



March - April 2017

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MND Tasmania 1986-2017: supporting people living with MND in Tasmania for 31 years

MND Tasmania—Annual General Meeting—5 March 2017

The AGM was held in Bellerive and it was encouraging for the old and new Board to meet with supporters of MND in Tasmania. The Annual Speaker was Michele Newton whose sharing of her family's and her experience with MND was appreciated and well-received. Note that the **President's Report** is a separate insert in this Newsletter.

New and Retiring Board Directors

We welcome William Maguire, Shane Chugg and Michelle Macpherson as the new Directors who were elected at the AGM and we wish them well as they work to ensure that MND Tasmania continues to fulfill its mission and vision into the future.

Tim Hynes and Mary Erickson were farewelled from the Board and we wish them every success as they embark on new challenges. We owe each of them a huge debt of gratitude for the many years they have served to support people and their families affected by MND.

At the launch of the DVD *Glass Half Full* about his father on 11 May 2009 in Brisbane, Tim Hynes spoke these words : “.... my role in MND Tasmania has involved assessing what people with MND really want and need and how it should be delivered by NGO's, government and our Tasmanian Association.” (MND Tasmania Newsletter July-August 2009.) MND Tasmania has been transformed during the past 10 years due to Tim's leadership, foresight, planning, drive and networking. Tim has been a wise, sensible, engaging President and Vice-President.

We now have a small though strong Association with a competent Board, comprehensive

governance protocols, a sustainable financial footing and an excellent and productive relationship with MND Victoria which improves and informs service provision for people with MND in Tasmania. The Association is now well known and respected in the health and disability service sectors in this State. During the 10 years, Tim represented Tasmania with excellence on the Board of MND Australia where he also served as Vice-President and on the Board of the MND Research Institute of Australia. Thank you Tim!

Mary Erickson became involved in the Association soon after her uncle Bill Braithwaite was initially diagnosed with MND in 1994. Whenever the storage of equipment was raised as an issue at Committee meetings, Bill would say that his niece had a



Santa with President Tim Hynes and his daughter



Past & present MND Tasmania Directors 27/11/16

container on her property and this was the MND equipment solution! Mary has been an integral part of the Northern Support Group, had a personal relationship with Santa and has been an energetic fundraiser and promoter of the cause of MND. She has been an Association Director for 9 years, Fundraising Coordinator for 4 and the leader of the Northern Support Group for even a longer time! She has a history of being busy during MND Week, initiating the MND Bunnings BBQ's in Launceston and travelling across the State to deliver MND merchandise and to assist and encourage fundraisers. Mary's compassion, enthusiasm and organizational skills were much appreciated by the many who have attended the Support Group. Thank you Mary!

Thirtieth Anniversary Celebration 27 November 2016

The 30th birthday of MND Tasmania was celebrated by over 30 people in Launceston on Sunday 27 November 2016. The first Report about this wonderful Anniversary was published in the January–February 2017 Newsletter which is on our website. The second part of the Report is below. We invite contributions from other past and present members who would like to add to their story or any corrections to this historical account. The history of the Motor Neurone Disease Association of Tasmania can be divided into three periods of time and events.



1. Beginning and establishing the Association—The first period commenced in 1985 with a number of people including local Lions Club members meeting together and deciding to commence a formal group of support for people with MND in Tasmania. They formed the Association in 1986 and John Hughes OAM described the people and events of this time in his speech at the Anniversary Celebration. An account of this history can be read in the MND Tasmania Newsletters of January-June 2009 and November-December 2015 which are on our website.

2. The relationship with Palliative Care—The second phase was described by Joyce Schuringa as follows - At the Annual MND Health Professionals' Forum on 24 November both Dr Helen Castley, Neurologist and Dr Christine Edwards, Palliative Care Physician stated that palliative care services in Tasmania provide the backbone of coordinated care from diagnosis until death to improve the quality of living and dying for people who have been diagnosed with a terminal condition such as MND.

Dr Paul Dunne was the first State-wide Palliative Care Specialist in Tasmania and he changed palliative care services to include people with MND and their families. Together with Jane Jupe RN and Jenny Fuller RN, Dr

Dunne served on the Board of the Tasmanian Association for Hospice and Palliative Care (TAHPC, now Palliative Care Tasmania) and opened up its services to include MND. He negotiated with the MND Association to host the first MND National Conference in Tasmania which was held in Hobart in 1996. He sent his staff to the Conference to educate them so that they could gain the knowledge to include people who had MND and other degenerative neurological conditions in their service provision.

Jane Jupe, a senior Registered Nurse in palliative care in Hobart and Jenny Fuller who managed palliative care volunteers in the TAHPC conducted day seminars about MND for health professionals. They also produced and circulated a brochure about MND and palliative care services. TAHPC has a team of trained volunteers and it was expanded to include those with specific training to assist people with MND. A MND multidisciplinary team meeting was commenced and continues to be held regularly in Hobart so that health professionals representing all services including the MND Tasmania Advisor can identify, track and liaise to ensure that every person who is diagnosed with MND in southern Tasmania receives timely and appropriate care.

Fast forward to 2016 and people with MND have access to a responsive and holistic service of palliative care specialist doctors, nurses, allied health professionals, volunteers, equipment and accommodation to support them and their families. Palliative care staff and volunteers attend our annual MND Forums in Hobart and Launceston and the MND National Conferences.

As Dr Castley and Dr Edwards explained, when people hear the diagnosis of MND they are left reeling and many cannot cope with hearing the words palliative care. However, the earlier the involvement of Palliative Care services, the earlier the provision of appropriate support, better understanding of the issues and more informed decision-making by people affected by MND.

3. The Memorandum of Understanding with MND Victoria—The third period could be defined as commencing in 2007 with negotiations between MND Tasmania and MND Victoria resulting in a Memorandum of Understanding to provide services for the Association and its members in Tasmania. Rod Harris, CEO of MND Victoria summarised this period at the Anniversary and it has been documented in MND Tasmania Newsletters since 2007.



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 heartfelt condolences to the families and friends of Mark Clemens, Jackie Barrow and of our other members who have recently passed away.

MND Advisor's Report

Hi everyone, Few words from me this time around as autumn creeps in and the leaves start to turn. I've really enjoyed being able to get around the state more this year, meeting you and your families, and other health professionals in the regions, and look forward to more of the same.

I'm a phone call/text or email away so don't hesitate to get in touch if I can be of assistance - 0412 599 365 or email htristram@mnd.asn.au

Best wishes, Hayley

Fund-Raising and Awareness-Building

Donations have been gratefully received in the memory of Mr Len Oates and Mrs Janet Fisher.

Thank you to our generous fund-raisers and awareness-builders including the Rotary Club of Longford and the CMPT4MND team.

CMPT4MND



It has been an exciting January for Craig Machen and Kirk Dicker. On January the 4th Craig set off from Burnie SLSC to paddle around Tasmania. He was accompanied by support boats and crew. Craig's long term ambition has been to circumnavigate Tasmania by sea kayak. As this had been achieved once before by Kirk Dicker's uncle, he put it to his good friend Kirk that he use his personal challenge to raise awareness of MND and raise funds for research and to support those living with MND.

Together Craig and Kirk planned the trip. Along the way, through their infectious enthusiasm and hard work they gathered a great team of supporters – family, friends and the wider community.

Craig gave himself a month to complete the challenge but managed it in 25 days. He reported that it was the toughest thing he had ever done both physically and emotionally. He had some very unfavorable conditions. Winds were side on and head on most of the time with up to nine hour paddling days. Surely there are very few people who have seen as much of the Tasmanian coastline as Craig. He commented that he really enjoyed seeing the wildlife up close – dolphins, seals and penguins.



On Saturday 28th January, as Craig was on the last leg, support for his circumnavigation increased immensely. Well-wishers gathered at Boat Harbour gave him a great welcome. As he paddled on this homeward leg more well-wishers were gathered at Somerset and then a great welcome home crowd and media at Burnie SLSC. Through Craig's great personal achievement and Craig and Kirks strong friendship they have raised awareness of MND and a tremendous donation to MND Tasmania. Craig, Kirk, your team and donors - thank you from the Board and members of MND Tasmania. A friend who accompanied Craig and the support crew on his trip is making a documentary. Look out for it! CMPT4MND lives on ...

MND Week: 7 – 13 May 2017



This annual event provides a window of opportunity 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 every year.

During 2016, \$14,699 was raised during MND Week. A tremendous effort! Thank you again to all who worked so hard.

Collection Day—Wednesday, 4 May 2017

We are looking for volunteers to participate in collections and raising awareness on as many streets around the State as possible. We have merchandise boxes with pens, cornflowers and wristbands for placement in sympathetic businesses and workplaces.

If you would like to participate, would like to know who is fundraising in your area and/or will need a copy of the Police Authorisation and Insurance documents and the MND Tasmania authorisation form for the collection of funds on public footpaths, please email us at info@mndatas.asn.au or phone the MND Victoria office on 1800 806 632 and leave your name and contact details for our Fundraising Coordinator. Please be patient if there are any communication delays as we are adapting to MND Week without Mary Erickson at the helm!

Information**Palliative Care Tasmania**

An article by a former President of TAHPC (now Palliative Care Tasmania) Rosemary Sanford was published in *The Mercury* on 10/2/2017 to refute reports stating that palliative care services had been reduced or ceased due to funding cuts. Palliative care services are continuing without change. Palliative Care Tasmania had utilised a 3 year grant from the Australian Government in 2013-2016 for the Networking End of Life Care project to improve the quality and sustainability of communities to support people who want to die at home or in their community. The Board of Palliative Care Tasmania will continue to fulfill its mission in other ways now that this 3 year grant has ended.

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 11a.m. to 1p.m. on the fourth Monday of every second month.

Meeting dates 2017: 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) 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 April 28 2017.

MND Tasmania

PO Box 379, SANDY BAY, 7006
Inc.No.01323C

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: vacant

Secretary: Michele Newton

Treasurer: Helen Fleming

Fundraising: Michelle Macpherson

Equipment: Libby Cohen

Social media: Shane Chugg

Ordinary Director: 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.