



## MND TASMANIA NEWS | November-December 2019

### FUND-RAISING AND AWARENESS-BUILDING

#### WALK TO D'FEET MND – HOBART

Another fabulous morning was had as around **200 walkers** gathered at the Athletics Track on the Queens Domain on **Sunday 20 October** for our third **Hobart Walk**. In typical Tassie style the weather threatened to storm over quite early, followed by a few gusts of wind that saw some of us using our bodies to shield paperwork and merchandise from blowing away and then just like that the skies cleared and we were able to enjoy the mornings activities.

Our wonderful Mr Peter Gee was on hand to keep us motivated and entertained as we circled the track and he even pulled in some surprise guests, being the Bawdy Panto who gave us a taste of what to expect in their upcoming show **Wuss in Boots**.

On the serious side we were able to hear from **Associate Professor Tracey Dickson** from the **Menzies Centre** on the work that is conducted on a daily basis. It was encouraging to hear that the extra injection of funding to find a cure for MND is making a difference and they truly believe that some form of treatment is not that far away.



**Jenny Fuller** one of our very own MND Advisors was there on the day and spoke about the role of an MND Advisor and how they work with and for those affected by MND. We are so fortunate to be able to hear first-hand from our local experts.

The kids enjoyed face painting, crafts and the various games and we think everyone had a good morning. If you have any suggestions for what you would like to hear or see at one of these events please make sure you email us: [fundraising@mndatas.asn.au](mailto:fundraising@mndatas.asn.au)

We say a big thank you to all our Sponsors, as the day would not have been such a success without them.

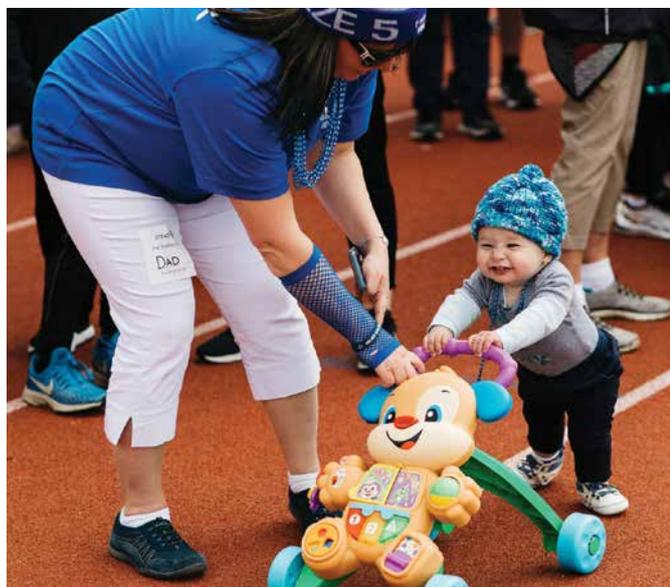
**Blundstone Australia; The Woolstore; Michael O'Keefe Photography; Pennicott Adventures; Tyre Power; Hill Street Grocer; Bream Creek Winery; Savoy Baths;**

**Tahune Airwalk; Fullers Bookshop; Daci and Daci; Zoo Doo; Anytime Fitness; Running Edge; ColesMyer; Shambles; Fragments; At 11 Accommodation; Wrest Point; I'm back Catering; Ben Dilger Photography; Small Prints; Silver Pet Print; Bunnings Hardware.**



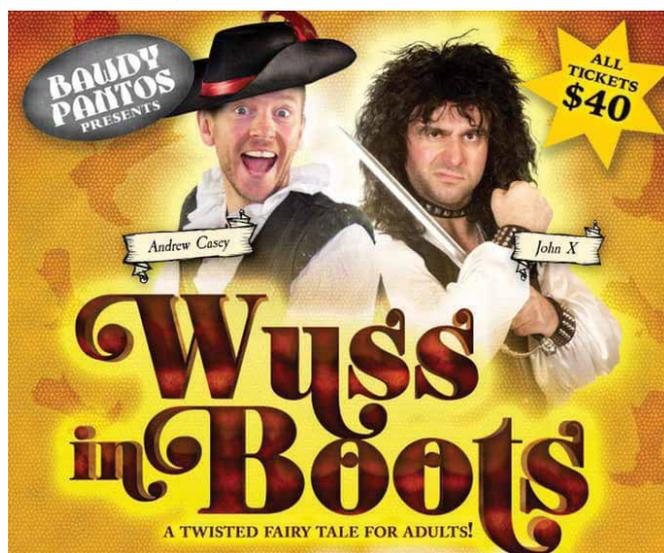
And finally, we say a massive THANK YOU to all our supporters who donated, fundraised or attended Walk to d'Feet. **Another mighty effort totalling \$25, 157.45**

I feel I'm extremely lucky, as in my volunteer role with MND it has me working with some amazingly generous people and I get to hear beautiful stories of the care, support and respect that people have for one another. Recently one of these stories involved the Valern Hotel in Moonah and the publican Steve. Apparently, Steve thought it would be a good idea to don himself a mankini and plunge himself into a kid sized ice pool to raise funds for the Walk whilst supporting one of the hotels social club members who has been affected by MND. It seems Steve was right, it was a great idea as the Valern Hotel made a very generous \$1000 donation – thank you Steve & Co. I hope that story made you smile as much as it did me – by the way I got to see the photos!!



## WUSS IN BOOTS

The Bawdy Panto will be performing Wuss in Boots (a twisted fairy tale for adults) at the Theatre Royal from Wednesday November 20 to Saturday 23. This will be a veritable “who’s that” of Tasmanian celebrities helping to raise funds for Motor Neurone Disease Research. If you are tired of political correctness, this is just the show for you! Tickets are \$40 and can be purchased online from the Theatre Royal or phone 6146 3300.



## GIN FOR A CAUSE

**It's happening!!**

We are very happy to say that we now have available a limited run of McHenry's Classic Gin available for purchase. MND Tasmania and the team at McHenry's have joined forces to raise awareness and funds as we work towards a world without MND.

**700ml Classic Dry Gin – citrus peel** is present and balanced with a small amount of star anise, coriander seeds, cardamom and orris root all beautifully balanced with the juniper.

Grab a bottle or two now by visiting:

**[www.mchenrydistillery.com.au/shop/mnd-tasmania-gin-for-a-cause](http://www.mchenrydistillery.com.au/shop/mnd-tasmania-gin-for-a-cause) ... the perfect gift for yourself or even a Christmas present for a loved one!**



## SAVE THE DATE IN 2020

- **January 17—Blue Moon Ball (South)**
- **March 1—Walk to d’Feet MND North West Coast (Ulverstone)**
- **May 3—First Walk to d’Feet MND North (Launceston)**
- **May 3 to 9—MND Week (State-wide)**
- **June 21—MND Global Day**
- **October 18—Walk to d’Feet MND (South (Hobart))**

Thank you to all who have generously donated over the last couple of months. MND Tasmania relies heavily on the generosity and efforts of the community to assist us in raising much needed funds and awareness for our specialised care and support services for those living with Motor Neurone Disease. THANK YOU!

## RESEARCH

### 30<sup>TH</sup> INTERNATIONAL SYMPOSIUM ON ALS/MND, 4-6 DECEMBER 2019, PERTH, WA



When you receive this newsletter, the Symposium will be (almost) over. The world's ALS/MND research, care and support community who attends this annual event is quite unique because it is relatively small, very interconnected and focussed on improving the outlook and care for people who have MND and their families.

Every year for 30 years, in a different country every year, people who have MND, carers, families and service providers have met up alongside researchers working in laboratories and out in the field. They include researchers and practitioners in disciplines including genetics, neuroscience, technology, biochemistry, epidemiology, psychology, occupational therapy, palliative care and nutrition who are working in universities, primary health practices, hospitals, disability services, nursing, allied

health and MND advocacy and support organisations such as ours.

The MND Tasmania president, secretary and treasurer attended the meetings held on the weekend of 1-3 December before the Symposium which were of most relevance to our roles. These were the Allied Health Professional forum, the Connect meeting (= Ask the Experts), the International Alliance of ALS/MND Associations AGM and annual meeting and the MND Australia Board meeting and AGM.

## MND TASMANIA RESEARCH TRAVEL GRANTS

MND Tasmania awarded its first ever MND Research Travel Grants to 3 Tasmanian researchers at the Menzies Institute, UTAS to assist them to present their research at the Symposium. Our aim was to assist new MND researchers to present their research in a prestigious international forum and to mingle with the larger ALS/MND world community to inform, motivate and assist them to plan their future careers.



The grants were awarded to **Laura Reale** and **Courtney Clark** who are Honours graduates and **Marcus Dyer** who is a PhD candidate and who was also awarded a MND Australia Scholarship in 2019. They are working in the Menzies Institute's Neurodegenerative Disease and Trauma Group led by Professor Tracey Dickson.

Joyce Schuringa (MND Tasmania president) awarded the grant certificates at a morning tea with 10 members of the Group at the Menzies Institute on a lovely spring morning in September.

As many of those present had received funding from MND Australia during their careers, they knew Janet Nash who has recently retired as Executive Officer of the MND Research Institute after 15 years of strong and innovative leadership. They discussed the memorable

Ice Bucket challenge of 2014 and how it dramatically raised the awareness of MND in the community. One of Janet's memorable quotes was also discussed in the context of the role of MND Tasmania, current research and the recent changes in services for people with MND in Australia -

*"Without awareness there is no funding.*

*Without funding there is no research.*

*Without research there is no effective treatment.*

*Without effective treatment there is no hope.*

*We all need to work together to  
make sure we can provide that hope."*

(Janet Nash MND Australia MND blog September 2019)



## NEW RESEARCH GRANT

We congratulate Associate Professor Anna King and her team at the Wicking Centre, UTAS as she secured a large Fight MND grant in September to lead a pre-clinical trial of a new drug in the fight against MND.

*"But trying to find a cure for MND has given  
me something to focus on and  
be positive about.  
An opportunity."*

## IMPORTANT DATES!

**15 March 2020:** MND Tasmania AGM, paranapple Convention Centre, 137 Rooke St., Devonport.

**27 March 2020:** MND Tasmania Health Professional Forum, Hobart. Tell your health professionals & support workers about the Forum and encourage them to join our email list for updates: [info@mnd.asn.au](mailto:info@mnd.asn.au)

(Neale Daniher, Sunday HeraldSun 10/09/2016)

## 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 Danny Reardon and of any other members who have recently passed away.

## DONATIONS

Thank you to members and other supporters who have sent us donations. As we are dependent on donations to operate as an association and to provide the MND Advisor service, they enable MND Tasmania to continue to provide practical care for people with MND and their families in Tasmania.

## 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 the MND Victoria office 6 times a year. They turn 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)

## WHAT IS PALLIATIVE CARE?

**At Palliative Care Tasmania (PCT), we often get asked questions like 'what is palliative care?' 'When can I access palliative care?' And 'isn't palliative care only for people in their last few weeks of life?'**

Through this article, we are going to address those palliative care myths and tell you a little more about what palliative care can offer for people living with MND.

Firstly, palliative care focuses on providing the best quality of life for anyone of any age, with a life-limiting condition. It identifies and treats a person's physical, emotional, spiritual and social needs. Essentially it creates a full 360-degree circle of support around a person diagnosed with an illness like MND.

Incredibly, palliative care can be provided at home, hospital, in an aged care facility or anywhere you live. The team of carers might include your GP, aged care worker, community nurses, hospital, after-hours services, pharmacist, allied health services, social worker, pastoral care, volunteers and family and friends. There are often many people that play an important role in someone's palliative care journey and therefore have a significant impact on that person's quality of life.

Palliative care further focuses on a person's individual goals and needs by managing their pain and symptoms, whilst providing social, emotional and spiritual support, and physical comfort and resources to enable you to live as fully as possible with your illness.

Undoubtedly, one of the most important things to know about palliative care for people with MND, is that it can be accessed in many ways from the moment you are diagnosed. It then forms part of your treatment plan in an effort to provide stability and continuity at an otherwise

uncertain time of your life. We fully encourage people to seek out palliative care options and services as soon as possible, as this can make a huge difference to how you live with MND.

In summary, as the peak body for palliative care in the state, we advise you to have the conversations early about what support and services are in your local area that you can access from the moment you are diagnosed with MND. Your GP or treating physician is a really great place to start, as well as attending one of our education sessions where we cover a range of topics on palliative care and the palliative approach.

For more information on local palliative care services in your area and our education sessions, please go to [pallcasetas.org.au](http://pallcasetas.org.au) or phone **6231 2799** – we are more than happy to help and provide advice where possible.

## 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:** 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, phone: 1800 806 632 (message) or email [info@mndatas.asn.au](mailto:info@mndatas.asn.au)

**WALK TO D'FEET MND ON 1 MARCH IN ULVERSTONE AND 3 MAY IN LAUNCESTON!**

NEVER  
GIVE  
UP

NEVER  
GIVE  
UP

NEVER  
GIVE  
UP

## MND ADVISOR & SUPPORT COORDINATOR SERVICE

The MND Tasmania MND Advisor & Support Coordinator service is fully staffed!!

**Emma Wilkinson-Reed** (photo top right) joined **Jenny Fuller** (photo bottom right), our Advisor based in Hobart to complete the Tassie team on the 14th October and has been starting to get to know the clients in the North and North West regions of Tasmania.

Emma is a registered nurse who has been working at the Launceston General Hospital for the last few years and has had experience of supporting people with MND in her nursing role. Emma has an office in Launceston. We are thrilled to have staff located in both the southern and north/northwest regions.

They are being supported by Eric Kelly, MND Advisor & Support Coordinator Team Leader who is based in Victoria, but is visiting Tasmania regularly to support Emma and Jenny.

### CLIENT NUMBERS:

We currently have 31 registered clients in Tasmania –

North region—11

North-west—11

South—9

## 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.



### CONTACT DETAILS:

**Emma**, (Mon to Thurs) email: [ewilkinson-reed@mnd.asn.au](mailto:ewilkinson-reed@mnd.asn.au)

or phone: 0456 182 551

**Jenny**, (Mon to Wed) email:

[jfuller@mnd.asn.au](mailto:jfuller@mnd.asn.au)

or phone: 0412 599 365

**Eric**, email: [ekelly@mnd.asn.au](mailto:ekelly@mnd.asn.au)

or phone: 0421 323 850

## MND HEALTH PROFESSIONAL FORUM —SAVE THE DATE!!

We are pleased to announce that a forum will be held in **Hobart** on **Friday 27th March 2020**. Venue and theme to be confirmed. More information to follow in the next newsletter!

*Jo Whitehouse*

*Manager Support Services*

*Ph: 0402 183 140*



### 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, Emma Wilkinson-Reed: 0456 182 551, [ewilkinson-reed@mnd.asn.au](mailto:ewilkinson-reed@mnd.asn.au)

Southern Tasmania, Jenny Fuller: 0412 599 365, [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 20 December 2019.