



July - August 2016

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MND Tasmania 1986-2016:

supporting people living with MND in Tasmania for 30 years

The Cost of MND

On 24 February 2016, a report which is a milestone in the story of MND was launched at Parliament House Canberra.

The Economic analysis of motor neurone disease in Australia report was written by Deloitte Access Economics. It reveals that the total cost of MND in 2015 in Australia was \$2.37 billion. This comprised \$430.9 million in economic costs and \$1.94 billion in burden of disease costs. The report which was commissioned by MND Australia has been prepared to raise awareness of the impacts of MND and contribute to improving policy in this area.

On 16 June 2016 Mr Guy Barnett MP spoke in the Parliament of Tasmania on MND and the Big Freeze 2 campaign. He noted that -

- 21 June would be MND Global Day,
- an estimated 1,900 Australians are living with MND,



- the total cost of MND in Australia in 2015 equated to \$1.1million per person and
- he congratulated and thanked MND Australia and MND Tasmania who have effectively advocated for MND for over 21 years.

On the same day, a broad mix of people including Guy Barnett MP, Joan Rylah MP, Nic Street MP, members and supporters of MND Tasmania, researchers from the Menzies Centre and various staff from health and palliative care services and advocacy groups attended an event in the Long Room at Parliament House Hobart.

Guy Barnett welcomed the guests and Lynne Pezzullo who is a Lead partner, Health Economics and Social Policy of Deloitte Access Economics in Canberra. Lynne presented the outcomes of *The Economic analysis of motor neurone disease in Australia*. Her outline included the -

- epidemiology of MND;



- costs of MND – both economic costs and the burden of disease costs;
- cost comparisons.

She then answered many questions from the audience.

During his summing up after Lynne Pezzullo's presentation, Tim Hynes, President of MND Tasmania, stated that -

- the cost per person per year of MND is one of the highest of all the measured diseases;
- during the lifetime of a person with MND, the total cost of MND per person is greater than \$1million but the total cost of MND research per person with MND is \$ 5,083;
- the Report provides objective and factual information for advocacy and for the research community.

issues informally over a light lunch which was hosted by Guy Barnett MP.

More information about *The Economic analysis of motor neurone disease in Australia* report can be found on the MND Australia website.

The Field of Dreams

In April this year Mark Clemens of Hobart was diagnosed with MND. This has made him increase the pace in producing *The Field of Dreams*, the first book entirely written about Mt. Field, Tasmania's oldest national park and one of Australia's most beloved. The launch date is set for August 29, 2016 at Hobart's State Cinema.

Read about Mark, his experiences and this project in this month's accompanying MND Victoria newsletter.

Fundraising and Awareness-Building

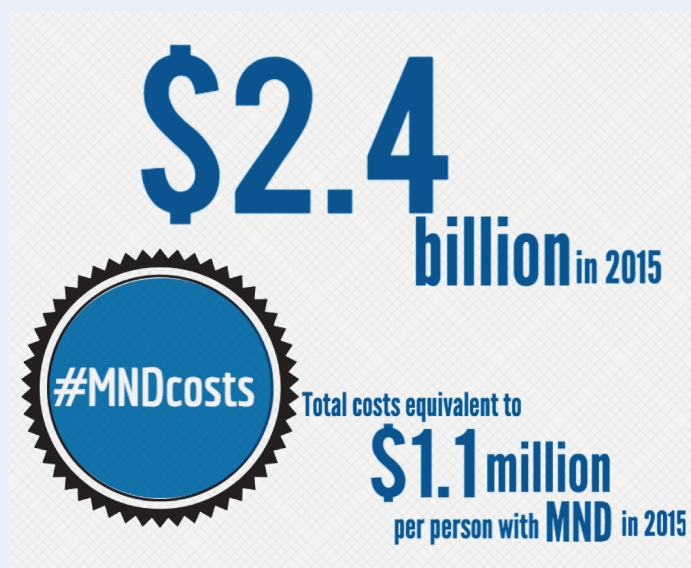
Donations have continued to be received from MND Week and the Big Freeze campaign. Thank you to all who worked hard to raise funds during these events.

The North Launceston Bunnings BBQ was a success thanks to Mary and her helpers, as was Margaret Eldridge's Bring and Buy Lunch in Sandy Bay. The Chugg, Collins and Macpherson families shook tins all around Hobart and the Upchurches and John Hughes with the St Brendan-Shaw College students were prominent around Ulverstone and Devonport. And there were others who we have not tracked down!

Meanwhile the IGA Ravenswood sends in regular donations. We have received generous donations from Bikram Yoga, Aurora staff and the Archbishop of Hobart's Charitable Foundation. MND Victoria applies for grants on behalf of MND Tasmania and we are pleased to be able to announce that The Hobart Friendly Society has provided a grant for us to assist members with the funding of equipment.

Weddings at the Albert

MND Tasmania was pleased to have been chosen by Timeless Elegance as the charity for this year's Weddings at the Albert expo on 29 May in Launceston. We are very grateful to Timeless Elegance for their donation and for this opportunity to have an MND display at such an event.



Tim also raised the question of "Where to from here?"

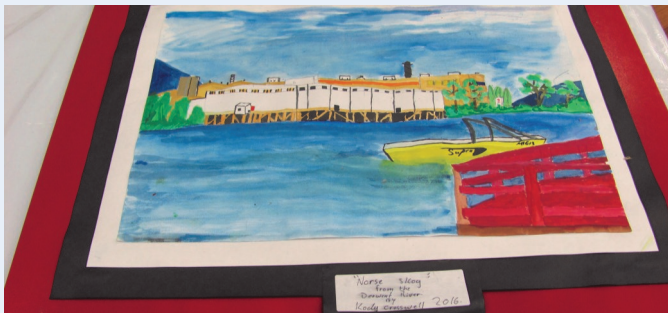
His answers were -

- an objective of MND Australia is to double the national investment in research;
- MND Australia aims to provide a resource balance between provision of care and research;
- it should not be left to "the Neale Danihers" and other prominent people who have MND to raise money for research;
- a rapid appropriate response to a diagnosis of MND is still vital to promote.

There was a subsequent opportunity to discuss these

Back to Boyer 1941 – 2016

Norske Boyer hosted a Boyer Mill 75th Anniversary Historic Day Celebration on 18 June at the Memorial Hall in New Norfolk. The entry fee was a gold coin donation for MND. Mary Erickson organised a display about MND with MND Tasmania merchandise and over \$550 was raised.



MND Advisor's Report

As many of you will be aware, Hayley Tristram (MND Advisor) has been on personal leave for the past few weeks recuperating from shoulder surgery. The operation went well and a full recovery is expected however Hayley will be away from work until late in August whilst she undertakes rehabilitation. Letters have been sent to all of Hayley's clients advising of her leave and providing contact details during this time. Please do not hesitate to call 1800 806 632 and ask to speak with Janette McDonald if you have any concerns or support needs.

You may have noticed a change in the title of Hayley's position in the heading of this section. During 2015, to encourage better understanding of the Regional Advisor role and consistency across

Australia it was agreed that MND Regional Advisors would now be known as MND Advisors as some people found the word 'Regional' confusing. Did 'Regional' mean that they only worked in rural and not metropolitan areas, were they allocated to one area only? - and so it went on. MND Victoria and MND Tasmania have determined to make this change in line with the other states so as of 1 July the correct title for Regional Advisor is MND Advisor. Over time, all references in our documentation and other media will be revised to address this change. There will be no change however in the role itself.

*Julie McConnell, Manager Support Services,
MND Victoria*

Anniversary celebration : 1986 – 2016 !

MND Tasmania turns 30 on December 6 !

Save the date: A celebration to commemorate this anniversary is planned for **Sunday 27 November** in Launceston at the Ravenswood Community Health Centre, 39 – 41 Lambert St., Ravenswood (excellent accessible comfortable facilities and parking).

Look out for notices in the next newsletter and on our website.

Invitation

You are invited to The Menzies Debate: The Stem Cell Revolution – more hype than hope?

A debate by six experts.

7 September 2016 – 5.30pm – 7pm at the Medical Science Precinct in Hobart.

ABC science communicator Bernie Hobbs will moderate what promises to be a stimulating and informative discussion on a topic with big implications for the treatment of many diseases including MND.

Register for this free event www.menzies.utas.edu.au

Vale

We extend our sympathy to the family and friends of members who have recently passed away. We have gratefully received donations in memory of Mrs Anne Rawlings.

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.

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: 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 806 632 (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 News

Please tell us your stories! Send them to the Editor at our postal or email address. The deadline for the next issue is 1 September 2016.

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.