



November - December 2018

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# MND Tasmania 1986-2018:

supporting people living with MND in Tasmania for 32 years

## Walk to D'feet MND 2018

*Sunday 21st October – Queens Domain Hobart*

This day always comes with mixed emotions for many – the memories of a loved one's life cut short from this wretched disease or the callous reality of having a loved one fighting the battle today makes this day enormously tough. It is therefore somewhat overwhelming and incredibly humbling for the organisers to see so many in attendance on the day and an even larger group of people in the background supporting those who could be there. And WOW what a day we had! The weather was perfect, the venue ideal and it was an awe-inspiring sight as 200 individuals took to the track wearing blue to complete the Walk.



It was encouraging to hear Dr Catherine Blizzard from the Menzies Institute of Medical Research talk about how finally momentum has gathered and research in this area is gaining the attention and appropriate funding, which is mandatory in discovering suitable treatments, and of course the ultimate outcome, a cure. If you would like to learn more of the work Dr Blizzard and the Menzies Institute are undertaking please visit <http://www.menzies.utas.edu.au/>



We had the usual fun with face-painting, zorb balls and other games but the addition of the Bunnings craft tent seemed to be a hit with the younger crowd, with many donning hand-made blue crowns for the day. Our lovely face-painter Jen also put her skills to the test with her first cornflower design.

Our major raffle was drawn on the day and all winners have been notified. You can find a full list of prizes and winners on our Facebook page. (cont. on page 5)

## 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 two 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 Adrian Bonde, John Case, Andrew Nicholls, Stephen Grove, Christine Boulter, Leigh Talbot and of any other members who have recently passed away. Donations have been gratefully received in the memory of Christine, John and Leigh.

## Donations

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

Any funds sent to MND Victoria and marked as being for MND Tasmania are transferred to us.

We are a small association with a volunteer Board and we don't employ any staff. However, we have a Memorandum of Understanding with MND Victoria and they assist us with administration, donor management, publication of our newsletter and they employ the MND Advisors and manage the MND Advisor service on our behalf in Tasmania.

Your support and donations enable MND Tasmania to continue to provide practical care for people with MND and their families in Tasmania.

## MND Advisors

Hi everyone, as we near the end of 2018, it's good to see that from January 2019, the rollout of NDIS in Tasmania will finally be complete. It's been a very long wait for some. That means anyone under 65 living with MND is eligible to apply for supports via NDIS.

MND Victoria are registered to provide Support



Coordination in Tasmania. The role of a Support Coordinator is to help you navigate NDIS and access services. There are many organisations who offer Support Coordination. If you do choose someone other than MND Tasmania in partnership with MND Victoria as your support coordinator, you will still have access to specialist MND information and support via the Information and Resourcing Team based in Melbourne, but will no longer be able to directly access the services of the MND Advisor and Support Coordinator.

If you'd like some information as to how this might work for you, how to register with NDIS, or some support at a meeting with an NDIS representative, please get in touch.

Best wishes, Hayley, MND Advisor and Support Coordinator 0412 599 365 / htristram@mnd.asn.au

## Other news from the Support Services Team

### New MND Advisor and Support Coordinator

As mentioned in the last newsletter, we have been in the process of recruiting a new part time MND Advisor and Support Coordinator who will be based in Hobart. We are really pleased to announce that Jacqui Holland has accepted the position and will commence the role on 14 February 2019!

We currently have 42 registered clients in Tasmania –

- **North region – 11**
- **North-west – 14**
- **South -17**

It will be fabulous to have an Advisor based in the south to work collaboratively with Hayley who is based in Launceston. From January, people aged 50 to 64 will phase into the NDIS which we anticipate will increase the workload considerably.

## Health Professional Forum - SAVE THE DATE!!

We are pleased to announce that a forum will be held in Launceston in March next year.

- **Date: Friday 1 March 2019**
- **Venue: Launceston Conference Centre**
- **Theme: 'Navigating MND: Charting a course for health professionals'**

More information to follow in the next newsletter!

**Jo Whitehouse, Manager Support Services**

## 9th National MND Conference

### Informing Influencing Innovating

The 9th National MND Australia Conference was held in Adelaide on Friday 31st August, hosted by MND Australia and MND South Australia. The theme of Informing, Influencing and Innovating covered a broad array of topics included MND Care, NDIS, Research and Technology. Each presentation reinforced the promotion of better outcomes for people living with MND in Australia.

The Conference allowed attendees to network, share and develop, both on a professional and supportive level. Presenters ranged from academics to clinicians working in rural and regional centres to people with MND. Over 200 people attended and for us MND Tasmania volunteers, it was a fantastic opportunity to meet delegates from varying backgrounds, including health and community support networks.

At the beginning of the day, we heard two keynote speakers who have MND and each gave their outlook on the disease and the impact it has on their lives. They were both enlightening and moving.



Several presentations discussed the importance of a palliative approach to care which is integrated into the care plan from diagnosis. This multi-disciplinary team assists in ensuring a client's medical, emotional, social and psychological needs are addressed right from the start.

Two presenters discussed the importance of identifying and addressing the mental health needs of the clients and carers and for a greater emphasis on bereavement services. Assessment tools are available to health professionals to enable early identification of the psycho-social needs of clients, their families and carers.

Throughout the conference there was emphasis on the work of multi-disciplinary teams. Samantha Mitchell from Goulburn Valley Health described new

initiatives of their multi-disciplinary team. These included conducting regular family meeting with relevant service providers, improved links with Calvary Health Care Bethlehem, development of MND Checklist Form which can be completed by any member of the team. Where beneficial this service also uses joint appointments for the client with clinicians from more than one discipline which reduces the number of appointments for the person with MND and can optimize problem solving for the best outcome.

Sarah Solomon, OT Calvary Healthcare Bethlehem, discussed the best practice model of providing OT care and interventions for people living with MND. Her presentation emphasized that clients with MND require flexible, responsive and ongoing OT input. Sarah's role extends to offering advice and support to community OTs who may have little or no experience with MND.

The presentation on 'The impact of assistive technology on Quality of Life' highlighted the benefits that advances in assistive technology provide to people with MND. Even though there is a decline in physical function the level of independence may not change when assistive technology bridges the gap.

The rollout of the NDIS has resulted in many health services becoming registered NDIS service providers. Previous models of service delivery have been modified to fit with the NDIS as well as continuing to provide best practice services to their non-NDIS clients. MND NSW has engaged with the NDIS over the past five years. Now a NDIS provider, MND NSW supports and resources clients through the NDIS pre-planning/planning for improved outcomes. MND NSW manages a very comprehensive equipment loan scheme, FlexEquip, to support both NDIS and non-NDIS clients. This model may be adopted by other State MND associations.

Development of "I have MND. Now What?" provides an excellent online reference guide for the person with MND. This guide was developed in response to a client asking just that – 'I have MND. Now What?' It involved a collaboration across different teams, disciplines and organisations – as well as the client. While the reference list is specific to NSW, ACT and NT at present, the aim is to adapt it to fit the other States of Australia. It is on the MND NSW website.

The conference closed with the final keynote speaker, Dr Shyuan Ngo, who discussed advances in research. Dr Ngo's work has appeared in recent MND Newsletters across Australia and her particular focus in recent times has been on MND and Appetite. Dr Ngo stated that the study of MND is unique in comparison to other medical research in that it focuses on understanding why cells die rather than why cells grow (as in cancer, etc). Dr Ngo told us about Project MinE which is a worldwide project looking to map the DNA of at least 15,000 people with MND and 7,500 control subjects in order to better understand MND. Through studying this bank of DNA there are a range of discoveries being made which are informing the way we understand MND. If these scientists can find out why and how MND develops, they can work to develop a cure.

Memorable conference quotes :

- I may have MND – but MND doesn't have me.
- Don't count the days – make the days count.

Further information about the proceedings of the Conference can be found on the MND Australia website at [www.mndaust.asn.au/national-conference/](http://www.mndaust.asn.au/national-conference/) Libby Cohen, Vice-president, Kate Todd, Secretary Julie Driessen, Treasurer

## Equipment

People who have MND discover a rapid change in their need for assistive technology which is often complex, unexpected, expensive and previously unheard of. This includes modifications to the home and to their vehicle or a new vehicle. A tangible use of the funds donated for our members with MND is the assistance we can provide with the provision of such equipment. All assistive technology prescription and supply is managed by the MND Advisor and the referring health professional.

Thank you to our fundraisers and donors who have provided the money for these services when gaps in government funding would result in otherwise unmet need.

## Newsletter Editor

**HELP NEEDED! What are your plans for 2019? 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)

## Mental Health Week – Stronger Together 2018

The Neurological Alliance of Tasmania (NAT) which includes MND Tasmania was fortunate to be successful in obtaining a small grant from the Mental Health Council of Tasmania to run an event to raise awareness of mental health issues for people with neurological conditions. This year's theme was 'Stronger Together' which NAT thought fits perfectly with the strong relationship between the organisations within the Alliance. Mental Health Week in Tasmania is part of a national mental health promotion campaign held in October each year and incorporates World Mental Health Day. The purpose of this awareness week is to engage communities in activities that promote mental health and wellbeing and to raise awareness and understanding about mental illness and how it impacts on the lives of people in our community.

NAT hosted a panel event on 11th October in Bellerive where audience members could ask questions. Panellists were: Dr Cynthia Honan (Neuropsychologist), Dr Helen Castley (Neurologist) and Assoc. Professor Des Graham (MSL board member and person with MS). Research indicates that people who live with a neurological or progressive neuromuscular condition are more likely to develop a mental health condition than the general population.

***Please remember, if you or a loved one are struggling at all, there are multiple numbers and people to contact – Lifeline 13 11 14, Suicide Call-back Service 1300 659 467, Beyond Blue 1300 22 4636, MND Victoria 1800 806 632, Mental Health Services Helpline (Statewide 24 hours/7 days) 1800 332 388.***



Skyline Roofing and Michael O'Keefe Photography for their generous support of Walk to d'Feet MND #2018. Organisation of this event is getting easier, but it is still a big job for just a few people, so we are on the hunt for volunteers to assist with preparations in the lead up Walk to d'Feet MND #2019. If you can spare some time and are interested, please contact us fundraising@mndatas.asn.au



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 MND Advisors, qualified health and community care professionals with extensive knowledge and experience related to MND.

This service delivery is considered as world's best practice and in partnership with MND Victoria, we are the only organisation to offer this service in Tasmania. Our combined efforts for this year's Walk saw us raise a whopping \$47,207.40. In real terms this equates to having an MND Advisor in the field helping individuals and their families living with MND for approximately 7 months! To all the individuals and businesses that attended, donated, bought a raffle ticket, a piece of merchandise, had their child's face painted - the Board of MND Tasmania sincerely thanks you for your contribution. YOUR generosity has made this possible and allows us to provide the care required until a cure is found. #togetherwecan



(from page 1) Thank you to everyone who purchased a ticket and also to all the wonderful businesses that donated prizes – it really was quite an impressive raffle! We would like to extend special thanks to our major sponsors - Blundstone Australia, Elite Appliances,



## Northwest Support Group Report

One of our member's son-in-law passed away due to MND during the year and several of our members with MND are experiencing a decline in their health. We are sending our thoughts to them.

We have had great attendances for our meeting each month, with several new members who have MND and their families attending. Our group gave a donation of \$150.00 to each member who has MND to use as they wish. Donation boxes are placed in Ulverstone, Devonport, Somerset and in the Camdale. We have been blessed to receive a total of \$450.95 from these boxes and we thank the businesses and sports club that have accepted our boxes. We had a successful barbecue at Bunnings where we sold \$811.35 of sausages and received several donations - thank you to all involved.

We are looking forward to our Walk to D'feet MND in Ulverstone on 3rd March next year along the beautiful Leven River and Parks in Ulverstone. Please keep this date free.

We thank all who make the time to come to our meetings. Thanks all our guest speakers who gave their time to attend our meeting and to the Ulverstone Returned Servicemen's Club for the free use of their rooms.

We wish for a cure to be found ASAP and Blessings to all for a peaceful and healthy Christmas. See you all in the New Year :

**WHEN:** The first Tuesday in every month at 10.30 a.m. Next meetings: February 5, March 5.

**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)

## Save these dates – March 2019

*More details will be in February's Newsletter*

**Friday, March 1 - Tasmanian MND Conference, Launceston**

**Sunday, March 3 – Walk to D'feet MND, Ulverstone**

**Sunday March 17 – MND Tasmania AGM, Hobart**

## 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: 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 and Support Coordinator

Hayley Tristram, Phone 0412 599 365

Email: [htristram@mnd.asn.au](mailto: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.

## 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 31 December 2018.

