to leave something for his two year old son Oliver to know about his Dad. It will be such a moving memory for Oliver. It was very moving for all thirty nine people who attended.

Many thanks to MND Victoria, MND Tasmania and the Tasmanian Association of Hospice & Palliative Care for hosting such an interesting, informative day, and a wonderful networking opportunity for all who attended.

Libby Cohen
MND Tasmania Committee member

Donations

Donations have been gratefully received from K.Murray, K.&V.Hamilton, R.Minchin, the Island Wanderers Chapter of the Campervan & Motorhome Club of Australia, K.Schwartz, K.Hudson and M.Viney.

Fundraising

Lions Tasmania

George Bugeja, District Governor of Lions Tasmania, wrote to the President of MND Tasmania on September 20 as follows:

In my travels to Lions Clubs around Tasmania I am making sure that all Clubs are aware of what MND is and how it affects those who contract it. I use my own experiences of when my mother contracted and passed away with the disease.

On top of making each Lion aware I have suggested that we raise funds to help in trying to find a cure. Some Clubs have already donated, so I have requested our Cabinet Treasurer to set up another column headed "MND Funds" and for all funds to be sent to him to be banked.

My idea is that in May 2014 when we have MND Week we present one 'hopefully' sizable cheque to your organization which will give both of our organizations some exposure...

The October 2013 Lions Tasmania Newsletter features the plans for the Lions District Convention to be held in Wynyard in November. MND Tasmania member Kerry Upchurch and his wife Sharon who live in Ulverstone have volunteered to speak about MND and their experiences. Kerry was diagnosed with MND 17 years ago.

Some of our members have also already been invited to speak about MND at their local Lions Club.

This is a lovely initiative by George and the Lions Clubs of Tasmania. We appreciate the support and look forward to the Lions network knowing more about MND.

Joyce Schuringa
President

Memorial Cricket Match

The ACL Cricket Club held their annual Memorial Match on October 12, a windy and wet day. The two teams were Skeggs in memory of Leon Skeggs (road trauma) and Crash in memory of Brendan Barry (MND).

Team Skeggs won the toss and batted first. MNDAA Ambassador Guy Barnett was the Umpire. The final score was 184 – 174 with Crash winning the match.

Many cornflowers and wrist bands were sold to supporters and the BBQ chefs were kept busy supplying plenty of sausages and hamburgers.

Thanks to our helpers including Guy, Craig, Kerry and Asleigh and to the ACL Cricket Club for their great ongoing support over the past couple of years. It was a pleasure to be invited once again to represent MND Tasmania at this annual event.



Members of teams Skeggs and Crash

Kim Evans – Cyclist

Kim has been riding his bike around Australia to promote the MND cause and he arrived in Tassie on 3 October. I met Kim in Launceston after his ride from Devonport and then again the next morning when he met the Launceston Lord Mayor Albert Van Zetten and MNDAA Ambassador Guy Barnett.



Left to right: Guy Barnett, Kim Evans, Lord Mayor Albert Van Zetten and Mary Erickson

Kim, his team and Guy then rode from the Launceston Town Hall to Oatlands via Longford and Cressy. Guy did a great job of keeping up with them! After the 144km ride they met the Deputy Mayor and General Manager of the Southern Midlands Council.

Kim is doing a wonderful job of raising awareness and donations for MND across Australia. You can follow his adventures on facebook at www.facebook.com/devilinme or on his website at www.nomnd.com.au

*Mary Erickson
Fundraising Coordinator*

Northern Support Group

The contact person for this group is Mary Erickson who may be contacted on 1800 806 632 (message).

Meetings are held on the last Monday of each month from 11am – 1pm at:

**Ravenswood Community Health Centre
39 – 41 Lambert Street
Ravenswood (Launceston)**

Dates for 2014:

February 24, March 31, April 28, May 26, June 30, July 28, August 25, September 29, October 27, November 24

*Mary Erickson
Northern Support Group Coordinator*

Information

Accommodation

A new respite facility has opened in Smithton. It is owned by Rural Health Tasmania and is a purpose-built wheelchair accessible house with four spacious bedrooms, two living areas and large bathrooms.

It was built specifically for persons with a disability and/or their carers. It may be used for day or overnight stays and the cost is \$55 per day or overnight.

Specialist equipment and services can also be arranged.

This is a prime location for exploring the beauty of north-west Tasmania.

For further information, call 03 6452 1266 or visit www.ruralhealthtas.com.au