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MND Tasmania

PO Box 379, SANDY BAY, 7006
Inc. No. 01323C; ABN: 21 877 144 292
MND Tasmania is a member of MND Australia.
The MND Research Institute of Australia is part
of MND Australia. MND Tasmania is a member
of the Neuro-muscular Alliance of Tasmania
(NMAT).

Telephone: 1800 806 632
Email: info@mndatas.asn.au
Website: www.mndatas.asn.au

Patron

Lady Sallie Ferrall

Support

Website: Shane Chugg

Regional Advisor

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

January - February 2015

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.

Board

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



MND Tasmania - Annual General Meeting

1 March 2015

All members, family and friends who are supportive of people with MND in
Tasmania are invited to attend

Sunday 1 March, 2 pm

**Clarence Senior & Citizens Centre
17 Alma Street
Bellerive 7018**



Care Foundation

The Agenda of the AGM will include the launch of the MND Tasmania Care Foundation.

As MND Tasmania received a number of bequests during 2013 and 2014, the Board
has formed a Foundation. The objective of this Foundation is to sustain an ongoing fund
dedicated to assisting people with MND and their families in Tasmania. The Rules
including the Mission and Objectives of the Care Foundation will be presented
at the AGM.

Nominations for the Board

The term of office for Board members is one year. Board members are nominated and
elected at the AGM.

If you are unable to attend the AGM and would like to nominate or be nominated for a
place on the Board, please contact Secretary Michele Newton on 1800 806 632
(message) or via email info@mndatas.asn.au

New members

We welcome new members living with MND and their families to the MND Tasmania community and network.

Please feel free to contact our staff member Leanne Conway, the MND Regional Advisor for Tasmania, or any member of the MND Tasmania Board via the MND Tasmania email address, website or telephone (message).

Vale

We extend our sympathy to the family and friends of Peter Fisher and Kym Parker.

Past members remembered

One of the many encouraging aspects of the Ice Bucket Challenge for the Board of MND Tasmania was to receive donations and accompanying notes from people with the familiar names of past members.

One of these was received from a niece of Trevor McIntyre who enclosed a copy of a newspaper cutting with a photo of Trevor and an article from 1983. It was reported that Trevor lived in Lindisfarne and that he knew at least four other people in Tasmania with MND. He planned to hold a meeting for people living with MND and it was noted that Lions Clubs throughout Australia were assisting people with MND by funding equipment and research.

The Motor Neurone Disease Association of Tasmania was subsequently incorporated on 9 December 1986. Lion John Hughes was the inaugural Chairman/Public Officer and Lion John Piggitt the Vice Chairman.

The full account of John Hughes' Annual Report of that time can be found on our website in the editions of MND Tasmania News: January 2009 – June 2009.

The article from 1983 about Trevor McIntyre provided yet another lovely reminder of the support we have received for a long time from Lions members.

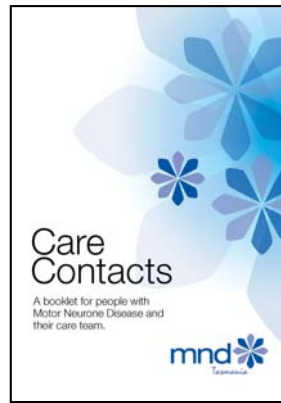
Lions and MND Tasmania

Care Contacts booklet

In September 2013 George Bugeja, the Lions District Governor of Tasmania, contacted the MND Tasmania President with the idea that MND should be the focus of Lions' fundraising for a year.

The 2014 MND Awareness Week culminated in a meeting between District Governor George Bugeja and MND Tasmania President Tim Hynes in Hobart where District Governor George presented a cheque for \$10,400 from Lions Tasmania to MND Tasmania. All funds raised came from Lions Clubs in many parts of Tasmania.

The Board has allocated a substantial part of these funds to a MND Tasmania Care Contacts booklet which is issued as a free service to all members living with MND in Tasmania.



One of the challenges of living with MND is finding out which services and service providers are needed, where they are, what they do, how they can be contacted, when they will be visiting, and so on.

This booklet can be used to assist members to keep track of their health professionals and service providers. It contains a brief overview of the roles of the various health professionals and other service providers, provides space for recording key information and for tracking appointments, contacts and milestones to act upon.

The first 100 of these Booklets were printed in November 2014 and Leanne Conway, our Regional Advisor, commenced issuing them to our members living with MND in December 2014.

Thank you Lions!

Regional Advisor's Report

Hello everyone,

2015 has started with a visit to Hobart meeting new clients and service providers. It is very heartening to know that people with MND receive such good care in Tasmania. My next visit will be to the North and North West in March. During this visit, I will also be attending the MND Health Professional Day in Launceston on 24 March, which will be presented by MND Tasmania and MND Victoria.

Care Contacts Booklet

These booklets have now been sent to all clients. This booklet is a handy way to keep track of all the people involved in your care. It will help all people involved know who to contact when an issue arises. The booklet has been used for some time in Victoria and the feedback from users has been very positive. If you have not received the booklet, please let me know so one can be sent to you.

Annual General Meeting

As you will have noticed on the cover page, the AGM will be held on Sunday 1 March 2015. I certainly encourage you to attend as this is a great opportunity to support the Association.

As always, please do not hesitate to contact me should you have any questions or concerns.

Until next time,
Leanne Conway
Regional Advisor Tasmania

MND Week: 3 - 9 May 2015

At this stage we expect that we will conduct our Charitable Collection Day on Wednesday 6 May.

The success of our raising the profile of MND and raising funds in Tasmania associated with the annual Awareness Week depends on a team of volunteers.

There are committed people who have faithfully worked hard to contribute to this cause every year.

Please look for Mary Erickson's notes in the next MND Tasmania News in April for information on how you can help.

If you would like to help, please contact Mary on 0438 523 382.

Northern Support Group

The contact person for this group is Mary Erickson, who may be contacted on 0438 523 382.

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

**Kings Meadows Community Health Centre
McHugh Street
Kings Meadows (Launceston)**

Meetings in 2015: March 30; April 27; May 25; June 29; July 27; August 31; September 28; October 26 and Sunday, November 22 (Christmas Party – date to be confirmed).

Christmas Party 2014

The Northern Support Group hosted our Annual Christmas Party on 23 November.

This was the first year it was held on a Sunday, which enabled some Board members to attend.

It was a jolly occasion at the Kings Meadows Community Centre with good company of young and older, good food, conversation and laughter and even Santa came along with gifts and fun for everyone!

Thanks go to Ashleigh and Bree for assisting in the setup and decoration of the venue and to all those who stayed behind to pack up.



Lisa Batge and Annette Viney preparing for the Christmas Party

Awaiting Santa's arrival



Santa with President Tim Hynes and his daughter

Donations

Donations have been received in the memory of:

Kym Parker, A. Finlayson, Alan Peattie and Trevor McIntyre.

Donations have also been gratefully received from people and organisations including:

- Friends and supporters at a BBQ in Wynyard
- St John's Women's Fellowship in Devonport
- A Christmas concert held in the Burnie Art Gallery with the Jones Boys' Choir, the Harmony Singers, the Happy Hour Ensemble, the Wynyard Concert Band and a few younger community members
- Supporters in the Burnie Walk
- Margaret Eldridge and her Aqua group
- The Hawker Newsagency of St Helens fundraiser
- The Huon and Esperance Hall Committee's 2-day weekend Sausage Sizzle
- Tasmania Golf Club Inc.
- Glenview Community Services Inc. (Ice Bucket Challenge)
- East Devonport Badminton Club
- Paul's Pinnacle Pilgrims
- Corpus Christie Catholic School, Bellerive.

Research

Many donations sent to MND Tasmania are specified to be for Research.

Every year, our Treasurer transfers the funds donated specifically for research to the MND Research Institute of Australia (MNDRIA).

MNDRIA allocates grants to Australian research projects which are described in the regular MNDRIA newsletters mailed out with this newsletter.

MND Tasmania has a close and cooperative relationship with researchers in the Menzies Centre of Tasmania. They have supported us for many years by providing presentations about the research they are undertaking into MND at our AGMs and at the MND Tasmania/Victoria annual forums for health professionals. The Menzies team were very active and proactive in raising awareness and funds during the 2014 Ice Bucket Challenge.

The researchers also appreciate meeting people living with MND and those who have lost relatives or friends to MND at these gatherings as it brings home the human and relevant aspects of the work they do in the laboratory.

The MNDRIA has awarded 22 grants to commence in 2015. Two of these were to Associate Professor Tracey Dickson and to Dr Catherine Blizzard from the Menzies Centre of Tasmania, and at least one went to a professor who started his medical research career in Tasmania.

In addition, Dr Jacqueline Leung has been funded by MNDRIA for an ongoing postdoctoral fellowship for 2014 – 2016, and two PhD students, Jayden Clark and Rosie Clark, are the recipients of MNDRIA PhD Top-Up grants continuing into 2015.

Ice Bucket Challenge – who started it?

The MND Tasmania Facebook site was commenced during the 2014 Ice Bucket Challenge due to the sudden increase in exposure, publicity and demand for information about MND/ALS.

For those who do not have a Facebook account, our Facebook pages can be accessed via our website at www.mndatas.asn.au and then click on 'Our Facebook Page'.

On 29 November 2014, a YouTube video was uploaded to the MND Tasmania Facebook page which provides an interesting and moving account of the "Frates Train" which is the name the Frate family used to describe their process of raising awareness and funds for MND/ALS after Pete Frates was diagnosed with ALS when he was 27 years old.

Pete's mother Nancy Frates speaks for 19 minutes on 'Why my family started the ALS Ice Bucket Challenge. The rest is history.'

Fundraising

We invite readers to contact

G. & M. Batge Locksmithing

for all of their locks and keys needs

If you quote this ad, 10 percent of a sale will be donated to MND Tasmania

Families of members of MND Tasmania may purchase car keys and car remotes at cost prices

Visit the e-bay store at **locksmithsgalore**

Contact: G. & M. Batge Locksmithing

Phone : 0439 394 230 or 0409 025 116

Email : g-mbatge@bigpond.com



MND Tasmania News

We invite everyone in the MND Tasmania network and community to send us:

- feedback to this newsletter
- reflections, thoughts and stories on living with MND in Tasmania
- information that may be helpful for others
- reports and photos on fundraising, raising awareness about MND and social activities.

Material may be sent to the Editor at our postal or email address (see page one).

The deadline for the March-April issue is 9 March.

Joyce Schuringa

Vice-president