



September - October 2017

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## MND Tasmania 1986-2017: *supporting people living with MND in Tasmania for 31 years*

### Advocacy

**State-wide Neurology Services:** The MND Tasmania Board wrote to the Minister for Health Michael Ferguson MHA on 10 July 2017 to express the Association's disappointment that "Dr Kurien Koshy will be leaving Tasmania without the seamless appointment of a replacement Neurologist." We requested that the Tasmanian Health Service (THS) "acts promptly to address the chronic inequities of access to Neurology services in Tasmania with a system that is sustainable, effective and equitable."

A letter of acknowledgement was received from the Minister's office and the President followed up on this by attending the Minister's Public Forum in Hobart on 27 July. She discussed the issue with Michael Ferguson personally before the meeting then during the Forum, questioned the Minister on the THS plans for Neurology services and Neurology multidisciplinary clinics in North and North-West Tasmania.

In addition, MND Tasmania is a member of the Neurological Alliance of Tasmania (NAT) which has been proactively in contact with the Ministers for Health and Disability services about this issue since Dr Andrew Churchyard died over a year ago. NAT President Debra Byrne also had an opinion piece about this issue published in The Examiner in July and spoke about it on ABC TV.

**Neurological Nurses:** NAT successfully lobbied for specialist neurological community nurses to support people with neurological diseases in Tasmania resulting in three positions being in place in the health regions of the time since 2011. This was a new service which is unique to Tasmania and is cited as 'best practice' by neurological support

groups in other States. However, the nurses' time has largely been allocated to the backlog and current needs of the many people living with Parkinson's disease. At the time, the Board of MND Tasmania thought that the MND Advisor role would be addressed by these nurses but as that has not been the case, the MND Advisor role has been continuously in place since 2007.

**MND Advisor:** This role has provided data on the amount of met and unmet need of people who have MND and their families in Tasmania. It has been funded since 2007 by grants, philanthropic funds and donations from MND Victoria and MND Tasmania. Our Board has established a Care Foundation to underpin ongoing funding for this role. As our Association is run by volunteers, we are grateful for the support of the Council and staff of MND Victoria who assist with the ongoing applications for grants to assist in the funding of this role and specific complementary projects to support people with MND in Tasmania, their families and their health and support workers.

**Legislative Council Inquiry into acute health services in Tasmania:** NAT has submitted a paper to this Inquiry and MND Tasmania has contributed case studies to illustrate how the issues affect people living with MND requiring hospital services. Details may not be released until after the Inquiry so watch this space.

### Fund-Raising and Awareness-Building

#### MANKINI KING

You may recall from the last newsletter the pledge of Robert Button to run from Rosebery to Boat Harbour in a mankini to raise funds for MND.

With over 800 followers on Facebook and a goal of

\$5000 Robert set out in the cold and dark at around 5am on the 10<sup>th</sup> August in his blue mankini. Unfortunately for Robert not too far into his journey his hip started to give him trouble but this did not stop him from completing 70km on the first day! It was fantastic to see the support from the local communities as Robert and his support crew passed through – from the ladies at the Tullah Café to Highclere Roadhouse, it is the kindness shown by yourselves that really does make our world a better place.

It was a very emotional finish to Roberts run on the 3<sup>rd</sup> day as he crossed the finish line to see his good mate and inspiration for this run, Kirk Dicker waiting for him. For anyone watching the live stream I'm guessing there wasn't a dry eye in the house...well there certainly wasn't at mine. Robert smashed his goal of \$5000 by raising well in excess of \$8000 and just as importantly the awareness that was raised through this cheeky campaign is invaluable. The MND community THANK-YOU Robert and all your support crew for the wonderful job you all did! #togetherwecan



### LAUNCESTON LADIES CHOIR

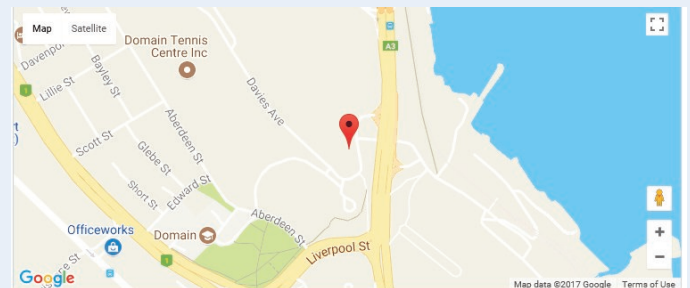
The annual choir event was held at the Launceston South Uniting Church on Sunday the 27<sup>th</sup> August. With guest speaker Guy Barnett and guest artists Jane Forrest, Choir for Seniors and Harmonia the day was enjoyed by all who attended. A donation from the proceeds raised on the day will be made to MND Research which will bring us one step closer to a world without MND. We thank you Launceston Ladies Choir for your support.

### WALK TO D'FEET MND

**Organising is coming along well for our first Walk to d'Feet on Sunday 29<sup>th</sup> October.** Robin Barnes along with Lauren Spilsbury have continued to work hard to make this day a success. At the end of August 2 major sponsors had been secured—Blundstone Australia, who picked up our Platinum level package and also generously gave a donation of 4 pairs of Blundstone Boots. Skyline Roofing & Sheetmetal located in Invermay came on board by big-heartedly selecting the Gold package. We have also had vouchers donated from taste.walk.talk, Fullers Bookshop, The Woolstore and Rebel Sports for our raffle, it is great to see local businesses recognising the importance of our cause. A HUGE thank you to all the businesses that have supported us - without you this event simply wouldn't happen.

We need as many people as possible to come along and help make this day a success so please pass the word around and encourage all family, friends, neighbours, work colleagues to come along and share in a morning of fun whilst raising awareness and funds to support Tasmanians living with MND. You should find a registration form accompanying your newsletter this month so please get this back to us as soon as you can or go straight to the online registration page at <http://www.mycause.com.au/events/walktodfeetmndtasmania>

Look forward to seeing you all there!



### ENTERTAINMENT BOOKS

Thank you to everyone that bought books through our fundraiser this year and special thanks to Café 176 for promoting the fundraiser instore. Together we raised nearly \$1000.

### RIDGLEY BIG FREEZE FUNDRAISER



On Sunday 16<sup>th</sup> July about sixty participants were sent down a waterslide into an icy bath, in a bid to raise funds for MND research and support. Entertainment including a jumping castle, face painting, raffles, a chocolate wheel and a bbq ensured the day was enjoyed by everyone with a massive 10,000 raised. Well done Michele McCulloch and crew on such a successful day!

If you have an idea for a fundraiser or would like to organise a fundraising event please contact us at [info@mndatas.asn.au](mailto:info@mndatas.asn.au) or message us on Facebook as we would love to hear about it.

**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 or any member of the MND Tasmania Board. The contact details are on page 4 of this Newsletter. 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 Michael Walsh and of our other members who have recently passed away. Donations have been gratefully received in the memory of Pedro Reyes and Michael Walsh.

## Donations

In addition to the donors mentioned in the Fundraising report, we were grateful to receive donations from the Rocky Cape Lions Club and Blundstone Australia.

## MND Advisor

Hi everyone, this month we have had multidisciplinary MND team meetings in each of the three regions of the state.

These are a great way for me to stay in touch with the changing staff who are working with people with MND and their families and carers. Its so much easier for us all to get on the phone and stay in touch if we know more about how we all work. I think, for our size, Tasmania “punches above its weight” (to use a dubious boxing analogy!) where care for people with MND is concerned, and that’s thanks to our committed and professional health professionals in the state. For those of you who aren’t aware, people from Tasmania can and do access the services of the Specialist Neurological Services based at Calvary Health Care Bethlehem in Caulfield in Melbourne. Here you can access a one stop shop specialist, multidisciplinary neurological team, who will then work with your local team here in Tasmania. Face to face visits are supplemented by phone or skype conversations and for many people in Tasmania this works very well. For more information about this service, or anything else you may need, please don’t hesitate to get in touch.

Best wishes, Hayley 0412599365 / htistram@mnd.asn.au

## Para World Sailing

Hayley Tristram, the MND Advisor for Tasmania, asked for me to share the recent experience I had in Germany at the Para World Sailing Championships. Firstly I must point out that I have Kennedys Disease (KD) not MND. KD, which has similar symptoms to MND, but slower progression, is supported by the MND Association here in Australia. I sincerely thank the MND Association for this support. Symptoms of KD caused me to cease full time work in 2010. Since then I have and continue to modify my home to make it safe and accessible for future needs. We are fortunate to live by the sea in Wynyard on the NW coast of

Tasmania where my wife Fayellen and I raised four wonderful children. My 88 year old mum lives nearby and we also care for her to live independently in her home as is her wish.

One of the things I am passionate about is sailing and mentoring youth and others with disabilities through the Sailability program run by the Wynyard Yacht Club (WYC). I have sailed all my life, mainly racing but owned a trailer-sailer for 23 years which we, as family, cruised many waterways in Tasmania. With the progressive effects of KD I became unable to climb into, change sides or start the small outboard of our trailer-sailer, so in 2014 I decided to change to a more accessible class of yacht. This yacht is called the Hansa 303, a small one or two person yacht that allows me to compete equally against able bodied sailors.

WYC now has five of these yachts and they are used for Sailability and racing. Last year 350 people were involved in WYC Sailability program. Sailability is an international program first introduced to Australia in the 1990s and is now available in every state. Although only a small regional club of 80 members, WYC has won many national awards for its diverse and inclusive programs, including 2015 Australian Sailing Club of the Year, Australian Sports Commissions Community Club of the Year and a finalist in the 2016 National Disability Awards. My journey (along with my coach and support person Mike Darby) in the Hansa 303 has allowed me to travel to Netherlands in June 2016, where we won the Open (for all abilities) Hansa 303 Singles World Championships and runner up Open World Champion in the doubles division. At Easter 2017 we travelled to Geelong and won the Open Asia Pacific Championships and Open Australian Championships in singles and again runner up in the doubles.

Just last month we have returned from my first Para Sailing World Championships, where we won silver in the Hansa 303 male singles. It was an amazing regatta to attend at Kiel in Germany where 1800 yachts and 4000 sailors were competing in 20 different classes of yachts. The Para Worlds were held in conjunction with the Olympic classes and is the world’s largest sailing regatta. To be amongst them and to share the same stage was special.

Before the regatta started all Para competitors were subject to a classification process by two doctors who assessed disability. My classification was a 3 .5 out of 7,



with seven being the least disability allowed to compete. The Hansa 303 I sailed in was one of 32 identical leased yachts competing in the regatta. So competency was all up to the sailors' skill and ability to handle the yachts in a wide range of conditions. We started the nine race regatta well with early wins, but stronger winds with a maximum wind range of 28 knots on the last days, cost me places due to limited strength. I was so pleased to finish in second place to Poland. Twenty five countries were represented in the Hansa 303 five day regatta. It was an honour to sail against a large fleet of Para Olympic sailors. In 2018. Mike and I hope to travel to Japan and possibly the US to attend future regattas.

I wanted to specifically thank my support team, because without them I would not be able to get onto the water to achieve these results. Special thanks to my team at Calvary Health Care Bethlehem and MND Tasmania for its ongoing support. I also want to hopefully inspire others. Even with KD symptoms where I cannot walk 10 meters unaided, with the right support and determination, I can still travel, compete and be successful against the best sailors in the world.

**By Chris Symonds**

## Communication Equipment

An agreement between MND Tasmania and Fight MND has enabled the purchase of a range of 'Assistive Technology equipment for communication'. The Independent Living Centre Tasmania (ILC Tas) has assisted with the equipment purchase and will administer this specialised service. New equipment available includes voice amplifiers and high end communication systems with different mouse controls such as eye control, head control and switch accessible. Members whose communication would be enhanced by such assistive technology will be referred to the ILC team by their Speech Pathologist. They will work together to assess needs, trial communication systems and organise a loan from the library. The main office of ILC Tas is in Launceston and the service provided is Statewide. If you need to know more contact Hayley Tristram our MND Advisor. This new service has been made possible with a donation of \$50,000 from Fight MND.

## Northern Support Group

This Group is currently in recess until further notice. The contact person is Libby Cohen who may be contacted at 1800 806 632 (message) or email [info@mndatas.asn.au](mailto:info@mndatas.asn.au).

## Northwest Support Group

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

**WHEN:** The first Tuesday in every month at 10a.m. The next meeting is planned for 7 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](mailto: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](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.

It is a member of MND Australia and of the Neurological Alliance of Tasmania.

### Board

President: Joyce Schuringa

Vice-President: Libby Cohen

Secretary: Michele Newton

Treasurer: Helen Fleming

Fundraising: Michelle Macpherson

Equipment: Libby Cohen

IT support: Shane Chugg

Governance: William Maguire

Ex-officio wisdom: John Hughes OAM

### MND Advisor

Hayley Tristram, 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 News Tasmania

Please tell us your stories! Send them to the Editor at our postal or email address. The deadline for the next issue is 20 October 2017.

