



## MND TASMANIA NEWS | September-October 2019

### FUND-RAISING AND AWARENESS-BUILDING STATE CINEMA – LATE NIGHT

What a great turnout we had at the opening of “Late Night”. A light-hearted comedy giving a glimpse of the behind the scenes of an American late night talk show. With about 150 attendees we raised around \$1500. Thank you to John and the crew at the State Cinema for generously providing this opportunity to MND Tasmania. Also, a big thank you to all those that came along and made the night such a success. All monies raised go towards vital care and equipment as well as funding research. **#togetherwecan**

### GENERATION NETBALL CLUB

Bring back the Ice Bucket Challenge!!



Well that was the message the Generation Netball Club sent when they held their fundraiser in late July. Coaches and players registered, gained sponsors and rallied together to raise funds for MND Tasmania and show support for one of their local families who are currently living with MND. Special thanks go out to Narelle and Ian Cameron for organising this event. Our very own Chris Symonds was on hand at the annual club dinner on the 21st September and was presented with the money raised from their collective efforts. Thank you to Generation Netball Club for being so caring and helping us to help others. That ice pool looks freezing!!

### #nevergiveup



## BIRTHDAY FUNDRAISERS

Raising money to help find a cure and care for those currently affected by MND is always a very kind gesture. BUT asking friends and relatives to donate to a cause that is close to your heart instead of buying you a present on your birthday is totally selfless. We say a huge thank you to Abbie Ferrall and Holly Townsend who have both recently held a FaceBook Birthday fundraiser raising in excess of \$1000. Happy Birthday to Abbie and Holly from all of us here at MND Tasmania.

If you would like to know more about running a birthday fundraiser please contact [fundraising@mndtas.asn.au](mailto:fundraising@mndtas.asn.au)

#loveandbekind

## DEVONPORT RACE CLUB

A Father's Day lunch and fundraiser was held on Sunday September 1 in Spreyton. One of the local trainers is currently fighting MND and they really wanted to do something to take us a step closer to finding a cure. Chris Symonds (MND Board Member) gave a presentation to those that attended which included talking about the role of the MND Tasmania Association. The Club ran a raffle raising \$500 for the cause and sold MND Tasmania merchandise to raise funds and awareness. Thank you to all involved. #caretocure



## WALK TO D'FEET MND

If you haven't already registered there is still time – Sunday, October 20

The Athletics Centre on the Queens Domain will again turn into a sea of blue as a sign that we will never give up until a cure is found. The Walk will commence at 10am with face painting, games and crafts available for the kids and the big kids at heart. BBQ available and lots more. Please show your support by showing up.

<https://www.mycause.com.au/events/walktodfeetmndtasmania>



**Thank you to all who have generously donated over the last couple of months. As we do not receive government assistance to provide the vital care and services needed by those living with MND your support means everything. THANK YOU**

## 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 the back page. 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 family and friends of Karine Radcliffe, Derek Bailey and of other members who have recently passed away.

## DONATIONS

Thank you to members and other supporters who have sent a donation on line or after receiving a newsletter.

In addition to the donors mentioned in the Fundraising report, we really appreciate the donations deposited or sent in by others including the many who support and donate via the North West Tasmania MND Support Group. These funds enable MND Tasmania to continue to provide practical care for people with MND and their families in Tasmania.

## MND ADVISORS

The Statewide MND Advisor service commenced in 2007 and has been one staff member working at 0.4 FTE (fulltime equivalent). In March this year it was increased to two staff positions with an increase of time to 1.2 FTE. Since that time we have been working to fill these positions with appropriately qualified staff.

We are pleased that Jenny Fuller has joined us in July and she is based in Hobart. We have been working hard to recruit the best person to be our Advisor who is based in Northern Tasmania and will keep you informed.

### JENNY FULLER, MND ADVISOR:

I am very pleased to introduce myself as the new MND Advisor and Support Coordinator for Southern Tasmania. I have been interested in MND for many years, through meeting people living with the disease when I was the Coordinator for Hospice volunteers based here in Hobart. I learned then how important it is to work collaboratively with a team of people to get the best support and care to suit each person who is living with MND, their families and friends.

As well as coordinating and training hospice volunteers I have also worked as an educator in palliative care related subjects and most recently I was the team leader for the activities program in a residential aged care facility.

My first few weeks in this new job have been spent building up my networks of contacts among service providers and health professionals. I am getting to grips with the systems, (NDIS and My Aged Care) and have been gradually meeting with MNDAT members to assist them with accessing services.

I look forward to meeting more of you, hearing your



stories, learning what you need and finding the best ways to support you. My working days are Monday, Tuesday and Wednesday. Please feel free to give me a call 0412 599 365 or send me an email: [jfuller@mnd.asn.au](mailto:jfuller@mnd.asn.au)

## VITAL STATISTICS

Annual data from the State and Territory MND associations is collected by MND Australia.

The data collected from MND Tasmania during July 1 2018 – June 30 2019 revealed the following information:

### MEMBERS

There were 66 members of MND Tasmania at 30 June. (We are a small bunch of people!)

### MEMBERS WITH MND

40 members of the Association had MND at 30 June. (So there were 26 members who joined to support people with MND).

16 new members with MND joined the Association during the year.

18 members who had MND died during the year.

Of the 40 members who had MND at 30 June -

- 16 were aged 64 or younger and were thus eligible to be participants of NDIS. 3 of these had their NDIS Plan while the other 13 were awaiting a Plan and the access to services funded by NDIS.
- 24 were 65 or older and therefore were not eligible to access the funding for services available through NDIS. (Hence MND Australia's Make Aged Care Fair campaign – see below.)
- 7 were living in a residential aged care facility.

### VOLUNTEERS

Over 40 volunteers supported MND Tasmania with specific tasks during the year.

380 people attended the two Walk to D'feet MND events in Hobart and Ulverstone.

### EQUIPMENT

There are 41 items of communication equipment in the MND Tasmania Communication Equipment Library managed by the Independent Living Centre (ILC) based in Launceston.

25 items of all types of equipment and home modifications were partly or fully funded by MND Tasmania for 24 members with MND.

## ADVOCACY

### MAKE AGED CARE FAIR

People who are diagnosed with MND at 65 and over do not have access to the same level of funding for supports and services as those who are under 65.

**You can see how this affects our members with MND in the statistics above – 16 or 40% of the 40 members with MND were not eligible for NDIS funding or its equivalent for the services that they needed.**

**We don't think this is fair.**

MND Australia and MND Victoria staff have been meeting on our behalf with politicians in Canberra to advocate for us on this issue.

Please join MND Australia's Make Aged Care Fair Campaign to inform your local politicians of your opinion about this inequity. Help us to make sure that everyone who has MND has access to the right care at the time when they need it in the right place and irrespective of age.

Tasmanian Senator Richard Colbeck is the Australian Minister for Aged Care and Senior Australians and Tasmanian Julie Collins MHR is the Shadow Minister for Ageing and Seniors.

For more information, please visit:

**[www.mndaction.org.au](http://www.mndaction.org.au)** phone

1800 777 175

## IMPORTANT DATES!

**1-6 December 2019:** 30th International Symposium on ALS/MND in Perth, WA. For information: **[www.mndaust.asn.au](http://www.mndaust.asn.au)** or **[www.symposium.mndassociation.org](http://www.symposium.mndassociation.org)**

**15 March 2020:** MND Tasmania AGM, Devonport. Watch this space!

**March 2020:** MND Tasmania Health Professional Forum, Hobart. Watch this space!

or **[www.mndaust.asn.au/Influencing\\_policy/MND Action](http://www.mndaust.asn.au/Influencing_policy/MND_Action)** or **[/How to influence government policy](#)**).

## NATIONAL DISABILITY INSURANCE SCHEME (NDIS)

The NDIS is a source of funding for private health and community services for people with disabilities who are younger than 65 when diagnosed. It is still a new system and access to appropriate services for people with MND have been seriously disrupted and delayed as a result.

People who are NDIS participants can no longer access most State government allied health and community services including equipment but they are now eligible to receive funding to access services in the private sector.

However, the private health and disability sector in Tasmania is small and people with MND are currently experiencing delays which are usually longer than those encountered when they could access the State government health and community services. Even when allocated funding by the NDIS, they are often unable to find suitable service providers in the private sector who will assist them.

While these 'thin markets' in the health, community and disability private sector in Tasmania are now being researched by the NDIS five years after its introduction (*continue reading p.5*)

## HELP NEEDED!

### What are your plans for 2020?

Do you enjoy reading, collating, writing? Would you like to have a vital role for MND? The editing of our newsletters involves about 3-4 hours every 2 months and being part of a team of people who want to make a difference for people living with MND in Tasmania.

A draft document is sent to Heidi at the MND Victoria office 6 times a year. She turns it into a colourful Newsletter which forms an archived history of MND Tasmania on our website and in the State Library.

You will be coached, supported and assisted by the committed members of the MND Tasmania Board. If you think you could help in this way, please email the Editor at **[info@mndatas.asn.au](mailto:info@mndatas.asn.au)**

(from p. 4) into our State, people who have MND and their families are often waiting for appropriate services for too long.

MND is a disease where immediate, well-informed and targeted assistance is required. Delays cause heightened distress and reduce the capacity of the person with MND to function independently for as long as possible. Our MND Advisors assist people with MND and their families to navigate the health, community, disability, residential and aged care sectors rapidly as the needs are immediate. People with MND are now meeting unprecedented delays, blocks and discrimination due to their funding category.

The MND Advisor service in Tasmania has been doubled this year due to the increased workload caused by NDIS and the consequential removal of access to Tasmanian government services for people younger than 65 years old. Our MND Advisors in each State are working hard to support people with MND who are trying to get funding from the NDIS for the services they need urgently. We are educating and providing information to the health professionals and other service providers who lack knowledge about MND.

Staff from MND Australia and the State MND associations have been meeting with the NDIS staff and politicians in Canberra and Tasmania to address these issues. We expect that the NDIS will improve and eventually there will hopefully be adequate allied health and other service providers to provide the services required.

Until that occurs, we request that all people who have been diagnosed with MND in Tasmania be given access to Tasmanian government health and community services including occupational therapy, physiotherapy, speech pathology, social work, orthotic and respiratory services and equipment from TasEquip irrespective of their age.

Please join us in informing your local politicians of your opinion about the disruption people with MND are experiencing due to the NDIS. Help us to make sure that everyone who has MND has access to the right care at the time when they need it in the right place and irrespective of age. Please inform your local politicians about the unacceptable and traumatic delays experienced by people who have MND – your Federal Member of the House of Representatives or Senator and also at a State level, Roger Jaensch, Tasmanian Minister for Disability Services and Community Development and Sarah Courtney, Tasmanian Minister for Health.

## PALLIATIVE CARE

During the extensive changes occurring in the disability and aged care funded services, palliative care services have continued to be there for people with MND as they have been for over 20 years. As stated in the MND Tasmania Newsletter of March-April 2017, “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.” ([www.mndatas.asn.au/newsletters](http://www.mndatas.asn.au/newsletters))

This care is optimised by early referral from the GP so that people with MND can access the allied health professionals, doctors, nurses, volunteers, equipment and other supports offered by the palliative care teams.

Palliative care services have evolved differently in each of the three health regions in Tasmania with consequential strengths and also inequities.

Lionel Bonde and the North  
West Tasmania MND  
Support

**WALK TO D'FEET MND – SUNDAY, 20 OCTOBER 2019!**



Group have been busy advocating for better palliative care inpatient services in the North West of the state and MND Tasmania and Palliative Care Tasmania work together to advocate for improved services for people with MND.

## NORTH WEST TASMANIA MND 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:** October 1; November 12 (NOTE CHANGE OF DATE AS ROOM NOT AVAILABLE ON THE 5TH); December 3; NO meeting in January; February 4; March 3.

**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](mailto:info@mndatas.asn.au)

## MND TASMANIA LEGGINGS!

New MND Tasmania Never Give Up leggings available in black 3/4 or full length style, womens sizes 8-18.

Contact: [fundraising@mndatas.asn.au](mailto:fundraising@mndatas.asn.au) to order yours today!



## 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](mailto:info@mndatas.asn.au)

Website: [www.mndatas.asn.au](http://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

President: Joyce Schuringa

Vice-President: Michelle Macpherson

Secretary: Kate Todd

Treasurer: Julie Driessen

Public Officer: Andrew Moy

Fundraising: Michelle Macpherson

Equipment: Libby Cohen

NWSG: Chris Symonds

## MND ADVISORS & NDIS SUPPORT COORDINATORS

Northern Tasmania, phone: 1800 806 632 (message)

Southern Tasmania, Jenny Fuller: 0412 599 365 or email: [jfuller@mnd.asn.au](mailto:jfuller@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 25 October 2019.