



May - June 2016

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MND Week, 1-7 May 2016

Thank you to the wonderful volunteers who shook tins, distributed and collected boxes and held BBQ's and morning teas and lunches for MND in the North, North-West and South of the State. Many people have supported us for a long time. For example, John Hughes has again liaised with St Brendan-Shaw College staff and students who have been raising funds for research during MND Week for over 30 years.

MND Australia was also busy during the Week with two launches.

For doctors and health professionals, MND Australia issued a new diagnostic tool for GP's.

'Painless, progressive weakness – Could this be Motor Neurone Disease?' outlines the 'red flags' for MND including signs, symptoms, features and factors that point towards a diagnosis of MND. For more information, visit the websites of MND Australia (www.mndaust.asn.au) and MNDcare (www.mndcare.net.au).

The new MND Australia Blog was also launched using the hashtag campaign #7DayswithMND. It has a growing number of stories from a broad range of people who have been affected by MND.



Harry & Pat Stafford – 70 years!

The Northern Support Group's March meeting happened to be held on the 70th wedding anniversary of Pat and Harry Stafford. Harry and Pat have been stalwarts of the Association since Pat was diagnosed with MND 23 years ago and they shared their anniversary celebration with the members of the Support Group at the Ravenswood Community Health Centre on Monday March 21. Andrew Nikolic MHR and his wife Christine also came along to congratulate the happy couple.



New Members

We welcome new members living with MND and their families to the MND Tasmania community, network and services. Please feel free to contact our staff member Hayley Tristram who is the Regional Advisor for Tasmania or any member of the MND Tasmania Board via the MND Tasmania email address, website or telephone (message). The details are on page 4 of this Newsletter.

The Regional Advisor service is part of MND Victoria and Hayley is based in Launceston. She travels Statewide as required to support our members on a needs-basis. For more information, refer to the organisational summary on the back page.

Vale

We extend our sympathy to the family and friends of Mrs Charlotte Gergely, Mrs Annette Rawlings and Mr Alan Gourlay. Donations have also been gratefully received in the memory of Mr Jon Martin.

Mary Erickson



Mary has been involved with MND Tasmania for over 13 years. Her uncle Bill Braithwaite was a Life Member of MND Tasmania until he passed away in 2008. After helping Bill with organising the Northern Support Group, storing equipment, fundraising and raising awareness of MND for many years, Mary became a Director of the Association. She continued to organise the Northern Support Group and became our Fundraising Coordinator in 2012.

Mary has advised that she will need to step down from the Support Group and Fundraising roles from June 30. She has been a wonderful support and encouragement to many people and we are glad that she will continue to be involved on the Board to work for people living with MND and their families in Tasmania.

Renewal of membership

Thank you to all those who have renewed their membership of MND Tasmania and are therefore continuing to receive this Newsletter as well as mail from MND Victoria. Your support for people living with MND in Tasmania and their families is significant and appreciated.

Members of MND Tasmania are automatically registered as members of MND Victoria due to the Memorandum of Understanding between the two Associations. MND Victoria assists us by providing administrative support which is the reason for your Renewal of Membership form being sent from and needing to be returned to the MND Victoria office. We value such support from MND Victoria as MND Tasmania has a volunteer Board and lacks the resources to employ staff.

HELP needed -

Would you or someone you know consider volunteering for one of the following roles?

If you are able to assist or have further queries, please contact Tim Hynes at (email): info@mndatas.asn.au

Northern Support Group Coordinator

We are looking for a volunteer who will take on this role for the rest of this year.

It involves setting the dates for and attending Support Group meetings, booking the venue and liaising with the people who attend regularly to provide a welcoming environment for people who come along. Mary Erickson and other Board members will assist and support this person.

Fundraising Coordinator

This person doesn't need to do any fundraising but their task is to assist people who wish to raise funds for MND. It involves providing information about MND and the Association, assisting with the supply of MND promotional merchandise, providing information about insurance cover and police permission for public events, and to represent MND Tasmania where necessary together with other Association members.

Support and assistance will be given by the MND Tasmania Board and MND Victoria staff.

Information

Special Satin Sheets

Easywear Australia specialises in making adaptive clothing and linen. They have satin sheets and pajamas available for people with bed-related mobility problems which are designed to make it easier to move by reducing friction. For information call Easywear Australia on (08) 9386 5450 or visit <http://www.easywearaustralia.com.au/>

Medical Cooling and Heating Concession

The Tasmanian Government offers a power bill rebate to assist with the cost of heating and cooling

for people who require extra use of the utilities due to their medical condition. Provided the account holder for Aurora Energy is a concession card holder and a member of the household meets the other medical eligibility criteria, the energy rebate includes electricity, gas or wood for heating. The Application Form can be accessed at the Aurora Energy website or telephone 1300 132 003. Further information can also be obtained at the Tasmanian Government Concession website.

Regional Advisor's Report

Hi everyone,

I hope this note finds you well.

I was heartened by the statewide activity during MND week recently, and the genuine interest and commitment of the people I connected with during that week.

It was great to see the fundraising action across the state and the Menzies centre doing regional talks on their current research focus. MND week seemed to me to very successfully meet its aims to provide the opportunity for community members to join to raise awareness and contribute positively to the search for a cure.

For those of you who have accessed Palliative Care services, just to let you know that the Tasmanian government is seeking to develop a Tasmanian Palliative Care Community Charter and keen to speak with anyone who wishes to contribute their thoughts and ideas. Focus groups will be held in each region and also an option to contribute via intranet. We will keep you informed via the MND website, but please contact me direct if you have any queries.

As many of you will know my travel has been curtailed these past months due to a shoulder injury awaiting surgery which is planned for next month, so my apologies for my physical absence. Thank goodness for technology in keeping the wheels turning. I look forward to being back on the road, and out to the regions again ASAP.

Meantime, as always, I'm a phone call/text or email away so don't hesitate to get in touch if I can be of assistance-1800 806 632/ 0412599365 and email: htristram@mnd.asn.au

Best wishes,

Hayley

Northern Support Group

The Northern Support Group invites all members and supporters of MND Tasmania to its meetings.

The Ravenswood facility is comfortable and suitable to use as a stopover venue for a day trip.

WHEN:

Meetings are held on Mondays at 11am – 1pm.

Meeting dates 2016: June 27, July 18, September 19, November 27 (SUNDAY Christmas party & MND Tasmania anniversary).

Note - no meeting in August and October.

WHERE:

The Ravenswood Community Health Centre, 39 – 41 Lambert St., Ravenswood (excellent accessible comfortable facilities and parking).

The contact person for this group is Libby Cohen who may be contacted at 1800 806 63 (message).



Southern Support Group

No Southern Support Group meetings are scheduled until further notice. Please note that members from any part of the State are welcome to attend the Northern Support Group meetings in Launceston.



MND Tasmania

PO Box 379, SANDY BAY, 7006

Inc.No.01323C

Telephone: 1800 806 632 (MND Victoria office)

Email: info@mndatas.asn.au

Website: www.mndatas.asn.au

MND Tasmania has a volunteer Board and no paid staff.

It is a member of MND Australia and of the Neuromuscular Alliance of Tasmania.

Board

President: Tim Hynes

Vice-President: Joyce Schuringa

Secretary: Michele Newton

Treasurer: Helen Fleming

Fundraising: vacant

Equipment: Libby Cohen

Ex-officio wisdom: John Hughes

Support

Website: Shane Chugg

Facebook: Jackie Chugg

Regional Advisor

Hayley Tristram

Email: htristram@mnd.asn.au

Support Service

MND Tasmania and MND Victoria work together to provide the Regional Advisor service which is based in Launceston and provides State-wide support for members.

Services include:

- needs-based support and assessment, home visits and referrals to appropriate care and support services as required;
- information and member support by telephone on 1800 806 632, Monday–Friday, 9am–5pm;
- information, support and training for service providers for people with MND in Tasmania;
- free membership and bi-monthly newsletters from MND Tasmania and MND Victoria for people living with MND in Tasmania.

Freecall 1800 806 632

This number is at the MND Victoria office. To assist the volunteer receptionist, please say that you are calling MND Tasmania. If you wish to speak to a Board member or the Regional Advisor, you will be asked for your contact details and your call will be returned by that person as soon as possible.

MND Tasmania News

Please tell us your stories!

Send them to the Editor at our postal or email address.

The deadline for the next issue is June 29 2016.