



January - February 2018

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MND Tasmania 1986-2018:

supporting people living with MND in Tasmania for 32 years

MND Tasmania – Annual General Meeting

Sunday, 18 March 2018 at 1pm at the Independent Living Centre, 275 Wellington St., South Launceston 7249 (The Centre has accessible facilities and parking)

All members, family and friends of MND Tasmania are warmly invited to attend the AGM at 1pm.

At 2pm there will be a presentation by invited speaker Karen Frost, Executive Officer, Independent Living Centre Tasmania (ILC Tas) about the ILC and the MND Tasmania Communication Equipment Library

Nominations for the Board: The term of office for Directors of MND Tasmania is one year. The election of nominated members of MND Tasmania to the positions of Directors is conducted at the AGM.

If you are a member who is unable to attend the AGM and would like to be nominated for a place on the Board, please contact Secretary Michele Newton via email at info@mndatas.asn.au

MND Advisor's Report

Hi everyone, Welcome to 2018. This time around I wanted to make mention of **Statewide Progressive Neurological Disease Assessment, Management and Education Services** at Calvary Health Care Bethlehem in Caulfield, Victoria (<https://www.calvarycare.org.au/public-hospital-bethlehem/services-and-clinics/progressive-neurological-disease-service/>).



For those of you who haven't heard of this clinic before, for people with a diagnosis of MND confirmed by a neurologist, they offer specialist neurological assessment and management in a multidisciplinary team environment. The health professionals you may work with at Calvary then liaise with your local health team in Tasmania. Telephone and skype can be used sometimes as follow up to reduce the need to travel. For those eligible, transport subsidies through the **Patient Travel Assistance Scheme** (<http://www.dhhs.tas.gov.au/hospital/ptas>) apply.

To attend this clinic, you will need a referral from your doctor. For more information, feel free to get in touch, or if there's anything else you might need assistance with. Best wishes,

Hayley, 0412599365 / htristram@mnd.asn.au

Vale

We extend our heartfelt condolences to the families and friends of Anton Ambroz, Mark Aspinall, Gayle Douglas, Wendy Fitzpatrick, Desmond Jones, Denis Lyne, Robert Parkes, Philip Smith, Harry Stafford, Graeme Welling and of any other members who have recently passed away. Denis Lyne was an active supporter of the Association and served as MND Tasmania Secretary in 2006 – 2009.

Harry Stafford passed away on September 27 2017. Pat and Harry Stafford have been active fundraisers and faithful supporters of MND Tasmania since Pat was diagnosed with MND in 1992. They celebrated their 70th wedding anniversary with the Northern Support Group (recorded in the May-June 2016 MND Tasmania News) and Pat has written accounts of their story for MND Tasmania newsletters in the early years of their MND journey.

Fund-Raising and Awareness-Building

Donations have been gratefully received in the memory of Desmond Jones, Denis Lyne and Graeme Welling.

Thank you to our generous fund-raisers and awareness-builders including the Carrick Guides, the staff and students of Romaine Primary School, St Michael's Collegiate School and the following – **Woolmers Art Exhibition Cocktail Party at Longford** - Liz Harris and her catering team in November donated proceeds from the event to MND Tasmania. A cheque has been gratefully received for the amount of \$1,076.55.

Margaret Eldridge's self-written Aqua Christmas Jingle in December continued her long-standing bi-annual tradition of raising funds for the Association.

Members of the Order of the Eastern Star, Tasman Branch

Margaret Stanton presents MND Tas Vice President, Libby Cohen with a cheque for \$1,500.



Exeter Golf Club – Memorial Day:

A nine hole course was played in memory of much admired and popular member Rick Putnam, who sadly passed away in late September just five months after being diagnosed. The Club came together and raised close to \$1,500.

Wynyard Chorale - Christmas Cantata:

Starting out 30 years ago The Wynyard Chorale today have a strong membership of fifty-six individuals who come together to share their love of singing. Every year they perform a Christmas cantata in their town, selecting a group to support by passing on all the donations they receive, to that cause. This year MND Tasmania was the selected 'group' and we were extremely pleased to receive a cheque for \$843.00.



Blue Illusion Fashion: During November a fashion parade was hosted by Elizabeth Hammer at Blue Illusion in Sandy Bay. A fun and successful evening raised just over \$800.00.



Riverside High School: Who would have thought so many people love Krispy Kreme doughnuts?! The Grade 8 Student Council sold 235 dozen - yes that is right! - 2820 doughnuts

to raise a mighty \$1,943.25! They certainly know to put the fun into a fundraiser!



Once again, a big THANKYOU to all our generous fund-raisers and awareness-builders. It is only through your work that we can continue to provide specialised care and support to the Tasmanian MND community. **#togetherwecan**

If you have an idea for a fundraiser, would like to organise a fundraising event or become a volunteer please contact us at fundraising@mndatas.asn.au or message us on Facebook to find out more.

FILM NIGHT – BEYOND THE RIVER

A true-life South African adventure story about the triumph of the human spirit featuring friendship and resilience (but not MND).

When: Thursday 22 February at 7pm

Where: Centenary Lecture Theatre, UTAS, Sandy Bay

Bring your family and friends to come along and enjoy the evening together.

No door sale tickets so visit our website or Facebook page for Booking details.

Michelle Macpherson, Fundraising coordinator

Advocacy

State-wide Neurology Services: MND Tasmania is a member of the Neurological Alliance of Tasmania (NAT) which has been proactively in contact with the Ministers for Health for many years about the lack of continuous and Statewide Neurology services. As reported in the November-December 2017 newsletter, the President of MND Tasmania and five representatives from other member associations of NAT met with the Minister for Health Michael Ferguson MHA and his Clinical Advisor Catherine Schofield in October.

A second meeting was subsequently held on December 7 2017 between Catherine Schofield, Jen Lowe (MS) and Joyce Schuringa (MND Tasmania). The following active issues were discussed -

- A number of Neurologists had been offered positions to work in the North and North-west of the State. The Tasmanian Health Service's (THS) aim is to have a hub of neurological excellence with the critical mass

to support each other State-wide and to form networks with other health professionals.

- A fourth 'neurological nurse' position is being advertised. The four full-time equivalent positions are permanent, Statewide and under the clinical supervision of Dr Frank Niklason. Even though a lot of their time to date has been taken up with people who have Parkinson's Disease, their role is to support people with other neurological conditions such as MS and MND as necessary. NAT should be included as the peak consumer body in the evaluation and restructure of this service.

- Enhancing the effectiveness of communication between NAT and the THS.

Legislative Council Inquiry into acute health services in Tasmania: NAT submitted a paper and spoke at a meeting to this Inquiry. In the meeting with the Minister for Health in October 2017 (reported in MND Tasmania Newsletter, November-December 2017), he informed NAT that their submission was noteworthy as it was clear and practical. The submission from NAT included the following *two contrasting fictitious scenarios from MND Tasmania* to illustrate changes to acute hospital services that could improve the quality of care for people with MND:

Scenario 1 – an example of Current practice

Jim is a 42 year old man from the North West coast of Tasmania. He is married and has three school aged children. He is the primary breadwinner for his family and a third generation farmer.

Jim presents at DEM, NWRH with extreme fatigue and breathlessness. A detailed clinical history and a raft of tests are performed as Jim is otherwise a fit and active man. Although his symptoms have been worse in the past few days, he does remark to the assessing clinician that he has noticed a general decline in energy in the past year. He has lost some weight, but he's been overweight in the past few years so he and his wife are not displeased about this.

Xrays confirm Jim has pneumonia, so he is prescribed antibiotics and told to follow up with his GP. Having visited his GP and having completed his course of antibiotics, Jim returns to his work. Jim's fatigue grows and he starts to do little outside of his work, not eat as much and falls to sleep early. He's had the occasional choking fit when he's drinking or eating dry foods but doesn't think much of it. He notices he's starting to have some trouble manipulating some of the tools he uses on agricultural machinery but he doesn't mention this to anyone. His wife thinks his voice is a bit slurry and suggests he goes to the doctor but he's not keen.

A few months later, his fatigue is severe again and this time he has chest pain and a headache. Again he presents to DEM, this time in an Ambulance. Again, Jim has pneumonia and he is admitted to the NWRH for further investigation and treatment. A Neurological consultation is required which involves a 4 hour trip from NWRH to Hobart (and 5.5 hours from Jim's home), with a several days' stay and arrangements needed for the care of their children. This takes some weeks to arrange. The Neurologist arranges more tests and subsequently diagnoses Jim with a progressive bulbar palsy form of Motor Neurone Disease (MND). Unwittingly, Jim has been aspirating fluids into his lungs which now have permanent damage. His lung function has regressed to the extent that a PEG (feeding) tube cannot be safely inserted, limiting his projected lifespan.

Jim and his family are distraught. The local multidisciplinary team works with Jim but as his condition is already quite advanced, the supportive relationships are hard to build as his condition deteriorates rapidly. Jim and his family struggle to cope with their rapidly changing circumstances. Jim dies in NWRH 6 months after diagnosis following another bout of pneumonia aggravated by his poor nutritional and respiratory status. Jim's family are angry that this wasn't picked up sooner and have lost confidence in their health system.

Scenario 2 – an example of Best practice

Jim is a 42 year old man from the North West coast of Tasmania. He is married and has three school aged children. He is the primary breadwinner for his family, and a third generation farmer.

Jim presents at DEM, NWRH with extreme fatigue and breathlessness. A detailed clinical history and a raft of tests are performed as Jim is otherwise a fit and active man. Although his symptoms have been worse in the past few days, he does remark to the assessing clinician that he has noticed a general decline in energy in the past year. He has lost some weight, but he's been overweight in the past few years so he and his wife are not displeased about this.

Xrays confirm Jim has pneumonia, so he is prescribed antibiotics and told to follow up with his GP. More detailed questions alert the clinician and she refers him to the Neurological Registrar who refers him for a Neurological consultation and some further testing to eliminate any other causes of the symptoms he's described.

Having visited his GP and having completed his course of antibiotics, Jim returns to his work.

Jim attends the monthly multidisciplinary Neurological Clinic at the NWRH and the Neurologist confirms that Jim has progressive bulbar palsy, a form of Motor Neurone Disease (MND).

Jim and his family are distraught. However, his early diagnosis allows the early introduction of the multidisciplinary team to provide care and support that meets best practice guidelines. Jim and his family have time to work out how he best wants to live his final years and to put their family, farm and financial affairs in order.

Jim dies at home 2 years after diagnosis, surrounded by friends and family. His family report that while the diagnosis was traumatic they felt well supported by their health system.

Research news

MND research in Tasmania:

Dr Catherine Blizzard is a neuroscientist with the MND research team at the Menzies Centre in Hobart. She and her students have often presented their research at MND Tasmania AGM's and Health Professional Forums. She was awarded the Tasmanian STEM Young Researcher of the Year in 2017. In response, she said, "This was a great honour as it demonstrates that my achievements are not only recognised in the STEM field but my contribution to the Tasmanian community is also valued. Tasmania has a small invested community and commitment to supporting up and coming STEM researchers is vital for our success." MND Tasmania is a member of and donates annually to the MND Research Institute of Australia (MNDRIA) which has funded a significant amount of the Menzies Centre's MND research.

MND research trials

The MND Australia website lists the current trials in which people who have MND may participate.

As the MND community in Australia is relatively small, participants may need to travel to interstate centres if they are eligible to participate in a trial. The most recent one is testing a drug called Tecfidera. For information, visit the MND Australia website or follow the links from the MND Tasmania website or Facebook page. <http://www.mndaust.asn.au/Discover-our-research/Latest-research/Clinical-trials/TEALS.aspx>

NWSG = Northwest Support Group

The NWSG invites all MND Tasmania members and supporters to its monthly meetings -

WHEN: The first Tuesday in every month at 10a.m. The next meeting is planned for 6 March.

WHERE: Ulverstone Returned Serviceman's Club, 21 King Edward St., Ulverstone.

The contact person is Junene Stephens who may be contacted at 1800 806 632 (message) or email info@mndatas.asn.au

MND News Tasmania

Please tell us your stories! Send them to the Editor at our postal or email address. The deadline for the next issue is 2 March 2018.

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MND Tasmania

PO Box 379, SANDY BAY, 7006

Charity ABN 21877144292

Telephone: 1800 806 632
(MND Victoria office so leave a message)

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 Neurological Alliance of Tasmania.

Board

President: Joyce Schuringa

Vice-President: Libby Cohen

Secretary: Michele Newton

Treasurer: Helen Fleming

Fundraising: Michelle Macpherson

Equipment: Libby Cohen

IT support: Shane Chugg

Governance: William Maguire

Ex-officio wisdom: John Hughes OAM

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.

