



July - August 2018

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MND Tasmania 1986-2018: *supporting people living with MND in Tasmania for 32 years*

MND WEEK

Sunday May 6th to Saturday May 12th

Thank you to all our generous fundraisers who shook the tin and sold our sought-after merchandise (especially the new beanies and caps) throughout MND Week this year. It was great to see all the familiar faces but was also just as inspiring to see a few new faces out there this year, raising awareness and making a difference. This year we were able to fund raise for the entire week (although the weather cut us short a few days) which allowed for greater flexibility for volunteers. We covered Burnie,



Ulverstone, Devonport, Hobart City, Kingston, Lindisfarne, Rosny and raised a massive \$7500.

It was also exciting to hear of all the conversations had during the week, awareness for MND is growing and people were really interested to learn how MND Tasmania supports our community.

Did you see our advertisement for MND Week on the TV? A copy has been placed on our FB page if you missed it. Thank you once again to the crew at Southern Cross who continue their long-term support of our cause by assigning prime time placements of our ad free of charge.



If you know anyone living in the Launceston area or surrounds let them know we are already working to recruit for next year, so drop us a line and learn how you can help out.

Stick Fishing Trip

The annual TJM Burnie Stick Competition was held on the 2nd June, and this year it was opened up for public attendance. Over 47 anglers fished Macintosh Dam in Tullah, as always it involved some serious fishing mixed with a fair bit of shenanigans, whilst raising money for a cause close to Shane’s heart. Huge thankyou to Shane who organises this event each year and all his sponsors and supporters who made this day such a huge success. \$1430 has been received from their wonderful effort.

Entertainment Books

Please help us to promote the sale of the Entertainment Books. For each book sold we receive 20% of the cost, so far this year we have raised over \$800. Visit our Facebook or Website for the link to get yours today:

<https://www.entertainmentbook.com.au/orderbooks/24004m3>

Global Awareness Day

Every year the International Alliance of ALS/MND Associations marks 21 June as the global day of recognition of ALS/MND – a disease that affects over 400,000 of the world’s population, and kills over 100,000 people every year.

This year the lovely Wendy Roberts organised to occupy some prime real estate in the popular Huonville shopping centre and continued her efforts

to raise the profile of this hideous disease and the lasting impact it has on so many lives. We thank Wendy, and all that helped out or bought merchandise or a raffle ticket. \$800 was received that will go towards making a difference in someone’s life that has been impacted by MND.



Walk to D’feet MND

Save the date: Sunday 21st October, 2018
Athletic Centre – Queens Domain Hobart



Walk or run, merchandise sales, face painting and other activities for the kids. BBQ and the best raffle going around!! Lots of fun for the family whilst raising awareness and funds for MND. Please tell all your friends to save the date, our mycause page will be

ready for registrations very soon!!

If you would like to be on the fundraising committee for this event or would like to organise your own event, please get in touch by dropping me a line at fundraising@mndatas.asn.au

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 community. #togetherwecan

Michelle Macpherson, Fundraising Coordinator

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 and our NDIS Coordinator of Supports. Board members may also be contacted. The contact details are on the back page. 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 John Case and Graham Crooks and of any other members who have recently passed away. Donations have been gratefully received in the memory of John and Graham.

Donations

Thank you to those members and donors who have noticed that our Newsletter cover sheet and donation form is now an MND Tasmania one and have been returning the form with a donation. Some have also noticed that the annual Christmas and tax appeals have been changed to be specific to MND Tasmania. Thank you for your donations.

Some may also have noticed that we have been having glitches with mailing lists – thank you for your patience and understanding as we work through the issues.

The names of the donors are familiar to some of us

on the Board who have been around for a while – names of relatives of recent members as well as from way back. We always find it poignant, moving and motivating to see many of the same names who continue to donate to support the association over the years. Remembered. Not forgotten.

The Hobart Friendly Society Foundation has donated \$10,000 per year for 3 years to assist in the provision of equipment for our members. We really appreciate their support.

Thank you Julie!



(Julie pictured left at MND Tasmania 30 year AGM)

MND Tasmania has had a Memorandum of Understanding with MND Victoria since 2007 to provide services for people with MND in Tasmania. The services have been continuously refined during this time. The MND Advisor role has been implemented in most states and territories in Australia and is regarded in the world-wide MND/ALS community as world's best practice. Just imagine how good it would be if we were well funded!

For the past 10 years, Julie McConnell has been the Manager of Support Services in MND Victoria. In this role she has supported the MND Advisors in Tasmania, managed the service provision for our member clients and ensured that our Advisor is registered to provide support coordination for the members who are eligible to be NDIS participants. She has visited us regularly for evening and weekend meetings (as the Board members have day time jobs) and has always been prompt, helpful, informative, sensible and supportive when we have phoned or emailed her for information or advice. Since July 16, Julie has had a month to work together with Jo Whitehouse who has been appointed to replace her.

We thank Julie for the excellent work she has done for people with MND in Tasmania and we wish her well as she embarks on this next big change in her life.

MND Advisor's Report

Hi all, I thought I'd take some time to talk about the valuable role occupational therapists play in the care team of people living with MND.



Occupational therapists can, amongst other things, assess and advise on

- helping people to continue to do what's important to them, whether that's things around the home, or leisure activities such as golf or fishing,
- modifying your home environment if needed to make doing things easier,
- help you with posture and positioning to increase physical comfort,
- help with ideas to manage fatigue and conserve of energy,
- use of adaptive equipment.

Equipment may include aids to support personal care, posture and mobility. This may include specialist head and neck supports, seating and wheelchairs, switches and other devices for accessing computers and using environmental control systems.

If you think a referral to an Occupational Therapist may be useful for you please get in touch.

Best wishes, Hayley

0412599365 / htistram@mnd.asn.au

Information

Genetic testing and support

Following the Australian Story episode on ABC TV about Associate Professor Justin Yerbury in March, we received some queries about MND and genetic testing. The Tasmanian Clinical Genetics Service (TCGS) is a Public Health Service with access criteria and is staffed by Genetic Counsellors who are based at the Royal Hobart Hospital and by Clinical Geneticists contracted from the Royal Children's

Hospital and the Peter MacCallum Hospital in Melbourne, who visit Tasmania to conduct monthly clinics in conjunction with the Genetic Counsellors. It can be accessed by a referral from a GP or Neurologist. For more information visit

http://www.dhhs.tas.gov.au/service_information/services_files/RHH/treatments_and_services/genetic_counselling

Difficulty turning in bed?

Different fabrics such as satin can help and can be purchased in local stores. A specially designed product from Queensland is the WonderSheet and further information can be obtained at www.thewondersheet.com or phone 07 5591 1629 . (This information is not an endorsement.)

9th National MND Conference

Informing Influencing Innovating

For all those who have MND or have an interest in MND

Friday 31 August 2018

Hotel Grand Chancellor, Adelaide

For information and registration -

Phone 02 8287 4940

Email: info@mndaust.asn.au

www.mndaust.asn.au/national-conference

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. The next meetings are planned for 7 August, 4 September, 2 October, 6 November.

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

Client survey report

The members of MND Tasmania living with MND and Kennedy's disease were sent the MND Tasmania Client Survey in January. The key purpose of the survey is to collect information from people who use the services provided by MND Tasmania with MND Victoria in order to inform us on how to deliver the best possible services to people living with MND in Tasmania.

38 surveys were sent and 13 (34.2%) were returned.

Most respondents rated their 'overall satisfaction' with the Everything Within Information Kit and Care Contacts booklet as 'very good' or 'excellent'.

4 or less respondents did not know of the MND Tasmania website, Facebook page, MND Advisor service or Equipment funding support. If you would like information on these resources, please contact the MND Victoria office (contact details on the back page).

The Board of MND Tasmania was very pleased to read that there was a very high (80%) level of satisfaction with the MND Advisor service. 11 respondents were 'satisfied' with the frequency of contact with the MND Advisor and 2 were 'not satisfied'. As this vital service is funded by donations, the ongoing importance of every hour and every dollar donated to MND Tasmania should not be taken for granted.

As the written comments in reply to two of the questions may resonate with some members, we have listed them for your information and consideration. If they raise any questions for you, please contact Hayley Tristram, MND Advisor.

Q./ What was the most valuable aspect of your contact with MND Tasmania/Victoria?

A./ "Having someone to talk to about any problems and being really helpful in general"

"Visits from Hayley the MND Advisor"

"Receiving a motorised wheelchair"

"Knowing there were many others out there sharing the same journey with MND"

"Learning about the services available for MND patients"

"Knowing someone is always there to help and prompt to do so"

"Receiving the MND Victoria newsletter"

"Understanding and support and knowledge of what is happening re medical advancement etc."

"Support and understanding"

"Gaining support in many ways early on (e.g. linking to Calvary Health Care Bethlehem)"

"General information of services available."

Q./ What was the least valuable aspect of your contact with MND Tasmania/Victoria?

A./ "MND Vic/Tas were not informed in the correct process therefore help came very late"

"Sometimes miscommunication with MND Vic in regards to being unaware of Tasmanian events"

"Excluding equipment donations, the meeting of mental/emotional needs allowing what remains of life to be more enjoyable. Information overload and lack of assistance in navigating the system. District nursing and home hospice were our saviours."

Q./ Are there any other comments/suggestions you would like to make?

A./ "Wonderful association, keep up the good work"

"The word 'disease' in MND should be replaced by the word 'disability' "

"No, I don't think it would make any difference"

"Just that MND Victoria/Tasmania are providing a wonderful service to all who need them as far as I can see and they need to be supported in return. THANK YOU"

"Good having a Tassie based support person."

Many people are disadvantaged by limited access to internet based electronic technologies. 8 of the 13 respondents wrote that they were 'extremely likely' to use email, Skype and Facebook to access online MND Tasmania/Victoria services/resources but 7 were 'not likely' or 'never' to use these modalities.

10 respondents were 'highly' or 'extremely likely' to recommend MND Tasmania/Victoria to a friend or colleague.

Thank you to all who sent in their opinions!

Our vision – a world without MND : care to cure.

HELP NEEDED!

MND Tasmania Newsletter Editor

If you enjoy writing, reading and collating, would you please consider this vital role?

It involves about 3-4 hours every 2 months while being part of a team of people who want to make a difference for people living with MND in Tasmania. Information and contributions are collated and a draft document and attachments are sent to Heidi at the MND Victoria office 6 times a year. Heidi puts it all into Publisher and turns it into this colourful Newsletter which forms an archived history of MND Tasmania on our website. You will be coached, supported and assisted by the current editor and other members of the Board as needed.

If you think you could help in this way, please email Joyce Schuringa at info@mndatas.asn.au

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 23 August 2018.



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: Kate Todd

Treasurer: Julie Driessen

Public Officer: Shane Chugg

Fundraising: Michelle Macpherson

Logistics: Dr Andrew Moy

Ex-officio support: Chris Symonds



MND Advisor (& NDIS

Coordinator of Supports)

Hayley Tristram

phone 0412 599 365

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

coordination of supports for NDIS participants who have MND or Kennedy's disease

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.