



March - April 2019

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MND Tasmania 1986-2019:
supporting people living with MND in Tasmania for 33 years

Walk to d’Feet MND NW Coast



Photo courtesy of Sharon Upchurch

By Michelle Macpherson

The weather was perfect as we arrived at set-up for our first Walk to d’Feet MND event in Ulverstone. The nerves started to set in as we wondered how many people would turn up and then all of a sudden, the flood of people arrived, around 180 people in fact! Our NW Support Group had worked hard for months to put this event together and the day spoke volumes to the important work that they do for the Association. I know first hand just how challenging and time-consuming organising an event like this can be, no easy feat in the best of circumstances and yet this small community



Photos courtesy of Gaylene Norton



shone in the hardest of times whilst dealing with the loss of more than one loved one. We extend our heart-felt thanks for all that you do in your local community and the wider Tasmanian community.

Postdoctoral researcher Emily Handley from the Menzies Institute for Medical Research travelled from Hobart on the day and was on hand to give us an insightful talk on the work being undertaken to deepen understanding of how healthy cells and cells in the early stages of MND in the motor cortex interact with each other. It is hoped that by

understanding how this part of the brain works before it is “broken” will lead to suitable treatments being developed and of course the end goal....finding a cure.

As we do not receive government assistance and are an Association of volunteers, we can only provide support services due to the generosity of others. One of the most vital services we provide is that of an MND Advisor, a qualified health and community care professional with extensive knowledge and experience related to MND. This service delivery is considered as world’s best



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practice and we are the only organisation to offer this service in Tasmania. We want you to know that the efforts for the NW Walk saw us raise an impressive **\$12,381**.

To all the volunteers, individuals and businesses that attended, donated, bought a piece of merchandise - The Board of MND Tasmania sincerely thank you for your contribution, **YOUR** generosity has made this possible and allows us to continue to provide the care required until a cure is found.

#togetherwecan

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 MND Advisors for Tasmania who are also our NDIS Coordinators of Supports. Board members may also be contacted. The contact details are on page 6. The MND Advisor service is managed on our behalf by MND Victoria with MND Advisors who travel Statewide as required to support our members on a needs-basis.

Vale

We extend our heartfelt condolences to the families and friends of members who have recently passed away including Kerry Upchurch, Wendy Cox and Dianne Fuglsang. Kerry and Wendy were members of the North-West Support Group and were diagnosed with MND in 1996 and 2016 respectively.

Their stories can be found on our website at: www.mndatas.asn.au (Kerry Upchurch in Newsletters: November-December 2014 and MND in the Media and Wendy Cox in Newsletters: March-April 2018).

Donations

Donations have been gratefully received in memory of Kerry Upchurch and Dianne Fuglsang. Thank you to those who have returned the newsletter cover sheet with a donation and to those who have donated on line.

Donations received enables MND Tasmania to continue to provide practical care for people with MND and their families in Tasmania.

Tasmanian Health Professionals' Forum 2019:

Navigating MND – Charting a course for health professionals

By Libby Cohen

This year's Health Professional Forum in Launceston was attended by over 50 people from across the state. Attendees ranged from Medical Specialists, Allied Health Professionals to others working and living with MND. We were treated to range of excellent presentations.

A big 'Thank you' to Charles Smith who talked about his journey with MND. An important story to hear to remind us of the enormous impact MND has on those with the condition and their families.



Dr Christine Edwards is a Staff Specialist Palliative Medicine, Tasmanian Health Service. She emphasized that early referral to Specialist Palliative Care services provides people with MND with the most appropriate support at the right time. Palliative Care is frequently misunderstood as being just 'end of life' care when in fact it is 'Supported Care' from the time of diagnosis.

Keynote speaker, Neurologist Dr Helen Castley is a staff specialist at the Royal Hobart Hospital. She discussed MND and the neurologist's role in providing



a diagnosis. She said some but not all patients continue to consult a neurologist after this.

Two members of the expert allied health team at Calvary Health Care Bethlehem, Sarah Solomon, Occupational Therapist and Marian McCarron, Speech Pathologist discussed the roles their disciplines play in supporting people living with MND. Together they demonstrated how Occupational Therapists and Speech Pathologists work together for the best solution to help clients. One example they gave was making functional hand and wrist splints for

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someone with deteriorating hand function to access a keyboard or touch screen of a communication device. Dennis Lo, Speech Pathologist from ILC Tasmania, talked about the MND Tasmania Communication Equipment Library. Dennis has much experience and expertise in the prescription of communication equipment. Tasmanian allied health professionals are able to consult him in finding improved solutions to their client's communication needs. A range of communication equipment is available to MND Tas members from the library.

Eric Kelly a Team Leader MND Advisor from Victoria spoke of the role of Advisors in supporting our members living with MND. We also met Alison Jones, the face behind the 'Information' service available to our members and others who make enquiries about MND.

The Forum gave delegates an excellent opportunity to learn from the experts and establish networks for sharing knowledge and skills.

Thank you MND Victoria for such an information packed day.

MND Tasmania – Annual General Meeting

Sunday 17 March 2019, Alma's Activities Centre, Bellerive

The report on the AGM, elections and guest speaker Jo Whitehouse, Manager Support Services MND Victoria & Tasmania will be published in the May-June 2019 MND Tasmania News.

MND Advisors

As noted in the January-February 2019 MND Tasmania News, Hayley Tristram MND Advisor resigned. Her letter to the MND Tasmania Board and members is below -

Dear MND Tas community – On 15 January, I accepted an offer to take on my Health Promotion Consultant role with THS full time. While this offer has been on and



off the table for some years, in the immortal words of Gough, this time around it felt like “It’s time”. I’m sure that for a while I will relish the relative simplicity of one job, one team, one set of policies, one town. Equally, I have no doubt at all that after a time, I will again seek the richness of the world of working direct with community.

I am sorry to be leaving the two organisations, both MND Tas and Vic. It has been a pleasure and privilege to have this role the past 3.5 years. It has been enriching and inspiring, a steep learning curve that never seemed to stop, and of course, the cruelty and the unfairness of the disease and sometimes our very health system, has fairly brought me to my knees. I have worked with splendid people in Tasmania and over there on the big isle, both community members and health professionals.

I often tell people that when I joined MNDVic/MNDTas, what I was most struck by was the professionalism of the organisations and the way they seemingly seamlessly integrated heart and head, compassion and precision into the work with clients and indeed with community and staff. Both MNDVic and MNDTas have navigated successfully and with great tenacity and wisdom the winds of change sweeping through the industry. What a ride. There is certainly nothing mundane in this work or workplace and I really do feel privileged to have been part of the journey.

I'd like to express my gratitude to the Board for your extraordinary commitment to people living with MND and your support of me in this role. I am very pleased to see Tasmania enter another new era in care for people with MND with 2 Tasmanian MND Advisors able to support each other, and a workload much more compatible with a quality service in this changed service system with all its demands.

I wish all of you the very best into the future.

Best wishes, Hayley

Meet Jacqui—MND Advisor and Support Coordinator



I am delighted to join the team at the MND Association. I will be working in Tasmania across the state in the role of MND Advisor and Support Coordinator. I'm looking forward to meeting clients, families and health teams in the coming months as I settle into the job. My usual days of work will be Monday, Tuesday and Wednesday. You can call me on 0412 599 365 or email me at jholland@mnd.asn.au. The ‘Navigating MND: Charting a Course for Health Professionals’ Forum was held on Friday 1st March in Launceston. It was a great day of learning and networking with colleagues. I'm looking forward to attending the AGM in Hobart on Sunday 17th March. I look forward to working with you and your teams and being part of the MND Association team.

Jacqui Holland

Research news

Professor Matthew Kiernan is on the Board of MND Australia and is the Chairman of the MND Research Institute of Australia Research Committee. On Australia Day this year, he received the award of a Member of the Order of Australia (AM) for his significant services to medicine and to medical education in the field of neurology. This includes his magnificent contribution to MND research and the care of people living with MND.

MND research trials - The MND Australia website lists the current trials in which people who have MND may participate. For information, visit the MND Australia website or follow the links from the MND Tasmania website or facebook page.

Northwest Support Group

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

WHEN: The first Tuesday in every month at 10.30 a.m. Next meetings: April 2, May 7, June 4, July 2.

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

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

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.

A member of MND Australia and of the Neurological Alliance of Tasmania.



Board (until March 17 2019)

President: Joyce Schuringa

Vice-President: Libby Cohen

Secretary: Kate Todd

Treasurer: Julie Driessen

Public Officer: Shane Chugg

Fundraising: Michelle Macpherson

Logistics: Dr Andrew Moy

Ex-officio support: Chris Symonds

MND Advisors & NDIS Support Coordinators

Jacqui Holland - Phone: 1800 806 632 (message)

Email: jholland@mnd.asn.au

Support Service

MND Tasmania and MND Victoria work together to provide the MND Advisor service which 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
- Coordination of supports for NDIS participants
- Assistive technology support
- 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
- 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 a MND 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 tell us your stories! Send them to the Editor at our postal or email address. The deadline for the next issue is 26 April 2019.