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MND Tasmania Annual General Meeting—6 March 2016

All members, family and friends of MND Tasmania are warmly invited to attend the AGM and to hear guest speaker Jacqui Bannon, Speech Pathologist, speak about and demonstrate equipment which is:

Assistive Technology for Communication

at 1.30 pm on Sunday 6 March 2016

at the Ravenswood Community Health Centre,
39 – 41 Lambert St, Ravenswood (Launceston).

(The Centre has excellent modern accessible facilities and parking.)

Nominations for the Board

The term of office for Directors of MND Tasmania is one year. Directors are nominated and elected at the AGM.

If you are unable to attend the AGM and would like to nominate or be nominated for a place on the Board, please contact Secretary Michele Newton on 1800 806 632 (leave message for Michele to contact you) or via email at info@mndatas.asn.au



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Australian comedian, actor and musician Tim Minchin has joined with the Sydney Symphony Orchestra to launch a campaign to raise awareness and funds for MND.

On August 25 2015 accompanied by the Orchestra, Tim played and sang a beautiful and haunting rendition of Neil Finn's 'Don't Dream It's Over' to launch MND Australia's new campaign "The Fading Symphony".

But there was more to the performance than what would be expected. Be surprised and captivated – access the video of the performance at <http://www.mndatas.asn.au>: *The Fading Symphony* and

read more about it and the background to the creation of the performance on our Facebook page which can also be accessed at the website.

Off the back of the Ice Bucket Challenge campaign during 2014 and 2015, awareness of MND has significantly increased but there is still no diagnostic tool nor cure.

MND Australia and the State associations continue to work hard to promote the cause of MND. Our goal is to strive towards a world without MND and in the interim, to strive for a cure and the most effective treatment for people who live with the disease.

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 members who have recently passed away including Mrs Dianne Ranson.

We gratefully acknowledge the gifts received in the memory of Mrs Dievertje de Jong and Mrs Pat (Agnes) Harris.

Fundraising and Building Awareness

Thank you to the families and supporters who have been organising and participating in fundraising and awareness activities during the past months, some of which are featured on our facebook pages which can be viewed at <http://www.mndatas.asn.au>.

Share your stories by posting on our facebook site and for this newsletter, please send them via email or post (see contact details on page 4).

MND Week – May 1 – 7, 2016

This annual event provides a window of opportunity every year to raise the profile of MND and to raise funds to support people living with MND in Tasmania. We are indebted to the committed people who faithfully work hard to contribute to this cause year after year.

Get ready! As MND Week is always the first full week of May, it will be early in 2016!

Be prepared by looking for Mary Erickson's notes in the next MND Tasmania News in April for information on how you can help. If you would like to plan now, you can contact Mary on 0438 523 382.

Northern Support Group

Christmas Party



The Northern Support Group hosted the MND Tasmania Christmas Party 2015 on Sunday November 22. Many new and longstanding members and their families had a joyous time of fun with good company, food and music. Santa came along again and the children had a great time as he had a gift for everyone!

We enjoyed another milestone as it was the first time our Regional Advisor could join us. We also were the lucky first to use the brand new Ravenswood Centre on a weekend!

Thank you to all who joined in and the many helpers from the setting up and decorating to the packing up.

Monthly meetings

All long-standing and newer members and supporters are very welcome to join these monthly get-togethers.

Thank you to the stalwarts of the Group who provided the backbone of support last year – Mary, Pat and Harry, the Batge family, Annette and Libby.

WHEN: Meetings will be held at 11am – 1pm on the third Monday of each month until April 18 (due to the Public Holidays) and then from May 30 onwards, on the last Monday of the month as usual.

Meetings planned for 2016 – February 22, March 21, April 18, May 30, June 27.

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

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

Southern Support Group

The Southern Support Group commenced in Lindisfarne in 2015 with meetings in September and October. We met different people each time and thank you to Jenny, Nicole and Michele who have provided the continuity of support.

Members and supporters are very welcome to join the gatherings planned for 2016.

WHEN: On the last Friday of the month at 12.30– 2pm.

Meetings planned for 2016 – February 26, April 29 (as Easter is in March), May 27.

WHERE: Lindisfarne Community Activities Centre, 37A Lincoln St., Lindisfarne.

Enter at the upper car park and park in the lower car park. Access to the building is via the door at ramp entrance at the top of the lower car park.

The contact person for this group is Michele Newton who may be contacted at 1800 806 632 (message).

Information

Judith Durham AO , Patron of MND Australia

Did you know that Judith Durham AO has been named the 2015 Victorian of the Year for outstanding public and community services? Judith's husband Ron Edgeworth died from MND in 1994 and together with her fellow Seekers, she has passionately raised awareness of MND and funds for care and research for over 20 years, including at concerts in Tasmania.

National Disability Insurance Scheme (NDIS)

The Tasmanian Government reached agreement with the Australian Government on the roll-out of NDIS in December 2015. From July 1 2016, eligible people with disability in Tasmania will enter NDIS in a carefully managed and supported way.

In each year of the roll-out, the number of Tasmanians in NDIS will roughly double and increase every 6 months, with about 10,600 people expected to be receiving individual support through the Scheme by July 1 2019.

The roll-out will be State-wide and the current age cohort approach will continue and expand out from the current 15 to 24 year old age group in both directions as follows -

- ⇒ 1 July 2016 – NDIS will also be available to eligible young people aged 12 – 14;
- ⇒ 1 January 2017 – NDIS will also be available to eligible adults aged 25 – 28;

- ⇒ 1 July 2017 - NDIS will also be available to eligible children aged 4 – 11;
- ⇒ 1 January 2018 - NDIS will also be available to eligible adults aged 29 – 34;
- ⇒ 1 July 2018 - NDIS will also be available to eligible children aged 0 – 3 and eligible adults aged 35 – 49;
- ⇒ 1 January 2019 – NDIS will also be available to eligible adults aged 50 – 64.

In the foreseeable future, MND Tasmania will continue to support members and their families living with MND whether or not they are eligible for NDIS. We also continue to lobby for equity of services for people with MND whether they are classified into the health, disability or aged care sectors.

Raising our Profile and Knowledge among Health Workers in Tasmania

In November there were two professional development events in Launceston relevant to MND.

I was fortunate to be one of more than 110 health professionals to attend a Primary Health Tasmania (TPN) education event in Launceston on November 14th 2015 on 'Managing Complex Neurodegenerative Disorders'.

The programme focused on Motor Neurone Disease and Huntington's Disease with presentations by visiting Victorian Neurologists **Dr Jim Howe** and **Dr Andrew Churchyard** and Clinical Neuropsychologist **Dr Luke**

Regional Advisor's Report

Hi Everyone, Happy New year to you all.

Since our last newsletter, my daughter and I were fortunate to attend the MND Support Group Xmas lunch in Launceston. It was a lovely day so well organised by Mary, complete with Secret Santa delivered by Santa him (her)self. We had lovely food and conversation and good fun, and I was able to meet some people I hadn't yet met.

I also participated in a health professional day in December about working with complex neurological conditions. We were fortunate to have Dr Luke Smith and Dr Jim Howe from the MND Clinic – Calvary Health Care Bethlehem (Victoria) present, and I participated in a panel with Luke and Jim along with Jacqui Bannon, Speech Pathologist from Launceston General Hospital. This was a very productive and positive day with well in excess of 100 health professionals attending. The emphasis was on how we as health professionals coordinate our care most effectively, and the discussion was rich, intelligent and informative. If anyone is interested in Luke or Jim's presentations for health professionals, they are available on the Primary Health Tasmania website http://www.primaryhealthtas.com.au/resources/chronic-conditions?user_type=for-health-professionals, or you can simply drop me an email and I can forward them to you. There's a health professional day planned for Hobart in 2016 though the dates are not yet set.

In planning for the coming year, you'll hear from me shortly via letter wanting to update contact details and also with proposed dates for the year ahead when I will travel to each region. It doesn't mean I can't travel outside of these dates as needed, but I'm hoping it may make it easier to catch up if desired.

Meantime, I'm a phone call/text or email away so don't hesitate to get in touch: 1800 806 632/ 0412599365 and email is htristram@mnd.asn.au

Best wishes, Hayley

Smith. A broad range of allied health professionals along with GPs and nurses attended.

The event was organized by Primary Health Tasmania's care co-ordination programme. Neurodegenerative disorders are among the conditions targeted by this programme.

Julie McConnell, Acting CEO, MND Victoria, chaired a Health Professional Panel which included our Regional Advisor Hayley Tristram and Speech Pathologist Jacqui Bannon. There was an interesting discussion, questions and answers on the 'Importance of Multidisciplinary care' in Motor Neurone Disease.

Dr Jim Howe is employed by the Statewide Progressive Neurological Disease Service (Vic) based at the Bethlehem Hospital in Caulfield. He spoke of the role of the Neurologist being to get the diagnosis right in the first place, quoting that "while MND is incurable it is not untreatable".

I was interested to learn more from him of the benefits of monitoring weight loss and respiratory function in people living with MND. The two interventions that can extend the life span and improve quality of life are: the PEG tube and non invasive ventilation (NIV).

Careful monitoring can ensure that decisions about whether these are suitable or wanted can then be made at the most appropriate time to enable optimal benefit.

I also learnt more about Pseudo Bulbar Affect (PBA). This dramatic disorder effects expression of emotions. It can be uncontrollable and excessive and is not a true expression of the mood of the patient. It is embarrassing, limits social activities and therefore quality of life. This symptom can be suppressed by medication.

It really was a great day for learning and networking. Thankyou TPN.

In addition, this year's Tasmanian Allied Health Symposium was held in Launceston. This is where different Allied Health services from all over the state can 'show case' their work.

One presentation relevant to our MND community was delivered by Speech Pathologist Peter Hockley – 'Eye gaze for independence'. Peter spoke about the application of 'eyegaze' in text to speech assistive technology. This tool is used to generate speech for those with limited hand function. Peter has worked with Occupational Therapist Katie Greatbatch to introduce a new level of independence with communication for their clients – another good example of the multidisciplinary team working for the best outcome for clients.

This day was another excellent opportunity for networking and learning what new things are happening and where to get the best advice and assistance for our clients.

Libby Cohen Director, MNDTasmania

MND Tasmania

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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: Mary Erickson

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 send us your stories! Contributions and information for this publication may be sent to the Editor at our postal or email address. The deadline for the next issue is 7 March, 2016.