



July - August 2017

M
N
D

T
A
S
M
A
N
I
A

N
E
W
S

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

Care and Cure, Support and Fight

The focus on curing and fighting MND in the past three years has given us who live with MND a boost of hope. Whilst having this beacon of hope, we still need care and support.

MND Tasmania has been providing care and support to people who have MND and their families in Tasmania for over thirty years.

During the past ten years, MND Tasmania has received generous donations from people and organisations from Tasmania, interstate and overseas. We have used these funds to -

- Fund the care, support, advocacy, education and referral service of the MND Advisor;
- Contribute to the cost of equipment and home modifications for members who have MND;
- Advocate and lobby so that there are now three Neurological Nurses working in the community as part of the Tasmanian Health Service;
- Lobby for better Neurology services in North and NorthWest Tasmania;
- Inform government, health professionals, GP's and medical specialists, health and disability services about the urgent needs of people diagnosed with MND and how to provide best practice for all aspect of MND care;
- Provide accurate up to date information and education about MND and best practice management through annual Statewide Health Professional forums;
- Send annual donations to the Motor Neurone Disease Research Institute of Australia (MNDRIA) for MND research;
- Inform NDIS and My Aged Care about the specific best practice care required for people diagnosed with MND;

- Link the Tasmanian MND community together - members, supporters, fundraisers, researchers, health workers, volunteers;
- Work together with MND Victoria to provide services for people with MND in Tasmania.

We are a bunch of volunteers. All of our lives have been changed by MND. We work together to care and support. We are dependent on each other.

Our hope is the cure. We fight together to increase the profile, funding, spending and targeting of research into the cure for MND.

The MND associations in Australia established the Motor Neurone Disease Research Institute of Australia (MNDRIA) in 1984. Since then the Institute has born and bred, nurtured and grown MND researchers in Australia and in the world. There are now over 100 well credentialed Australian researchers focussed on MND.

The fantastic huge funding boost for research through the Ice Bucket Challenge in 2014 and from the Cure MND Foundation and FightMND this year has been able to build on this foundation of nurture and growth. Read about this at www.mndresearch.org.au

Our objective—With the support of the MND and broader community, MND Tasmania will care, support and fight ... until and after there is a cure.

Fund-Raising and Awareness-Building

MND Week: May 7 - 13 2017

The Upchurch and Hughes families along with the continued support of the students from Brendan-Shaw College had tins shaking and awareness being raised in and around Ulverstone and Devonport whilst the Hobart area was covered by the Macpherson and Collins families and their helpers.

Merchandise boxes were prominent in several locations and through the generosity of NAB donation boxes were placed in several of their branches. Our sincere thanks to all with efforts raising just on \$4000.



Photo: John & Nancy Hughes with Brendon-Shaw College students

Guy Barnett continued his support of MND Tasmania by presenting a Motion in Parliament during MND Week. All politicians wore their cornflowers to help raise awareness.



Jenny Jarrett held a very successful Fashion Parade during MND Week where approximately 130 women attended a night of entertainment at the Taroona Bowls Club.

The Club very generously waived their hiring fee for this event and the barman donated his time. The evening kicked off with a lively performance of Cuban Salsa dancing, which was enjoyed by all. Fashions were provided by Capri Body and Sotto Boutique which are located in the upper level Centrepont, Hobart. Models for the evening consisted of friends and family, who graced the catwalk like professionals, most of whom enjoying the experience of the catwalk for the first time. Models provided much entertainment with their 'laissez-faire' attitude, causing much laughter from the enthusiastic, fun crowd! The owner of Capri Body and Sotto Boutique, Sandra Jones, provided a commentary on the fashions, also generously donating 10% of sales on the night to MND.

Talented Melbourne singer Emily Jarrett [Photo, right], provided additional entertainment singing and playing guitar, as well as modelling.

Organiser Jenny Jarrett from Sandy Bay, spoke about the devastating effects of Motor Neurone Disease, and how it affected her family when her husband, the late Eric Jarrett, (formerly from Geeveston) was diagnosed with the insidious, cruel disease.

Eric [Photo, right] was an elite sportsman representing

Australia in several world triathlons, his last world triathlon was in Budapest, 2010. Eric had intended to travel to New Zealand for another world event, representing his country in September 2012, when tragically he was involved in a horrific cycling accident, lucky to survive. Only a few months after the accident, and not fully recovered, he planned to compete in a big event in Devonport. Such was his drive and determination to succeed.



On April 25, Anzac Day 2013, they received the devastating news that Eric had MND and was given an estimated three to five years to live. As Eric was rapidly declining, a family holiday ensued to Cairns. Soon after arrival, Eric was admitted to hospital with clots in his lungs. After a rather anxious couple of weeks, the family finally arrived home. Adult children Emily, Tegan and Lewis put their jobs on hold to come home and assist with the care and support of their much loved and adored father.



Sadly, six months after receiving the diagnosis Eric passed away. Jenny and her small team of helpers were overwhelmed with the support received. A huge thankyou goes out to all who helped with the organisation, the donation of prizes, and all the amazing individuals who attended the event. \$4,500 was raised on the night and continues to grow over \$5,000, boosted by \$600 donation from 'Little bird' dance school.

Thank you, Jenny for your amazing talent on organising such a successful event and for sharing your very personal and difficult story to help raise awareness.

Entertainment Books

Sales of the Entertainment Books continue which is not that surprising as they are jammed packed with value – sales to date have raised well over \$700. If you haven't got yours yet visit <https://www.entertainmentbook.com.au/orderbooks/24004m3> or visit our website or Facebook page and click on the link to pick up either a digital or book membership.

Fishing Competition

Another great event was held during May where "Sling" supported his good mate "Stig" who is living with MND by continuing the legacy of the Tasmanian Trout Classic Fishing competition that "Stig" began several years back. Fishing Lake Mackintosh on the west coast an amount of

\$450 was raised for MND Tasmania and from the looks of the photo's a little bit of shenanigans may have gone on.

Photo: Trout fishing for MND!



EXCITING NEWS! SAVE THE DATE



Sunday 29th October will see Tasmania's first **Walk to D'Feet** be held at the Queens Domain Athletics Ground in Hobart. Thanks to Robin Barnes and her small team for working so hard to make this happen. More information about the day will be posted on our website and Facebook pages in the weeks to come.

Inner Wheel Club of Hobart Sunset

What a wonderful surprise when the Inner Wheel Club rang to say that they had chosen MND Tas to receive a donation of \$1500. The beginnings of Inner Wheel can be traced back to Chicago where the first club was formed in 1905, spreading to other countries quickly. Australia's first club was formed in 1931 and they now have coverage nation-wide. Supported by a membership of 4000 women, their aim is to work together to improve the lives of others. Thankyou Inner Wheel for selecting us to be a beneficiary of your hard work.

Mankini King

Keep your eyes open (or maybe just one) on our Facebook page to follow the journey of Robert Button and his mankini run where he will be fundraising for MND Tasmania. The run will be in August (when snow is more than just a possibility) starting from Rosebery on the West Coast and finishing in Boat Harbour. Good luck Robert!

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 Mark Hill and of our other members who have recently passed away.

Donations have been gratefully received in the memory of Mark Hill, Susan Bester and Millie Hudson.

Donations

In addition to the donors mentioned in the Fundraising report, we were grateful to receive donations from organisations including the Lions Club of Wynyard, the Federal Group and the Catholic Archdiocese of Hobart. Also, MND Victoria has received a grant from Perpetual Philanthropic Services to assist with the operation of the MND Tasmania MND Advisor service.

Communication equipment

A collaborative agreement between MND Tasmania and the Cure MND Foundation 'Fight MND' will significantly improve access to essential communication equipment for members. 'Fight MND' has donated \$50,000 for the purchase of a range of Assistive Technology equipment for communication assessment, trial and loan. The Independent Living Centre Tasmania (ILC Tas) will administer this service. Members may be referred to the ILC team by their Speech Pathologist. If you need to know more contact Hayley Tristram our MND Advisor (contact details on page 4). There will be progress updates as the scheme is rolled out.

Thank you to 'Fight MND' and all the hard-working donors in Tasmania who have enabled this new service, with a special mention to the 2016 Tassie Freeze MND Ball committee.

MND Advisor

Hi everyone, I hope you've all managed to stay warm this winter. I believe in some parts of Australia it's been the coldest for 100 years!

In June, it was great to see MND the focus of two lectures in Launceston delivered by Professor Matthew Kiernan, one aimed at health professionals and one at the public. It's great to see other health professionals in the state carrying the torch for greater awareness of MND. Unfortunately, it was not possible to record these lectures as I had hoped.

Other good news is the establishment of the North West Tasmania MND Support Group, a great grass roots community effort.



This last couple of months, I've been helping more people than ever navigate their way through systems such as My Aged Care to access the support they need. It seems that attempts to centralise and streamline these support system have not quite been achieved and for many it is more complex and confusing than ever before!

Please feel free to get in touch if you are struggling getting access to what you need, or indeed if there's anything else you might need assistance with.

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

Help Wanted! MND Tasmania Newsletter Editor

If you enjoy writing, reading, collating, just fiddling about with letters and words on your screen, would you please consider this useful task?

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

If you think you might be able to help us in this way, please email Joyce Schuringa at info@mndatas.asn.au

Northern Support Group

The Northern Support Group invites all members and supporters of MND Tasmania to its meetings. The Ravenswood facility is comfortable and suitable to use as a stopover venue for a day trip.

WHEN: Monday 25 September 2017 from 11a.m. to 1p.m. NOTE: This will be the final meeting for the year.

WHERE: The Ravenswood Community Health Centre, 39 – 41 Lambert St., Ravenswood (excellent accessible comfortable facilities and parking).

The contact person for this group is Libby Cohen who may be contacted at 1800 806 632 (message) or email info@mndatas.asn.au.

NWSG = 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 5 September.

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

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: 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: htistram@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 30 August 2017.