



MND Tasmania News

March - April 2012

MND Tasmania
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Patron

Lady Sallie Ferrall

Committee

President: Joyce Schuringa
Vice-President: Tim Hynes
Treasurer: Dora Hugo
Secretary: Michele Newton
Public Officer: John Hughes OAM
Northern Support Group: Mary Erickson
Fundraising coordinator: Mary Erickson
Libby Cohen

Regional Advisor

Jennene Arnel: ra_tasmania@mnd.asn.au
(note the underscore between ra and tasmania)
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.

Support Service

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

- Information and support for members 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.

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 Jennene Arnel, you will be asked for your contact details. Your call will be returned by that person as soon as possible.

New Members

We welcome new members M.Coggan (S), L.Cohen (N) and G.& T.Batge (N).

Vale

We extend our sympathy to the family and friends of L.Blackwood.

Donations

Donations have been gratefully received in memory of L.Blackwood and from R.Minchin and the Samaritan Projects of the Archbishop of Hobart's Charitable Foundation.

Annual General Meeting: 4 March 2012

Committee

The 2011 office bearers were re-elected except for Kate Barnett who has stood down after serving on the Committee for many years. Libby Cohen was elected as a new Committee member.

President's Annual Report

I would like to welcome the new members who have joined our Association during 2011. On behalf of our members, I extend our sympathy to those families who have lost someone due to MND during the past year.

The number of members with MND has been declining during the past two years or so. Demographically, we would expect there to be about 30 people with MND or Kennedy's Disease in Tasmania at any one time. However, we currently know of 18 such people and this number has remained quite constant during the past year. However, unlike before Jennene Arnel started working with us, we are now sure that we expect to hear about anyone who has been diagnosed soon after they are referred to a community health service provider. We don't know why the numbers have dropped but believe that it does not reflect that our Association is not being linked up with people who have MND.

The Committee has continued to steadily turn goals into actions since we signed the Memorandum of Understanding (MOU) with MND Victoria in 2008.

Jennene Arnel has been our Regional Advisor since that time. That first MOU ended last year. Together with MND Victoria we have signed a new agreement, which Rodney Harris has written about in this month's newsletter.

During the past three years we have received generous donations from fundraisers, our members and from the families of people who have had MND. This has resulted in our ability to allocate ongoing funding for the agreed period to partially support the Regional Advisor position and for administrative and member support. MND Victoria provides the balance of the funds. We aim to spread these funds over as many years as possible.

The lobbying of DHHS undertaken by Parkinsons Tasmania and by MND Victoria with MND Tasmania culminated in the appointment of three registered nurses as the Statewide Neurological Support Service. We have held meetings with the nurses and with Dr Jane Tolman their Clinical Supervisor to clarify their roles. However, the MOU describes the ongoing role of a regional advisor because we believe that our members still need this specific service and support. She visits members if they require specific assistance which is not being addressed by other service providers. She spends many hours a year teaching service providers about MND.

The Committee is grateful for those members who continue to faithfully attend Support Group meetings and support MND Awareness Week and fundraising activities. I would like to thank some people in particular while being mindful that there are many others who continue to generously support us. During 2011 Shane Chugg revamped and maintains our website, Jackie Chugg agreed to be filmed for MND Awareness Week and therefore continues to be seen in Southern Cross Community Awareness advertisements and on our website, Anna Macpherson revitalised and coordinated fundraising (and her new daughter arrived safely on 28/2/2012). Mary Erickson agreed to take over fundraising from Anna for 2012, while she continues to manage the Northern Support Group. Michele Newton stepped up into the role of secretary. Kate Barnett and her family have contributed actively to the Association since it was formed in 1986 and we thank her for her dedication and support for people with MND. We are grateful to Rodney Harris, Jennene Arnel and the Board of MND Victoria who have supported people with MND in Tasmania with positive and proactive action. Jennene has built up networks within all sectors of the health and community services in the three health regions of Tasmania. Her wisdom and advice is invaluable to all of us.

I would like to thank the members of the Committee who work hard to implement our goals. We have updated the Strategic Plan today and look forward to another year of continuing to provide better services and support for people living with MND in Tasmania.

Memorandum of Understanding (MOU)

On 4 March 2012, MND Tasmania and MND Victoria signed a new Memorandum of Understanding (MOU) to continue the work of the Regional Advisor Tasmania for another three years.

The partnership between MND Tasmania and MND Victoria has been essential to develop the regional advisor service in Tasmania, and deliver quality support for people living with MND.

Under the Memorandum, MND Victoria will continue its role of intake and information provision, as well as responding to 1800 calls from people in Tasmania. It will employ and support a regional advisor whose role will be to support people with MND in Tasmania by identifying their needs, referring them to appropriate service providers, supporting service providers through advocacy and education, and monitoring the person with MND as needs change and new needs emerge.

MND Tasmania plays an essential role in advocacy and influencing within Tasmania for the development and delivery of services and policies that are responsive to the needs created by MND.

Rodney Harris, CEO of MND Victoria, said "This MOU is another step forward for people with MND in Tasmania, and MND Tasmania. It demonstrates the Association's commitment to deliver the best possible care and support for people living with MND". Tim Hynes, Vice President of MND Tasmania, thanked MND Victoria for their work in funding and developing the service. "MND Tasmania is proud to be able to fund this service in partnership with Victoria, and we look forward to the development and enhancement of services for people with disabilities and MND, in Tasmania".

For further information, or to contact the regional advisor, Jennene Arnel, please call **1800 806 632**

Rodney Harris,
CEO MND Victoria

MND Week: May 6 – May 12, 2012

MND Week is celebrated nationally in the first full week of May every year. MND Associations work together during this week to raise awareness of MND to realise our vision of a world free from MND. If you would like to assist, please contact Mary Erickson via our email address info@mndatas.asn.au or telephone 6339 3742 or 1800 806 632 (leave a message for her to phone you).

Button Day - Thursday 3 May. We are looking for volunteers to participate in collections and raising awareness on the streets. We also have merchandise boxes (with pens, cornflowers, wrist bands) for placement at businesses and workplaces.

Bunnings Sausage Sizzle Fundraiser - Friday 11 May from 8.30am – 4pm. Please come and support us at 1 Connector Park Drive, Kings Meadows 7249.

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 at 11am – 1pm at the John L.Grove Centre, Howick Street, Launceston. The following dates have been booked: April 30, May 28, June 25, July 30, August 27, September 24, October 29, November TBC.

Mary Erickson
Northern Support Group Coordinator

Regional Advisor's Report

At the time of writing this report, I have just returned from a Statewide visit where I visited members and health professionals who are providing support to people living with MND, both at home and in residential facilities, in the North West, North and South of Tasmania.

Included on this trip was a visit to Bruny Island to visit Derry. Derry and her family and friends kindly agreed to the following story and photos to be printed in our Newsletter.

Derry is a fourth generation Bruny Island girl. She has lived her entire 61 years on Bruny Island, leaving only to go to work. The sea has always been an important part of her life and going to the beach with her dogs has been her sanctuary. Since being diagnosed with MND some 12 months ago, Derry's beach and water activities have been curtailed. However with some creative thinking, warm sunny days and the help and encouragement of the local occupational therapist, family and friends Derry has been back on the beach and in the water again – and with her dogs.

The first step was a visit to the sea in an all terrain wheelchair borrowed by the occupational therapist. Derry loved being back in the water, but the chair had to be returned. Family and friends were challenged – how to get Derry back to the sea again. They were not daunted by the challenge.

In the words of Derry's family and friends "there are always ways and means of making impossible things happen". In this case the solution included sheets of plywood (placed across the sand), a tractor (to transport the lifting hoist, banana lounge and Derry to the beach) and a manual wheelchair to transport Derry down to the water and then many loving hands to carry the banana lounge, with Derry, into the water and then to securely

hold the banana lounge afloat, complete with Derry and her dog.

From all accounts, there was much laughter and a great day was had by all.

Derry and her friends were pleased to share these photos with Newsletter readers. Their message is **ANYTHING IS POSSIBLE.**

Congratulations and well done everyone.

The next visit to Tasmania will be towards the end of April.

Jennene Arnel
MND Regional Advisor

