



May - June 2015

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MND Tasmania Health Professional Forum, Launceston

The Forum hosted by MND Tasmania and MND Victoria was a success again this year and we are thankful for the staff of MND Victoria who have worked for months behind the scenes and then flew over from Melbourne for the day to run an excellent program.

Around 100 workers and volunteers from the health, aged care, community and disability sectors learned from and enjoyed presentations from a wide variety of speakers, all about MND. It was an excellent networking opportunity for them as well as for MND Victoria staff and three MND Tasmania Board members.

MND Tasmania President Tim Hynes spoke at the end of the day and summed it all up so succinctly, we have recorded it as follows:

What another great turn out of health professionals



that we have had today and I hope you'll permit me in summarising the presenters from today.

First up we had **Jim Howe from Calvary Bethlehem** discuss the importance of palliative care in journey of people living with MND. Jim's tagline that stayed with me was to remember that MND "is not curable but it is treatable". Palliative care play a big role in treating this disease.

Kerry and Sharon Upchurch followed Jim by giving their very personal story with MND. Kerry being diagnosed in 1996 has lived with the disease longer than most and in that time managed to celebrate a great marriage with his wife Sharon and raise 3 sons. It's truly inspiring to hear firsthand from those living with MND.

Dr Thirukkumaran (otherwise known as 'Dr T') gave us a look at the inside at Palliative Care. Dr T emphasized that palliative care is holistic care and for MND patients engagement should start at diagnosis. He discussed many aspects of end of life care including clinical approaches to pain management and nausea. As Dr T was being ushered off for being over time he confessed to being able to talk ad nauseam about nausea!

Jacqui Bannon (speech pathology) and Ellen Eade (Dietician) took us through Lilly's journey of a bulb-ar onset of MND. They both gave practical and insightful detail on both the timeline and interventions used to treat Lilly's symptoms. A great exam-



ple of how case studies can assist knowledge and understanding.

Luke Smith a Clinical Neuropsychologist presented next and the most striking thing afterwards was a comment that someone made to me after his presentation. It went along the lines of: "he's

like your brother from another mother". Apparently we looked quite alike! Despite my oblivion to a long lost brother, his presentation was incredibly engaging. From the start he explained things in my language. For example think about Fronto Temporal Syndrome (FTS) as light beer and Fronto-Temporal Dementia (FTD) as heavy beer. Most striking for was the discovery that MND is not just 'motor'. In fact 50% of MND patients have some cognitive impairment throughout the disease.

Next up we had the panel of service providers including **Lynette from Tasmania Medicare Local, Bec and Marg from Baptistcare and Leanne from MND Victoria**. During the presentations it highlighted to me again that the services available to people in Tasmania with MND can be complex to understand making it important as ever to have effective partnerships between providers. Critically, the issue highlighted that impacts people with MND



significantly is the inability to access disability services if they are diagnosed with MND over the age of 65.

Emily and Jayden from Menzies Research Institute, probably the smartest people in the room, took us through their mouse models and research projects into MND. My comparatively tiny brain concentrated hard in this session and left me at the end with Emily's research conclusions: Are the dendritic spine events upstream or downstream? Good luck Emily on the next project in your PhD to explore the 60-day intervals! Jayden outlined his research on the axons transport from neuron to muscle. An interesting finding for him was that the fast fatigue muscle fibers deteriorate early. An interesting finding for me is that Jayden has a disturbing taste for mouse manipulation and torture! Did I understand most of their presentations? No I didn't. What matters to me is that the MND Research Institute of Australia is going from strength to strength and competition is high for research grants. Some of the best junior and senior researchers are coming to the MND field.

MND Victoria have done another stellar job in organising today's forum and on behalf of MND Tasmania we thank

you again for taking part. See you again next time.

New members

We welcome new members living with MND and their families to the MND Tasmania community and network.

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 MND Tasmania email address, website or telephone (message) – find the details on the back page of this Newsletter.

Vale

We extend our sympathy to the family and friends of Miriam Viney who was an active supporter of MND Tasmania since her son Peter had MND over nine years ago.

Donations

Donations that have gratefully been received at the PO Box include those in the memory of Miriam Viney and from the Smithton CH Lions Club.

Privacy Act 2014

Please note that the names of people will not be published unless we have received their authorization to do so.

Regional Advisor Update

Hello everyone

I hope you are all keeping well in this cold weather. Since my last visit I have been kept reasonably busy in the office catching up with people who I haven't seen for awhile and talking with people or families of people who have been recently diagnosed with MND. There are currently 33 people registered with MND Tasmania.

My May visit has been to Hobart where I met with some of the new clients and caught up with some of the health professionals who support people with MND.

Tasmanian Hospice and Palliative Care Forum

I was fortunate to attend the above forum which was held on 28th & 29th May in Hobart. The forum's theme was "Tassie Communities Talk Death" and reflected the Tasmanian Association for Hospice & Palliative Care (TAHPC) Inc's recent project encouraging all Tasmanians to discuss their end of life care wishes and how people in local communities can actively support friends, neighbours and work-mates facing life-limiting illness and bereavement.

MND Health Professional Day

As mentioned in the last newsletter, MND Tasmania in partnership with MND Victoria presented a Health Pro-

fessional day in Launceston. The day was a great success and feedback I have received has been very positive. I think the highlights for most who attended were the presentations by Dr Jim Howe and Dr Luke Smith as well as the great insight of living with MND given by Kerry and Sharon Upchurch.

As always, please do not hesitate to contact me should you have any questions or concerns.

Until next time,

Leanne Conway, Regional Advisor Tasmania
Telephone: 1800 806 632 or Email: lconway@mnd.asn.au

MND Week : May 3—9 2015

Thank you to supporters who were busy promoting MND and collecting donations during May.

Donations have been gratefully received and receipts are still being processed. Any outstanding funds may be mailed to our Treasurer at our PO Box (see back page) or deposited into our CBA account at 067-013 2800 5202. Please mark your name and address on the deposit comments or transaction description, or send us an email, or send the transaction receipt with your details to our PO Box - so that we can send you a receipt.

MND Week is celebrated nationally to raise awareness of the needs of people living with MND and their families. It is a time to acknowledge the MND community and people living with MND and to remember those who have passed away.

This year we have again received good coverage on Southern Cross TV.

Our Button Day was on Wednesday May 6. Thank you to all of the volunteers who organised and assisted with collections and who raised awareness on the streets and in shopping centres on that day and at other times during the week.

At this stage we are still collating information on the people who were involved and the monies collected. A full report will be in the July - August MND Tasmania News.

Northern Support Group

The contact person for this group is Mary Erickson who may be contacted on 0438 523 382.

Return to Ravenswood!

Following its refurbishment, the Ravenswood Community Health Centre is better than ever with excellent parking, access and facilities.

All long-standing and newer members and supporters will be very welcome.

Meetings are held on the last Monday of each month from

11am – 1pm at the **Ravenswood Community Health Centre, 39-41 Lambert St., Ravenswood** (Launceston).

Meetings in 2015: June 29, July 27, August 31, September 28, October 26, Sunday, November 22 (Christmas Party – date to be confirmed).

MND Tasmania News

Please share your MND Week stories and photos on our Facebook page or send them to us for MND Tasmania News.

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 page 4).

The deadline for the July – August issue is June 24.

Neuromuscular Alliance of Tasmania (NMAT)

NMAT consists of MND Tasmania, Alzheimer's Australia (Tasmania), the Australian Huntington's Disease Association (Tasmania), Multiple Sclerosis Tasmania, Muscular Dystrophy Association of Tasmania, Parkinson's Tasmania, Brain Injury Association of Tasmania and the Spina Bifida Association of Tasmania.

NMAT is currently working to influence policy and increase awareness on issues including –

- the operation of the National Disability Insurance Agency (NDIA) in Tasmania;
- the restructure of the health system in Tasmania;
- the collection of data about people with neuromuscular conditions;
- staff and services with appropriate specialist knowledge in the health, disability and community services in Tasmania;
- appropriate residential care for young people with disabilities, in suitable independent living units and in residential facilities outside the aged care sector;
- driver re-assessment and training of people whose skills change due to a neuromuscular disorder.

NMAT meetings are an important networking activity to improve knowledge and for the dissemination of information between the member organisations.

Fundraising

We invite readers to contact

G. & M. Batge Locksmithing

for all of their locks and keys needs.

If you quote this ad, 10 percent of a sale will be donated to MND Tasmania

Families of members of MND Tasmania may purchase car keys and car remotes at cost prices

Visit the e-bay store at [locksmithsgalore](https://www.ebay.com/str/locksmithsgalore)

Contact: G. & M. Batge Locksmithing

Phone : 0439 394 230 or 0409 025 116

Email : g-mbatge@bigpond.com

Jewellery



Margaret Eldridge sells jewellery – necklaces and earrings – to raise funds for MND Research.

She will make special items to order and also restrings broken necklaces and bracelets (except pearls) for a donation to MND Tasmania for the MND Research Institute of Australia.

She can be contacted on 6225 1801.

MND Tasmania

ABN: 21 877 144 292; Incorporation.No.: 01323C

PO Box 379, SANDY BAY, 7006

Phone: 1800 806 632

Email: info@mndatas.asn.au

Website: www.mndatas.asn.au

Patron

Lady Sallie Ferrall

Board

President: Tim Hynes

Vice-President: Joyce Schuringa

Treasurer: Helen Fleming

Secretary: Michele Newton

Northern Support Group: Mary Erickson

Fundraising Coordinator: Mary Erickson

Equipment: Libby Cohen

Ex-officio wisdom: John Hughes OAM

Regional Advisor

Leanne Conway: lconway@mnd.asn.au
or telephone 1800 806 632.

Support

Website: Shane Chugg

Membership

MND Tasmania is a member of MND Australia. Tim Hynes serves on the MNDA Board.

The MND Research Institute of Australia (MNDRIA) is part of MND Australia.

MND Tasmania is a member of the Neuromuscular Alliance of Tasmania (NMAT).

Support service

The MND Associations of Victoria and Tasmania work together to provide:

- The Regional Advisor who provides needs-based support and assessment, home visits and refers members to appropriate support services as required.
- 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.
- MND Tasmania and MND Victoria bi-monthly Newsletters.

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.

MND Tasmania News

Contributions and information for this publication may be sent to the Editor at our postal or email address. The deadline for the July – August issue is June 24.