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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](mailto:info@mndatas.asn.au)  
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### Patron

Lady Sallie Ferrall

### 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

### Support

Website: Shane Chugg

### Regional Advisor

Leanne Conway: [lconway@mnd.asn.au](mailto:lconway@mnd.asn.au)  
Telephone 1800 806 632

### Awareness-building

How many people in Tasmania participated in  
the **Ice Bucket Challenge**? A lot!!

The force of the enthusiastic uptake resulted  
in the **MND Tas facebook** page being  
established on 26 August by Jackie Chugg.  
Thank you Jackie!

The outpouring of **support** from people in  
Tasmania has been really encouraging, lots of  
fun and has provided a boost of hope to  
people living with MND and their families.  
The impact will be enduring.

The **media** coverage has been relatively  
prolific with The Advocate, the Examiner and  
The Mercury publishing articles and photos.  
Our President Tim Hynes was kept busy with  
early morning radio interviews.

However, even before all the excitement in  
August, there was a positive and informative  
full page article in 'Sunday Read' in The Sun-  
day Examiner on July 20 which featured our  
member Colleen Peardon. Thank you Colleen.

## September– October 2014

### 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.
- Tasmanian and Victorian Newsletters for  
members living in Tasmania.
- 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

Welcome to new members living with motor neurone disease 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 email address, website or telephone (message).

## Vale

We extend our sympathy to the family and friends of the late E. Brownlie.

## Tasmanian Ice Bucket Challenges

### The Symonds family

Kennedy's disease is a rare inherited neuromuscular disorder. Like MND, it causes the loss of motor neurone cells. Thus it is at times initially diagnosed as MND.

MND Tasmania currently has five members who have been diagnosed with Kennedy's disease. One is Chris Symonds who features in a delightful ice bucket film clip with his wife and daughters. The Symonds family can be viewed on our facebook page (4 September) or search *Ice Bucket Challenge 2014 Allison Cox* (YouTube).

### Menzies researchers

Associate Professor Tracey Dickson and her neuroscience research team at the Menzies Research Institute in Hobart have been proactive supporters of our Association.

They used the Ice Bucket Challenge to draw attention to MND and the research into MND that is being undertaken at the Menzies.

### Glenview staff

Glenview residential and community care is seeking to provide respite residential care and day support for young people with progressive neurological conditions such as MND, MS and Parkinson's disease.

Glenview staff gathered between wintry rain showers on 3 September to stand in the cold in front of warmly dressed colleagues, residents and guests while their individual donations were read out.

They were then each allowed to sit down one by one to be dunked individually from behind by a gleeful warmly dressed donor with a bucket of ice blocks and water.

The champion fundraiser was then congratulated by being dunked again, this time by a bucket of yellow ice!

The photo in the next column shows Clinical Nurse Educator Hannah Rothbauer handing the cash bucket across yellow-iced champion Jeremy Eaton to MND Tasmania Vice President Joyce Schuringa.



### Launceston leaders

Guy Barnett MHA, Launceston Mayor Albert van Zetten and Michael Ferguson MHA, Minister for Health, participated in an Ice Bucket Challenge at the Launceston Tennis Centre on 24 August. They are pictured *below* with Taylor Warde and Kate Barnett.



Guy Barnett MHA paid tribute to Neale Daniher in a speech in the House of Assembly on 20 August. An excerpt of the speech from Hansard follows:

*I am pleased tonight to stand and pay tribute to Neale Daniher, a famous Australian footballer and football great who played for Essendon from 1979-90 and coached Melbourne from 1998-2007.*

*He was born a year before me. Just two days ago Neale Daniher went public with the fact he has motor neurone disease.*

*I congratulate him for his bravery for standing up and being willing to fly the flag for people with motor neurone disease in Australia. I have a vested interest, being the ambassador for Motor Neurone Disease Australia and having had my father die of motor neurone disease.*

*I want to say thank you to the president of MND Australia, David Ali, for his leadership and drive to make a difference. He is supported by Tim Hynes, the vice-president, who is from Tasmania.*

To be continued on page 3 ...

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*I want to highlight the work of Mary Erickson, based in Launceston, who is the driving force behind the support for people with MND in the north.*

*The monthly support group meeting in Launceston is terrific. It is attended often by my wife, Kate, who is a speech pathologist and was able to provide practical help and support in past years.*

*My mother, Lady Sally Ferrall, who was married to my dad, John Barnett, is the patron for the Association in Tasmania.*

*There are some wonderful special people: Pat and Harry Stafford who are impacted by MND; Anne Steer, who is a dear friend and has seen loss in her family, including recently - and my condolences to Anne; and Kerry and Sharon Upchurch. This is a family from the north-west coast with determination and passion and a willingness to make a difference in their space. I take my hat off to them. Kerry has MND and is supported in a wonderful way by Sharon.*

*Together with others I have been challenged to what is called the 'Ice Bucket Challenge'. I was challenged 48 hours ago and I had to respond within two days and yesterday I accepted the challenge.*

## Regional Advisor's Report

Hello everyone,

I can't believe that twelve months have passed since I began in this role. The past year has been a steep learning curve for me in many ways, and I have spent a lot of the time building relationships with clients and health professionals as well as learning to navigate the health system.

MND Tasmania is currently supporting 26 clients by providing some funding to assist with equipment purchase and working in partnership with MND Victoria to provide the Regional Advisor Service.

### Ice Bucket Challenge

Hasn't this been an extraordinary success? At time of writing more than two million dollars has been raised throughout Australia. This includes money donated to MND Australia, MND Research Institute and the individual state associations. It's been a fantastic effort – not only in monetary terms but also with raising awareness. I hope that you have all taken the challenge and helped spread the word.

### Tasmania Medicare Local

Earlier this year, MND Victoria successfully applied to Tasmania Medicare Local (TML) Care Coordination Program for funding to continue to deliver the Regional Advisor Service in Tasmania.

The funding is provided by the Commonwealth Government to implement the Care Coordination Program and targets four types of chronic disease including Neuro-degenerative Disorders.

The Care Coordination Program includes flexible funding that can be accessed to address any urgent unmet support or equipment needs of our clients.

For people living with MND in Tasmania, this will mean that:

- there will be extra money to help with the purchase of equipment or allow clients to visit private health professionals if necessary
- the Regional Advisor will have support and assistance with increased access to the health professional network throughout Tasmania
- additional methods can be sourced to 'spread the word' about MND and the Association
- information about what is happening within the Tasmanian health system will be easier to access

TML will promote professional development and the upskilling of health professionals with regard to MND. This additional funding also means that beginning next year, visits to Tasmania will be every six weeks.

My last visit for 2014 will be in November

Please do not hesitate to contact me should you need anything. My telephone number is 1800 806 632 and email is [iconway@mnd.asn.au](mailto:iconway@mnd.asn.au)

Until next time,

Leanne Conway  
Regional Advisor Tasmania

## Christmas Party Invitation



The Northern Support Group would like to invite all members, supporters and friends to our Annual Christmas Party to be held in the Joan Marshall Room at the Kings Meadows Community Health Centre on:

**SUNDAY 23 November, 11 am – 2 pm**

**The day has been changed to a Sunday to make it easier for all from far and wide to attend!**

Drinks will be supplied, and please bring a small plate of food to share.

Also please bring a small gift to share marked M (male), F (female) or C (child).

Best of all, SANTA will be coming along with his supply of presents!!



## Donations

Many donations have been received as part of the Ice Bucket Challenge. Thank you to all those who have participated and who nominated others to participate in this innovative movement.

Donations have been received in the memory of:  
B. Dwyer, A. Finlayson (UK) and M. Jacklyn

Donations have also been gratefully received from other sources including: Autobarn Launceston, M. Viney, G. Batge, S. Upchurch's Ulverstone friends, IGA Ravenswood collection box donors, Tasmania Golf Club Inc., Jazzercise, Huon Valley Council, OHA Netball, South Launceston Uniting Church A.F. Group, Three Steps on George and Woolworths Rosny TPC Social Club.

Donations to MND Tasmania which are specified to be for research are forwarded to the MND Research Institute of Australia (MNDRIA)

– see [www.mndaust.asn.au](http://www.mndaust.asn.au)

Donations which are specified for member services or have no specific instructions are utilised by the Board of MND Tasmania to contribute towards:

- the cost of the Regional Advisor service provided through a Memorandum of Understanding with MND Victoria
- the purchase of equipment and assistive technology for members living with MND in Tasmania
- The provision of information and education about MND and its management in Tasmania
- the governance and administration expenses of MND Tasmania such as insurance, annual financial audits, membership of MND Australia the website, and Telstra listings.

MND Tasmania has no paid staff and the volunteers on the Board are not paid an allowance.

During 2013, MND Tasmania received a number of significant bequests. The Board has therefore decided to utilise these donations to establish a Foundation for the benefit of people living with MND and their families in Tasmania now and into the future.

The Foundation will be launched at the MND Tasmania AGM in March 2015.

### Privacy Act 2014

Following changes to Australian Privacy legislation in March, this newsletter will no longer publish the names of donors and new members unless we have received their authorization to do so.

## Northern Support Group

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

Meetings are held at 11 am – 1 pm at:

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

Dates for 2014: - Monday 27 October  
- Sunday 23 November (Christmas Party)

*Note: please note the two changes: change of venue due to refurbishment of the Ravenswood Community Health Centre, and change of day of the Christmas Party.*

Mary Erickson  
Northern Support Group Coordinator



More 'ice bucketing' at Glenview

## MND Tasmania News

We invite everyone in the MND Tasmania network and community to participate in our facebook page and also to send us material for this newsletter.

Each newsletter is placed on our website. We invite you to send us:

- feedback about this newsletter or events
- 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 November - December issue is 10 November and the mail out date will be 9 December 2014.