



July—August 2014

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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

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.

MND Week: 4 – 10 May 2014

Button Day

Once again, a huge thanks to all of the volunteers who joined in
collecting donations and raising awareness for MND and its
research. It was a highly successful event this year, raising
more than we did last
year.

Without our volunteers
and the generous
support of the commu-
nity we would not be
able to raise any funds
for research and our
support services so
thank you all for your
support.



Our volunteers enjoyed their roles at the MNDWeek stands! Mary Erickson promoting the MND cause

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
Telephone 1800 806 632

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.

Launceston Bunnings Sausage Sizzle

Held on Saturday 10 May, the Sausage Sizzle raised \$1,308. Once again this was a very successful day and this BBQ has now stood the test of time as a worthwhile annual event. Thank you to everyone who supported and participated to raise as much as possible for MND research by the end of the day.



Volunteers of the Bunnings BBQ team with Guy Barnett and Mary Erickson



Taking a break from the BBQ

Media

John Hughes has again done a wonderful job in enlisting the support of local media. We received good coverage on Southern Cross TV.

Privacy Act 2014

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

New members

We have welcomed two new members living with MND and their families to the MND Tasmania community and network during the past two months. 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 B.Dwyer, M.Jacklyn and S.O'Donnell.

Regional Advisor's Report

Each time I visit Tasmania, I am in awe of the beautiful scenery and am grateful my job gives me the opportunity to visit new places.

During my recent visit, I visited a number of clients. I always consider it a privilege to visit people in their homes to talk about MND and how they are managing. I really enjoy getting to know our clients and their families and talk about how we can support them.

As I mentioned in my last report, providing information to health professionals is one aspect of my role. Whilst in the North West, I was invited to provide an information session to a care facility in Smithton and had a very informative discussion with the Palliative Care team about some of the issues around PEG feeding.

Whilst in Launceston, I took the opportunity to visit the Independent Living Centre. I was given a tour and was shown some of the many aids that assist people to maintain a 'normal' life. I am amazed at how some of the gadgets are so simple, yet can make such a huge difference to someone's life.

My next visit will be in mid-September. In the meantime, please do not hesitate to contact me should you need anything. My telephone number is 1800 806 632 and email is lconway@mnd.asn.au.

Until next time,

Leanne Conway
Regional Advisor Tasmania

Lions and MND Tasmania

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.

We have therefore enjoyed joining with Lions members in a year of enriching, community-building and awareness-growing activities and events.

The Lions 34th District 201T1 Convention was held in Wynyard on 8 -10 November. The special guest speakers were Kerry and Sharon Upchurch from Ulverstone, who presented their story of living with Kerry's MND since 1996. They received a standing ovation.

One of the first events this year was Cathy Clayton's Pianola and Picnic Day in the Paddock near Devonport. MND Tasmania Public Officer and Lion John Hughes reported that "the weather was beautiful and Lion Cathy and her friends spent many hours organizing the event. We had fun and good food and enjoyed the company of many new friends of MND, some of whom had lost a loved one recently. Our Lions District Governor George Bugeja and his wife also attended and enjoyed themselves very much. The \$500 profit was a great result."

DG George visited all of the 50 Tasmanian Lions Clubs to promote MND awareness throughout the state. In a media release on 22 May, he stated, "I wanted to raise awareness and also funds for research towards this extremely terrible disease to help find a cure. My mother passed away from it, that was the first time I had heard of MND."

The 2014 MND Awareness Week culminated in a meeting between DG George and MND Tasmania President Tim in Hobart where DG 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.

A delightful twist to this tale is that exactly 30 years ago in 1983-1984, the current Public Officer and a past Chairman of MND Tasmania John Hughes was the District Governor of Lions in Tasmania. In the MND Tasmania Chairman's Annual Report of March 17 1996 he wrote:

At the 31st Lions Multiple District Convention in April 1983, we were asked to pledge our support for patients with MND ... Lion Ken Blackmore of Victoria had set up the Lions MND Fund ... also visited the Founder President of the Victorian MN Society, Andy Kaszonyi, who was then unable to move his arms or legs and had lost the power of speech ... I was determined somehow to set up a Society here in Tasmania.

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 can be found on our website in the MND Tasmania News January 2009 – June 2009.

Donations

Donations have been received in the memory of B.Dwyer, S.O'Donnell and M.Jacklyn. Donations have also been gratefully received from many sources including the Archbishop of Hobart's Charitable Foundation, M.Viney, M.Eldridge and St Mary's College.

Drink Tea for MND Afternoon Tea

A Drink Tea for MND event was held at the Richmond Wine Centre on 18 May. This afternoon tea was thoroughly enjoyed by 50 people and raised much needed funds for MND research. A welcome speech was presented by MND Tasmania President Tim Hynes. The guests enjoyed a range of savoury and sweet treats as well as some fundraising activities. Amazing raffle and lucky cup prizes were kindly donated by many generous businesses.

We would like to thank all those guests and businesses who contributed to make this lovely event a wonderful success. \$1,242 was raised for research into MND.

As the tickets sold very quickly, we hope to hold a Drink Tea for MND Afternoon Tea again next year at a larger venue so that we can accommodate more than 50 guests.

Jackie Chugg & Anna Macpherson



Freedom Health & Wellness Cross Training Class

On Tuesday 5 May 'Freedom Health and Wellness' organized a fundraising Cross Training Class with all proceeds going to the Motor Neurone Disease Association of Tasmania. Twenty-four willing participants raised \$500 for this very worthy cause. Thank you to all who attended the class and supported raising awareness for MND.

Anna Macpherson

Northern Support Group

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

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

Ravenswood Community Health Centre
39 – 41 Lambert Street, Ravenswood (Launceston).
Dates: August 25, September 29, October 27 and November 24.

Mary Erickson
Northern Support Group Coordinator

Information

Question and Invitation

What do people living with MND and other progressive neurological diseases and/or their carers want to know to be prepared for the next phase of the disease?

People living with MND or Multiple Systems Atrophy and their carers (present or past) are invited to take part in a research project about preparing for the changes brought about by the disease processes and being prepared for end of life.

The study is being conducted by Dr Robin Ray from James Cook University and Ms Anne Kavanagh from Queensland Health both of whom have experience working with people with MND and MSA. Taking part in the research may increase your ability to ask your healthcare practitioners for the specific information you need to manage your care and prepare for the next stage.

If you agree to participate we will organize a telephone or face-to-face interview with you. During this interview you will also be asked to fill in a short questionnaire.

If you would like to participate or would like further information, please contact Dr Robin Ray phone (07) 4781 4474 or email robin.ray@jcu.edu.au

Accommodation Guide

Paraquad's Tasmanian accommodation guide for people with disabilities can be found at www.wheeliegoodguide.co.au

Mobility aids

A new classified website specifically for second hand and unwanted aged, disability and mobility aids in Australia is www.reusability.com.au Manager Greg Ryan writes: "When I worked in the mobility aids sector one of the most frequent and difficult questions to answer was 'will you buy back my barely used mobility aid?'"

I have built this website for this industry only and we are doing our best to enforce that all listings placed on the site are by private sellers only. The listings are Australia-wide. Please keep in mind that as we only went live on 20 May 2014 there is very little there at the moment."

MND Tasmania News

Due to the generosity of many donors to MND Tasmania and the support we receive from MND Victoria, the Board has been able to commence a new format for our bi-monthly newsletter with this issue. We have decided to trial a larger more chatty and informative newsletter for 12 months.

We would like to acknowledge the special support we have received from MND Victoria staff Inez and David in implementing this new design.

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 front page). The deadline for the September – October issue is 10 September and the mail out date will be 7 October.

Joyce Schuringa
Vice-president