



MND TASMANIA NEWS

MND Week : May 3 - 9 2015

Thank you to all of our volunteers who promoted MND and collected donations during May.

It's always a cold chilly day to shake the tin on MND Button Day in May but every year we are warmed by the generosity of people donating to the cause as they pass through shopping centres and along footpaths.

We were pleased to see that all the recent media attention to MND is increasing awareness. MND has been particularly well featured in The Advocate and The Examiner this year.

Emails were flying around with reports, highlights and queries. The excerpts of communication between some of our volunteers below provide an insight into some of the activities around the State:

Hi Joyce – This year we were able to set up our little table and shake the tin over two successful days. The table was filled with MND merchandise, from dog leads, blue cornflower wrist bands to blue cornflower seedlings!

Jackie and Shane were there me again. Many more people seem to recognize Jackie from the TV ad or MND from the Ice Bucket Challenge and were keen to support us.

We would like to thank the other volunteers around the State who also helped with fundraising during MND Week. — Anna.

Michele – I don't get the paper but thanks for the copy and great publicity .

Things went reasonably well up here with Sharon raising over \$700, her mother Yvonne \$270, Nancy and myself and two students from St Brendan Shaw College \$450. Yvonne is going again tomorrow for another 3 – 4 hours.

I only saw one Southern Cross ad. Speaking to people today they saw quite a few Vic. advertisements of a man – do you know anything about this?

Our money will be banked tomorrow. — John.

July - August 2015

Hi John – Nationally MND Australia have also produced an ad campaign with the funds raised being distributed between State associations and the MND Research Institute.

I've been in Brisbane most of the week and back tonight so haven't seen any Tas TV to look out for the Southern Cross ad.

Tim.

Hi All – Thanks for the phone call this morning, Joyce. We were on our way to Devonport delivering more biros to Yvonne as she sold a lot yesterday. Mary, we sold 20 puppies in half an hour!

Thank you, Tim and Joyce for explaining the national TV ads. I spoke with Southern Cross and they will be sending me copy of their schedule of when our MND Tasmania ads went on air. — John.

Hi Teams – Well done all. Waiting to hear from all in Launceston including Harry and Pat.

Agfest is on too!

I've seen both ads on TV on Southern Cross and on 7MATE.

I've also had calls from people who have been on our website and asked about fundraising. Keep up the good work everyone! — Mary.

Hi Mary – FYI I have the following people organized to shake the tin this week -

New Norfolk – Mrs Scott and my mother Margaret.

They have obtained permission from the NN Council and will set up a table with merchandise, etc. in High St. on Friday 8th.

Centrepont – Sonia and me on the 8th. Jackie, Shane and Cornel on the 6th.

Hobart – Nadine and Tania in different locations.

Eastlands – Eileen and Hazel on the 6th.

Sandy Bay – Margaret Eldridge.

I think that's it so far. — Anna.

Thanks Anna – Hope it all goes well for all down there in Hobart. With all this awful weather so glad I've got 3 days to do the fundraising. Good luck. — Mary.

Hi All – Just seen the national MND ad on SBS2! Mary.

Hi Mary – We banked \$1,026.15 from shaking the tin yesterday! I think having Jackie and little Indigo with us attracted the donations! I'm going tomorrow to Centrepont again so will see how that goes. Hope all goes well up north, Mary. — Anna.

Regional Advisor

In 2007, MND Tasmania and Victoria formed a cooperative partnership to change the quality of care for people and their families living with MND in Tasmania. Jennene Arnel was subsequently employed by MND Victoria as the first Regional Advisor for Tasmania.

Funding for the position was obtained from philanthropic sources in Victoria and Tasmania and supplemented by donations from MND Tasmania.

In 2014, an application to Tasmania Medicare Local was successful in obtaining funding for most of the Regional Advisor position during the 2014-2015 financial year.

Last month we were pleased to hear that Primary Health Tasmania (previously Tasmania Medicare Local) has advised that the Regional Advisor Service has been allocated funds to provide care coordination for the 2015

-2016 twelve-month period. There is a budget shortfall which will be met by donations from MND Tasmania. In addition, MND Victoria continues to generously provide administrative support and employment management for MND Tasmania.

Leanne Conway

Leanne has been working with people living with MND in Tasmania, their families, friends and health workers as their Regional Advisor since 2013. During this time, she has continued to live in Melbourne and work as the MND Victoria Coordinator for Volunteer Programs while undertaking studies in Social Work.

Early this year, Leanne advised that she would like to change her focus and would resign from the Regional Advisor position when a replacement was appointed. She has been an invaluable support to the Board and members of MND Tasmania during the past 2 years and continues to be supportive in her role in the MND Victoria office. We are thankful that Leanne was willing to take over from Jennene at a time of uncertainty and change and that she extended her initial commitment to 2 years. We wish her well as she moves into new areas of work.

Hayley Tristram

We are delighted that Hayley Tristram has been appointed by MND Victoria to the position of Regional Advisor for Tasmania. She has qualifications in nursing, social sciences and psychology with experience in health promotion, counselling, training and nursing.



Hayley commenced her week-long induction program in Melbourne on July 20. This month she has been travelling around Tasmania with Leanne Conway to meet the new members and their families who are living with MND and various health professionals.

Hayley will be based in Launceston. As the first MND Regional Advisor living in Tasmania this marks a new phase in the MND Tasmania and Victoria cooperative partnership. The position is 32 hours per fortnight with flexible hours to work with MND Tasmania members and their families and health workers on a needs basis.

Regional Advisor Update

Well, the time has come for me to say goodbye. As mentioned earlier, I have decided to resign from the Regional Advisor role and concentrate on my other role at MND Victoria.

Your new Regional Advisor is Hayley Tristram. Hayley will be based in Launceston which is really exciting. Hayley and I spent a week together meeting our newest clients and key health professionals. I'm sorry we couldn't make it to everyone but Hayley will be in contact with you all soon.

As this will be my last report, I would like to take the opportunity to say thank you to everyone who has crossed my path in beautiful Tasmania.

To the Board of MND Tasmania – a dedicated group of people who volunteer their time and put so much effort into making sure that people with MND living in Tasmania are well supported - it has been a pleasure working with you and I thank you for all your support over the past two years.

To all the Health Professionals I have met along the way – another group of people dedicated to their clients; many who bend over backwards to make sure that people with MND are well supported - thank you for steering me in the right direction when I haven't known where to turn.

To our clients, their families and friends. It has been a pleasure to meet you all. Thank you for always making me feel so welcome and comfortable in your homes especially when the reason for my visit is not pleasant. Working with you has been a real privilege. I will miss you all.

Leanne Conway, Outgoing Regional Advisor Tasmania
Telephone: 1800 806 632 or Email: iconway@mnd.asn.au

Vale

We extend our sympathy to the family and friends of Mike Davis, Ruth Porteus and Helene Wickham.

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 Hayley Tristram 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.

Donations

Donations have gratefully been received in memory of Mike Davis and Helene Wickham.

We have also received donations in our PO Box including from Southern Green Energy, Freedom Health and Wellbeing, Catholic Development Fund Tasmania, Lions Club of Ulverstone Inc. Charity Golf day, Lions Club City of Devonport Inc., Qantas Hobart, Lindisfarne Primary School, New Norfolk High School, Ulverstone Fundraiser and the East Devonport Fellowship Group.

Privacy Act 2014

Please note that the names of people will not be published unless we have received their authorization to do so.

Where does the MND Week fundraising money go?



Where does the money raised during MND Week go?

All proceeds marked for MND Research are sent to the MND Research Institute of Australia (MNDRIA). For example, in 2014 over \$22,000 was sent to MNDRIA by MND Tasmania, much of it being donated during the inaugural Ice Bucket Challenge.

The balance of donated funds is used to provide support and services for the people living with MND and their families in Tasmania. MND Tasmania is run by volunteers and is dependent on donations for income. Refer to the back page of this newsletter to read about the services we offer through our partnership with MND Victoria.

Fundraising and Awareness

Burnie Mud Challenge

Karen Murray, her sisters and friends were featured in The Advocate on Monday March 30 after they turned the Burnie Challenge into a fundraising challenge. The six "Team MND" women had spent the previous six months raising money and asking people to sponsor them for the Burnie Mud Challenge. They had placed donation tins across the North-West and one of Karen's sisters set up a number of tins across Hobart and the other one flew down from Sydney to participate.

The family has been touched by MND and decided that this would be a great chance to raise money for a good cause. They had their blue T-shirts printed on the back,

raised well over \$1,000 and "all had fun and got very muddy and are planning to do it again next year." They were pleased with the positive support they received from the Challenge organizers.

Freedom Health and Wellness Boot camp and Morning Tea

A fun and challenging Boot Camp was held at new Norfolk on May 2nd followed by a morning tea. The event was organized by Stacey Aldous, owner of Freedom Health and Wellness. Stacey said that MND is very dear to her heart because her best friend, Jackie Chugg, unfortunately has MND. "We are working hard at Boot Camp to support the struggles my friend encounters on a daily basis and do our part in a search for a cure," Stacey said. She couldn't have been happier with the turn-out for the fundraiser.

The event was thoroughly enjoyed by 22 people at Boot Camp and 40 people at the morning tea afterwards. Over \$1,000 was raised for MND research. A raffle and lucky door prizes were drawn, with fantastic prizes donated from many generous people.

East Ulverstone Football Club Charity Game

Great community support was seen in Ulverstone in the buildup to the season's charity footy game when Brownlow medalist and Western Bulldogs legend Tony Liberatore wore the guernsey on the field for the East Ulverstone Football Club on Saturday July 4.

Liberatore's appearance with ex-Melbourne champion Brian Dixon at a post-game function held in the evening helped the Club raise over \$10,000 for MND. Dixon lost his son to MND 10 years ago.

The event had the full backing of the NWFL as well as the Rosebery-Toorak footballers who also took to the field to support people living with MND.

MND/ALS Global Day—June 22



To mark MND/ALS Global Day 2015, MND Australia held a morning tea at Parliament House in Canberra. The opening speech was by Prime Minister Tony Abbott who highlighted his personal connection with MND and the Government's ongoing commitment to MND research. The Prime Minister took the time to meet members of the MND community and showed his support for people living with MND by signing the MND Charter (www.mndaustralia.org/MNDCharter).

It was significant for MND that the Prime Minister could attend and it meant a lot to those people living with MND who were there. In total there were about 50 people at the morning tea.

The MND Australia President David Ali was delayed flying into Canberra so the Vice-President stepped up to meet, greet and give the opening words. Our President Tim Hynes is the Vice-President of MND Australia so Tasmania is well positioned on the MND map!

For more information on the MND/ALS Global Day 2015, morning tea at Parliament House, visit our Facebook page at www.mndatas.asn.au.

Northern Support Group

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

Return to Ravenswood!



Following its refurbishment, the Ravenswood Community Health Centre is better than ever with excellent parking, access and facilities.

All long-standing and newer members and supporters will

be very welcome.

Meetings are held - on the last Monday of each month at 11am – 1pm at the **Ravenswood Community Health Centre, 39-41 Lambert St., Ravenswood** (Launceston).

Meetings in 2015: August 31, September 28, October 26.

Sunday, November 22 (Christmas Party – date to be confirmed).

Southern Support Group

The MND Tasmania Board is considering organizing an event for our members, families and friends in Southern Tasmania who would be interested in meeting once or on an ongoing basis.

If you would be interested in being included, keep an eye on our facebook page (www.mndatas.asn.au: Our Facebook Page) or contact our MND Tasmania Regional Advisor (phone 1800 806 632 – message).

We will be sending our southern members an invitation by mail when we have the details.

MND Tasmania News

We invite everyone in the MND Tasmania network and community to share your MND stories and photos on our Facebook page or send them to us for MND Tasmania News.

Contributions and information for this publication may be sent to the Editor at our postal or email address.

The deadline for the September - October issue is September 4.

MND Tasmania

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Patron

Lady Sallie Ferrall

Board

President: Tim Hynes

Vice-President: Joyce Schuringa

Treasurer: Helen Fleming

Secretary: Michele Newton

Northern Support Group: Mary Erickson

Fundraising Coordinator: Mary Erickson

Equipment: Libby Cohen

Ex-officio wisdom: John Hughes OAM

Regional Advisor

Hayley Tristram: htristram@mnd.asn.au

Support

Website: Shane Chugg

Membership

MND Tasmania is a member of MND Australia. Tim Hynes serves on the MNDA Board.

The MND Research Institute of Australia (MNDRIA) is part of MND Australia.

MND Tasmania is a member of the Neuromuscular Alliance of Tasmania (NMAT).

Support service

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

- The Regional Advisor who provides needs-based support and assessment, home visits and refers members to appropriate support services as required.
- 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.
- MND Tasmania and MND Victoria bi-monthly Newsletters.

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 Board member or to Hayley Tristram, you will be asked for your contact details. Your call will be returned by that person as soon as possible.