



March - April 2015

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MND Tasmania Annual General Meeting — 1 March 2015

The Annual General Meeting was held in Bellerive on Sunday 1 March 2015.

Thirteen people attended and the Board Directors were re-elected to their current portfolios except for John Hughes who retired as Public Officer.

John has been associated with MND Tasmania since its inception and he will continue to serve Ex-Officio to the Board.

Following the meeting, Margaret Eldridge, Anna Yard-Cumming and Melissa Yard-Smith spoke of their experiences relating to MND and their subsequent journeys of raising awareness and funds for MND.



Scenes at the AGM on 1 March, 2015

President Tim Hynes presented the Board's Report for 2014 as follows -

During 2014 we have had one of the greatest turning points for Motor Neurone Disease (MND) across the globe. For many years people touched by MND have been seeking to bring the disease out from the shadows and shine some light on it.

Last year the Ice Bucket Challenge took the world by storm. It started with an MND sufferer in Boston, Massachusetts. He took it upon himself to dunk a bucket of ice-cold water on himself, challenge his peers in the athletic community who in turn challenged other professional sports personalities. Before long American personalities like Justin Timberlake jumped on-board and MND or as known in the US, ALS, suddenly had a spotlight.

Australia quickly followed suit with Rod Harris (MND Victoria) jump-starting the first known ice bucket challenge on our shores followed by Carol Birks and the MND Australia staff. It took off across Facebook, YouTube and mainstream media. Three things emerged from this ice bucket challenge: a rapid increase in donations, awareness and exposure for MND and greater scrutiny on MND associations around the country and the globe.

For MND Tasmania we generated approximately \$20,000 from the ice bucket challenge, which is a significant injection to our budget. We also created a Facebook page and received over 1,000 followers during the campaign many of whom were engaged in ongoing conversation about the disease. What is most impressive about this is that one of our members Jackie Chugg created and managed this page and continues to do so. Thank you Jackie!

Nationally, the response to the Ice Bucket Challenge was impressive. By the 5th September 2014 donations were tallied and totalled just over \$2 million! It is fair to say that across the MND Australia Board we were bowled over with the response from the community. We quickly turned our attention to what would best support national MND activities and the obvious choice was injecting more than \$1 million into the MND Research Institute. A new 3 year research grant has been funded that will provide an Australian research team the opportunity to investigate the biological basis for human MND and with the aim of targeting therapies.

In a couple of months we'll know who the successful research team is!

Ultimately, our hope through this grass roots Ice Bucket campaign is greater recognition of MND in the broader community. This is the light we've been hoping to shine on the disease.

Following the large donations and bequests we received in 2014, the Board considered the use of the funds to deliver the best outcomes for MND Tasmania members. As such we are proud to form the *MND Tasmania Care Foundation* which will provide ongoing financial support for the association. This is our own "future fund" to ensure financial viability for the services we provide.

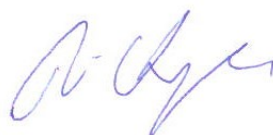
Through our ongoing and strengthening partnership with MND Victoria we have renewed a Memorandum of Understanding to continue providing an information and support service through the 1800 telephone number and im-

portantly provide a Regional Advisor service to members state-wide. As such I'd like to acknowledge and thank Leanne Conway (MND Tasmania Regional Advisor) for providing great service to members again this year.

The Committee is continually grateful for those MND Tasmania members who faithfully support MND Awareness Week and donate to our cause. MND Awareness Week in May 2014 was again supported by the tireless workers in the Northern Support Group and the dedicated volunteers in the North-West and South. Special mention must go to Mary Erickson our volunteer fundraising coordinator for her huge efforts last year and also John Hughes (OAM) for rallying the troops again in the North-West.

I'd liked to extend my thanks to my colleagues on the Board of MND Tasmania who all share the commitment and personal sacrifice to serve the Board and members of MND Tasmania. 2014 has been a hyperactive year yet also a turning point for our growth and sustainability.

I look forward to another year in which we can continue to strive for better services to people living with MND in Tasmania and contributing to MND Australia for research into this devastating disease.



Tim Hynes, President, MND Tasmania: 1 March 2014

Regional Advisor's Report

By the time you read this I will have spent a week in the North and North West visiting clients and health professionals as well as attending the Health Professional Day which was presented by MND Tasmania and MND Victoria.

The Health Professional Day was held on the 24th March at the Tailrace Centre in Riverside. The theme was "Partnerships – Supporting People Living with MND". Keynote speakers were Dr Jim Howe, Neurologist and Dr Luke Smith, Clinical Neuropsychologist, both from Calvary Health Care Bethlehem in Victoria. A research update was provided by Jayden Clark and Rosie Clark from the Menzies Research Institute Tasmania.

Sharon and Kerry Upchurch gave an insight into living with MND from a carer's point of view. Other presentations included, 'End of Life Care' by Dr Thirukkumaran, Palliative Physician and 'Feeding tubes and Oral Health' by Jacqui Bannon (Senior Speech Pathologist) and Ellen Eade (Senior Dietitian) from Launceston General Hospital. The afternoon session looked at the future direction of service access for people with MND.

More details in the next newsletter.

Leanne Conway, Regional Advisor Tasmania

Telephone: 1800 806 632 or Email: lconway@mnd.asn.au



MND Week: 3-9 May 2015

Collection Days

The Charitable Collection Day is Wednesday May 6.

This year we have the bonus of additional authorized days being Thursday May 7 and Friday May 8.

However, Launceston is excluded from this authorization on Friday May 8 due to it having been allocated to another charity on that day.

A copy of the Police Authorisation document for the collection of funds on public footpaths is available from Mary Erickson (see below).

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.

We are looking for volunteers to participate in collections and raising awareness on as many streets around the State as possible.

We have merchandise boxes with pens, cornflowers and wristbands for placement in sympathetic businesses and workplaces.

If you would like to help or would like to know who will be fundraising in your area, please contact MND Tasmania Fundraising Coordinator Mary Erickson on mobile 0438 523 382.

Bring and Buy

Margaret invites you to a BRING and BUY fundraising event at:

43 Maning Ave, Sandy Bay on Saturday May 2 at 10am – 2pm.

Entry donation: \$2 which includes lunch with soup and bread.

Bring a gift and be prepared to buy one!
Please mark your gift with a price.

All monies raised will go to the Motor Neurone Disease Research Institute of Australia in memory of two dear friends Kate McPherson and Doreen Walker.



Enquiries and offers of help will be gratefully received by Margaret Eldridge on phone 6225 1801.

Behind the Scenes

Since 2007, MND Tasmania has been supported through a Memorandum of Understanding by MND Victoria. This means that staff and volunteers assist us with reception, administration and other services.

Inez van Polanen's support has been invaluable in many ways, including formatting and publishing our newsletter every two months, assisting us with mailing lists, organizing the annual Health Professional Forums in Launceston and Hobart and being a friend at meetings and confer-

ences where we feel like small fish in a big pond! Inez has now retired from MND Victoria and we wish her well as she embarks on her next stage of life after working with MND Victoria.

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 who is the MND Regional Advisor for Tasmania or any member of the MND Tasmania Board via the MND Tasmania email address, website or telephone (message) – find the details on the back page of this Newsletter.

Vale

We extend our sympathy to the family and friends of Barry Pateman, Olwen Quirk and Robert Johnstone.

Donations

Donations have been gratefully received in the memory of Olwyn Quirk and Robert Johnstone.

Congratulations and thanks to Jane Sharp and Ruth Stendrup who held a well-publicised Open Garden fundraiser in Boat Harbour in January.

Donations were also gratefully received from the North-West Porcelain Painters Association, Ulverstone who sent their Christmas fundraising proceeds and from IGA Ravenswood.

Research

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

During 2014, \$22,251.00 was donated to MND Tasmania which has been sent to the MND Research Institute of Australia (MNDRIA).

Since the first of two friends were diagnosed with MND, Margaret Eldridge has sent over \$10,000 dollar by dollar, cheque by cheque of donations from her friends and contacts at Aquarobics classes, morning teas, lunches and similar events. THANK YOU Margaret!

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 the Kings Meadows Community Health Centre, McHugh St., Kings Meadows (Launceston).

Meetings in 2015: March 30; April 27; May 25.

Please note that we hope that the Ravenswood Community Health Centre will be available after refurbishment on the following dates - June 29; July 27; August 31; September 28; October 26 and Sunday, November 22 (Christmas Party – date to be confirmed).

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](https://www.ebay.com/str/locksmithsgalore)

Contact: G. & M. Batge Locksmithing
Phone : 0439 394 230 or 0409 025 116
Email : g-mbatge@bigpond.com

Jewellery



Margaret Eldridge sells jewellery – necklaces and earrings – to raise funds for MND Research.

She will make special items to order and also restrings broken necklaces and bracelets (except pearls) for a donation to MND Tasmania for the MND Research Institute of Australia.

She can be contacted on 6225 1801.

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 1).

The deadline for the May-June issue is 30 April 2015.

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.

Membership

Have you renewed your membership of MND Tasmania for 2015?

If your membership is due for renewal, you should have been sent a notice on our behalf from the MND Victoria office.

Please remember to renew as your support for people living in Tasmania with MND and their families is invaluable.

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

Freecall 1800 806 632

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Board

President: Tim Hynes

Vice-President: Joyce Schuringa

Treasurer: Helen Fleming

Secretary: Michele Newton

Northern Support Group: Mary Erickson

Fundraising Coordinator: Mary Erickson, Libby Cohen

John Hughes OAM (ex-officio)