



November - December 2016

M
N
D

T
A
S
M
A
N
I
A

N
E
W
S

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

National MND Conference – 12 September 2016, Melbourne

Many health professionals and others involved with MND in Tasmania attended the National MND Conference which featured MND scientific research updates, advances in best practice care and symptom management, community services and palliative care collaborations and initiatives related to caring for carers and children.

MND Australia is to be congratulated for this conference with the focus being on **Care, Collaboration and Support**.

MND Australia Directors: David Ali, Tim Hynes, Samar Aoun and Carol Birks



The first presenter was Dr Jim Howe, a neurologist from the Statewide Progressive Neurological Disease Service, Melbourne. He spoke of the improvement in treatment of MND over his medical career and highlighted that the most important disease-modifying intervention is support from an optimistic, expert multidisciplinary team using the skills and knowledge of neurology, palliative care and rehabilitation medicine.

Duncan Bayly and his wife Kat presented 'Living well with MND - a Personal Perspective'. Duncan presented via a speech synthesizer with apologies for the 'voice' – emphasizing that the machine

Duncan Bayly & Kat Barnett



spoke 'for him' not 'as him'. He discussed his focus on living a 'normal life', acknowledging that there was a team of experts behind him to listen to his problems and to translate them into solutions as well as the immense amount of support from family and friends. Duncan's advice to others living with MND is to take advantage of all available supports you can to provide you with the independence you need to achieve your goals. 'Eye Gaze' communication has made a great difference to Duncan's life, enabling him to express himself fully and giving him an indispensable lifeline to those around him. Duncan and Kat are also members of the Board of MND Victoria and Duncan is a PhD student at RMIT.

Occupational Therapist Rachael Russell presented 'A clinical reasoning framework for implementation of eye gaze technology for individuals with MND'. Her paper presented a clinical framework to assist therapists in the assessment and implementation of this technology for people living with MND. She noted that eye gaze technology is becoming more economically viable and flexible in its ability to

integrate with main stream technology. Her key messages were -

- Eye gaze is just one option of accessing a computer and may be used for communication, leisure, full computer access or environmental control.
- There are many factors to consider when prescribing an eye gaze system and understanding the MND phenotype of the individual can help to guide the assessment process.
- Therapists should be proactive in their assessment of alternative computer access options.
- Early implementation can allow the individual to become familiar with the system before the later stages of the disease.
- Ongoing assessment and monitoring is required as the disease progresses.
- When successful, eye gaze technology can have a positive impact on the quality of life for an individual with MND.

Dr Samantha Graham, Co-Founder of 'Out of Your Mind', delivered a paper outlining the major learning from the 'Out Of Your Mind Program' run for the carers for people living with MND in Queensland in 2015. She described the practices taught and the new behaviours adopted by the participants which transformed their lives and their relationships as carers. She discussed the importance of up-skilling carers to stay healthy and resilient in order to maintain quality care for the person with MND and for themselves beyond the time of their caring. The participants greatly valued meeting other carers and sharing experiences. The program gave carers permission to keep on living and changed the trajectory of their lives and their ability to care for their family member.

At the conclusion of this presentation there was much interest from the conference floor as delegates from across Australia including our Tasmanian team were keen to know if such a program could be implemented in our home regions. Dr Graham's response was that consideration could be given to running a Train the Trainer program and so broaden the scope of delivery to carer groups.

The Trade Exhibition area was filled with equipment and services to assist people living with MND and was so extensive, it was not possible to see everything. The Conference day was an excellent networking opportunity for health professionals, researchers, carers and families from the wider MND community.

Libby Cohen

Director, MND Tasmania Board

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 MND Advisor for Tasmania or any member of the MND Tasmania Board. The contact

details are on page 4 of this Newsletter. The MND Advisor service is managed on our behalf 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 Ian Bates, Jackie Chugg, Denise Feldmanis, Colleen Peardon, Melvyn Temple, Paul Yard and of any other members who have recently passed away.

Jackie Chugg passed away on October 16. Jackie was diagnosed with MND in 2006 when she was 25 years old. She promptly joined the Association and was active in fundraising and in promoting the MND cause. Jackie spoke for all people living with MND in the powerful and moving advertisements shown on Southern Cross TV.

In 2014 Jackie launched MND Tasmania into the world of social media when she took on the creation and management of our Facebook pages after the Ice Bucket challenge took us by storm. "Jackie, her husband Shane and twin sister Anna have contributed a huge amount to the cause of MND in Tasmania." (Tim Hynes, President).

HELP needed – Can you be a volunteer in 2017?



Would you or someone you know consider volunteering for the following roles next year?

If you are able to assist or have further queries, please contact Tim Hynes at email info@mndatas.asn.au or phone 1800 806 632 (message at MND Victoria office).

Fundraising Coordinator:

Would you like to assist people who wish to raise funds for MND?

You would provide information about MND and the Association, assist with the supply of MND promotional merchandise and provide 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.

Northern Support Group coordinator:

We are looking for a volunteer who will set the dates for and attend Support Group meetings, book the venue and liaise with the people who attend regularly to provide a welcoming environment for people who come along. Libby Cohen and other Board members will assist and support this person.

Image designed by Freepik: http://www.freepik.com/free-vector/blue-hands-with-hearts-charity-background_894424.html

Neuromuscular Alliance of Tasmania

The Neuromuscular Alliance of Tasmania (NMAT) celebrated its 10th anniversary at a luncheon hosted by Speaker Elise Archer (photo below) at Parliament House on 18 October.

This group was formed in December 2006 to increase influence by collaboration.

The seven founding members of NMAT were MND Tasmania, Australian Huntington's Disease Association (Tas), Muscular Dystrophy Association of Tasmania, Alzheimer's Australia (Tas), Multiple Sclerosis Tasmania (recently changed to MS Limited), Parkinson's Tasmania and the Spina Bifida Association of Tasmania. The Brain Injury Association of Tasmania (BIAT) and Epilepsy Tasmania have joined NMAT recently.

The event was well-attended by Members of the House of Assembly and it was a valuable opportunity to inform them and their advisors about the issues facing people living with progressive neurological diseases in Tasmania.



Elise Archer

Fund-Raising and Awareness-Building

Donations have been gratefully received in the memory of Mrs Pamela Tonta, Mr Melvern Temple and Mr Ian Bates.

Thank you to our generous fund-raisers and awareness-builders including -

- Crowe Horwath Launceston who held a dress-down day in July
- David Lee and the Westbury Rotary Car Show (photo below)
- the 'Care and Share' ladies from the Perth Baptist Church
- Taylor Warde and the November Walk to D-feet MND
- Rosemary and Jude's Dunedin Garden Lunch for Menzies Centre MND research
- Charlie and Lachie Warren (photo below) who climbed Mt Kilmanjaro
- Citywide Fitness Hobart's 24 hour Sweat for a Cause.



Libby & David Lee



Charlie and Lachie Warren

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 from 11am to 1pm on the fourth Monday of every second month.

Meeting dates 2017: January 23, March 27, May 29, July 24, September 25, November TBA

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 Advisor's Report

You may have noticed there is no MND Advisor report in this edition. Hayley was on leave at the time of printing, however, she is back now. She will be travelling to the **South** from 5th-6th December and the **North West** from 14th-15th December 2016.

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 4 January, 2017

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: vacant

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.