



September - October 2016

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MND Tasmania 1986-2016: supporting people living with MND in Tasmania for 30 years

Members, Friends, Families, Colleagues and Supporters of MND Tasmania—On behalf of the Board of MND Tasmania I invite you to a celebration of the 30th anniversary of MND Tasmania.

11:00am to 3:00pm on Sunday 27 November 2016

Ravenswood Community Health Centre, 39 – 41 Lambert St, Ravenswood, Launceston

Welcome address, Continuous Slide show, Past, present and future, Light lunch

Please RSVP to Michele Newton michele@mndatas.asn.au or 1800 806 632 before 1st November 2016. We would love to see you there! Warm regards, Tim Hynes, President

Members' survey report

The members of MND Tasmania living with MND and Kennedy's Disease are sent an Annual Quality Survey by MND Victoria. 42 surveys were sent out in August 2016 and 12 (29%) were returned.

9 (75%) of the respondents rated their 'overall satisfaction' with the Everything Within information kit and the Care Contacts booklet as 'very good' or 'excellent' and one respondent did not know each of these are available. If you would like a copy of these resources, please contact the MND Victoria office (contacts details on page 4).

The Board of MND Tasmania was pleased to read that nearly all respondents rated our website, the newsletters and our contribution towards equipment supply as 'very good' or 'excellent' with no dissatisfaction being recorded. As these vital services are almost totally provided and funded by volunteers, the ongoing importance of every hour and every dollar donated to MND Tasmania should not be taken for granted.

As the written comments in reply to three questions may resonate with some members, we have listed them for your information and consideration. If they raise any questions for you, please contact the MND Advisor.

What was the most valuable aspect of your contact

with MND Tasmania/Victoria? 11 people responded to the question with 1 skipping. Their responses are listed below:

- I have only been in contact with the MND Assoc since July 2016, so it is not really long enough to give feedback. I am still trying to get my head around everything. I was totally impressed with all the literature and information I have received so far. I do feel reassured that there is help out there when the time comes for me to access any help etc.
- From day 1 found everyone so helpful. Everything fell into place when I came to Tassie.
- Katherine was very helpful.
- Letting me know about Calvary Healthcare Bethlehem and supporting allied health professionals - Advice of neurologists familiar with KD.
- Support, resources and awareness of others with MND/Kennedy's Disease, and also the involvement of the medical and care organisations.
- Help with equipment, information on research and other peoples' stories.
- Local group meetings and the equipment purchased for me.
- The tablets that are available.
- Information kit.
- Gaining support and information, as well as equipment and advice.

- Definitely our new Regional Advisor.

What was the least valuable aspect of your contact with MND Tasmania/Victoria? 7 people answered with 5 choosing to skip the question. 3 responded with "NA". The remaining 4 responses were:

- We did not see our local MND only once.
- Losing my first advisor Jennene. So much experience and top advice - I found that I had to educate one of the advisors about KD.
- Unavailability of the regional adviser.
- Nothing particularly. Big area to cover and most advice is given by local palliative care team.

Is there any other comments/suggestions you would like to make? 5 answered the question with 7 choosing to skip. Their responses are below:

- Don't really feel part of a "group". Seems to be huge community MND support in VIC & TAS but not in Tas. Small proportion of sufferers obviously but not inspirational.
- Please find enclosed two cheques.
- Just stay as sweet as you are and thank you.
- Top work but at times visits need to be regular. Good that a Tassie person is on board but only seen her once.
- Would be good to know what equipment MNDTAS does have available.

Thank you to all who sent in their opinions!

New Members

We welcome new members living with MND and their families to the MND Tasmania community, network and services. At the time of writing we have 44 members who are living with MND. Please feel free to contact our staff member Hayley Tristram, the MND Advisor for Tasmania or any member of the MND Tasmania Board. Contact details are on page 4 of this Newsletter. The MND Advisor service is managed by MND Victoria and Hayley is based in Launceston. She travels Statewide as required to support our members on a needs-basis.

Vale

We extend our sympathy to the family and friends of Mr Greg Batge, Mrs Pam Tonta and of any other members who have recently passed away. We were also saddened to hear of the death of Dr Andrew Churchyard who was a visiting neurologist from Victoria to Tasmania, particularly to the North-West. He had been assisting in the provision of neurology services in Tasmania since the death Dr Stan Siejka of Launceston in 2009.

MND Advisor's Report

Hi everyone, I hope this edition finds you well as we roll into Spring. I'm pleased to back at work following an extended

rehabilitation time following shoulder surgery, and currently making plans to travel around the state again for those who'd like to meet up. As always, you're welcome at any time to contact me to arrange a home visit if the timing of my planned trips doesn't work for you.

Just some advance notice that my next planned regional trips around the state are: **North West**—29-30th September, **South**—10th-11th October, **South**—5th-6th December, **North West**—14th-15th December.

It's been encouraging to see local people finding new ways to support the work of MND Tasmania in recent times, raising awareness and funds—Craig Machen's solo kayak around Tasmania planned for early in 2017 <http://www.theadvocate.com.au/story/4093332/epic-journey-for-mate/>, and the young Warren brothers climbing Mount Kilimanjaro at the time of writing this <http://www.examiner.com.au/story/4138265/young-trekkers-climb-high/>.

Perhaps you have seen recently that some promising progress has been made in unlocking the complex puzzle of MND? New research has found several new genes associated with sporadic, or non familial, MND. Understanding what these new genes do could help to identify potential targets for therapies in the future. <https://mndresearch.wordpress.com/2016/07/26/new-genetic-discoveries-tell-us-more-about-what-causes-mnd-part-1/> Some clinical trials are also starting in Australia this year <http://www.mndaust.asn.au/Discover-our-research/Latest-research/Clinical-trials.aspx>.

You may be aware that the National Disability Insurance Scheme (NDIS) has commenced in Tasmania, but for the moment only for 15-24 year olds, so not relevant yet for the majority of people living with MND. The NDIS represents a change in the ways services are delivered to people living with a disability, and the potential for more flexible services and personal choice in care. We'll be watching carefully and staying in the conversations with the NDIS team about MND.

Soon I will be attending the National MND Conference being held in Melbourne on September 12th. There's an interesting mix of presentations in the program covering genetics, technology, and aspects of care. Following this on the 13th is the Support Services meeting, a great opportunity to benefit from the wealth of experience of MND health professionals from across Australia and New Zealand.

November 24th sees us running a Health Professionals day in Hobart, with presenters from Tasmania and also interstate. These days are generally well attended and a

valuable opportunity to not only catch up with the latest information regarding MND, but to share ideas and strategies for working with MND.

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: 0412 599 365 and email htristram@mnd.asn.au

Best wishes, Hayley

Health Professionals' Forum 2016

MND Tasmania in association with MND Victoria would like to invite you to a seminar on Motor Neurone Disease (MND) for health and community professionals and people living with MND.

8.30am-4pm, Thursday, 24th November 2016 at Wrest Point, 410 Sandy Bay Road, Tasmania 7005.

Keynote presentations:

Dr Helen Castley, Neurology – Royal Hobart Hospital

Dr Christine Edwards, Palliative Care – Royal Hobart Hospital

Cost: \$99 (GST inclusive) includes morning tea & lunch

Email: info@mnd.asn.au, Freecall 1800 806 632

Fund-Raising and Awareness-Building

Thank you to our generous donors including the Tarooma Rugby Club and St Kilda Supporters Club of Launceston.

The Norske Boyer Back to Boyer celebration described in the July-August Newsletter resulted in matching the donations from visitors so that \$1,000 was sent to the MND Research Institute of Australia.

MND Tasmania has recently received a grant from the Hobart Friendly Society to underwrite the provision of equipment for members living with MND in the Greater Hobart area. Members may apply for funds to assist them with the purchase of equipment or home modifications following assessment by an appropriate health professional and the MND Advisor.

There has been increased fundraising activity for MND in Australia since Neale Daniher's diagnosis focused the media spotlight on MND. This resulted in the independent Cure for MND Foundation being established in 2014. Similarly, Kirk Dicker has been very successful in raising the MND profile, especially in the North-West of our State. (See MND News March-April 2016). Now his friend Craig Machen from Somerset is planning to paddle around Tasmania in January 2017. An auction is planned for January 2 2017 at the Burnie Surf Club and Craig plans to leave from there on January 4. For more information visit

our Facebook pages.

Our Facebook site can be accessed via our website even if you have not subscribed to Facebook. We have an active Facebook community and following us on social media is a great way to keep up to date with what is happening. If you join Facebook you can for example, participate in discussions, find out about events, share information, join a discussion devoted to communication between carers and raise the profile of MND by clicking the like button.

Every year, independently run events such as morning tea's, concerts and cricket matches contribute funds to assist MND Tasmania to support people living with MND in our State and to support research into MND.

We currently need a person who would be willing to take on the role of the MND Tasmania Fundraising Coordinator.

This person doesn't need to do any fundraising as their task would be to assist people who wish to raise funds for MND. This would involve providing information about MND and the Association, assisting with the supply of MND promotional merchandise and providing information about policy, insurance cover and police permission for public events. Support and assistance for this role will be given by the MND Tasmania Board and MND Victoria staff. If you are able to assist or have further queries, please contact Tim Hynes at (email) info@mndatas.asn.au

In the meantime, if you are planning an MND Awareness or Fundraising event in Tasmania, please contact Kathy Nightingale, Manager Fundraising at MND Victoria on 1800 806 632 or at knightingale@mnd.asn.au. Kathy can provide information, practical advice and support for people who wish to raise funds for MND Tasmania.

Talking with Young People about MND

How do we explain MND to children? How can we assist teenagers to understand and to cope with MND in the family? There is an information pack which can assist adults to talk about MND with children. The series includes booklets for parents (on how to keep communication strong with children), 8-12 year olds, teenagers, young friends and schools. This pack of booklets is available from MND Victoria via its telephone helpline (see page 4). The publications can also be downloaded from the MND Australia website at <http://www.mndaust.asn.au/Get-informed/Information-resources.aspx>.

How have others lived with MND?

LINC Tasmania has a selection of biographies, autobiographies and other resources about MND which can be borrowed from your local library. In the LINC library catalogue, the most information is seen under a search for

amyotrophic lateral sclerosis (or ALS which is another name for MND).



My Donkey Body is one of the autobiographies in the State library. Michael Wenham wrote his story in response to the urging of others and he says that it is “the passing on of a whisper”. His focus was to encourage “people struggling to carry on in spite of the pains and protests of the physical body which carries them.” However, he admits it was also very good for himself, as he enjoyed and benefitted from writing his thoughts. It is a beautifully written story which is honest, asks the questions, poses few answers and yet is humorous and encouraging.

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: Mondays at 11am–1pm. Meeting dates 2016: September 26 (not 19 as previously written), 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.

HELP needed

Would you or someone you know consider volunteering for the following role? **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.

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

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

MND Advisor

Hayley Tristram

Email: htristram@mnd.asn.au

Support Service

MND Tasmania and MND Victoria work together to provide the MND 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 MND Advisor, you will be asked for your contact details and your call will be returned by that person as soon as possible.

MND News Tasmania

Please tell us your stories! Send them to the Editor at our postal or email address. Deadline for the next issue is 10 November 2016.