



MND TASMANIA NEWS | July-August 2019

MND WEEK

People with motor neurone disease (MND) who are older face long waiting lists for disability care that meets their needs, and in some cases, are dying before they receive help.

Research shows that 50% of people with MND are diagnosed when aged 65 and over. But due to their age, they do not have access to the NDIS and have to rely on Aged Care services for their disability care and support. This often means they are pushed into financial hardship and have to depend on their family to meet their care needs. "Aged Care services are designed for people who are frail-aged or experiencing dementia. The system doesn't work for someone with a progressing neurological condition like MND. It doesn't come anywhere near to meeting their complex disability needs," says Carol Birks, CEO of MND Australia.

"The waiting lists for Aged Care services are really long. MND often progresses rapidly and some people die before they get to the top of the list,"

MND Australia believes everyone with MND deserves access to the care and support they need, regardless of

their age, and the focus Australia wide this MND Week was to have this message heard loud and clear.

We were very fortunate this year to have so many people all around the State volunteer their time to help us raise awareness and "shake the tins" to raise much needed funds to help those currently battling this beast, to live better for longer. Freedom Fitness at New Norfolk, Brighton Bowls Club and St Johns Hospital staff all held their own awareness events to help make the week a great success. We extend our thanks to all our supporters throughout MND Week, without YOU we couldn't deliver the critical services and care that we do.



#spreadtheword #makeagedcarefair #caretocure



LINGS FISHING TRIP

The annual TJM Burnie Stick Competition was held during June and we were grateful to receive a donation of \$1500 from this event. Each year a group of guys congregate on Macintosh Dam in Tullah to have a fun weekend fishing, whilst furthering awareness and raising funds for a serious cause, that's close to the heart of the organiser, Shane (aka Sling). After Gary (aka Stig), a good mate of Shanes was diagnosed with MND, Shane says he was determined to raise awareness for this awful disease. Three years later this event just keeps getting bigger and better. Thank you to sponsors and donors who help make his event so successful. A special thank you to Shane for your continued support.



TAYLORED HAIR

Thank you to the Meaghan and her team at Taylored Hair in Sorell who for the month of June promoted the work of MND Tasmania and sold our merchandise to raise funds to assist those living with MND.

Do you own a business or know someone in your community who could promote an MND Tasmania fundraiser by selling merchandise within their business? Please contact fundraising@mndatas.asn.au to register your interest. #togetherwecan

ENTERTAINMENT BOOKS

Do you like to eat out? Would you like to save \$\$ whilst trying some new places or revisiting old favourites. With over \$20,000 worth of savings on offer in one book, the Entertainment Book is a great way to support MND Tasmania whilst doing the things you enjoy. To grab yours today visit our FB page or Website to find the link below: www.entertainmentbook.com.au/orderbooks/24004m3

PARKLAND HIGH SCHOOL

On June 14th these guys ran MND Awareness day, providing valuable information to their school community on this horrid disease and sold some of our merchandise to raise funds for the care of those currently affected. THANK YOU for your help Parkland High, much appreciation goes out to all involved. #raisingawareness

ROSEBAY HIGH SCHOOL

The Student Council of Rosebay High School ran a car wash to raise funds to assist MND Tasmania in providing care for those currently living with MND. We were told the students had heaps of fun. THANK YOU to all involved, we really appreciate our fundraisers and all that they do to help the cause. #fundraisingisfun

MERCHANDISE

It was fantastic to get the call for an order of 40 beanies from our long-time supporters Hash House Harriers! These guys have chosen us to be the recipient of fundraisers such as the Red Dress Full Moon Run (what a sight!) and special fundraising nights in the past. Purchasing and wearing our merchandise is a great way of showing your support – help spread the word! Message us at fundraising@mndatas.asn.au if you would like more information.

MY HERITAGE – SPECIAL EVENT

Author Minh Hien decided that 21 June, Motor Neurone Disease (MND) Global Day was the appropriate date for an event to honour the memory of her mother who sadly passed away as a result of MND 30 years ago. Held at Glebe Town Hall in Sydney, signed copies of Minhs' book, My Heritage were available for purchase. In honour of Kim Nga (Minh Hiên's mother and Ellyse and Emily's grandmother), they donated the gross proceeds of sales on the night to MND Association of Tasmania. Minh said "we have very fond memories of MND Association of Tasmania whose volunteers supported our mother/grandmother during the last three years of her life"

We were very humbled to receive these funds and would take to take the opportunity to thank those volunteers from 30 years ago for their impactful work. Thank you also to MNDNSW volunteer Amelia Brock who spoke on our behalf at this event, we also send Minh and her family a heartfelt thanks for their continued support 30 years on.

#nevergiveup

GIN FOR A CAUSE

As mentioned in our last newsletter we are putting the GIN in GINEROSITY. We have collaborated with Tasmania's McHenry's Distillery to bring you a bespoke bottle of their high-quality classic gin. Keep an eye on our FB page to grab your bottle or secure yours now by contacting us at fundraising@mndatas.asn.au

MND ADVISORS

I'm sorry that this will be my last article for the newsletter as I have resigned from the role of MND Advisor and Support Coordinator. During my time in the role I have been based in the south. I have really enjoyed meeting

so many of you and I am sorry that I have not had the opportunity to meet everyone. My last day was Wednesday 10th July.

I am pleased to be handing over to Jenny Fuller who comes with a wealth of experience working with people with MND. Jenny is starting on Monday 15th July. You will be able to contact Jenny on the same mobile phone number 0412 599 365. As always, there is also support available from the broader MND team on 1800 806 632.

I would like to acknowledge and thank the MND Tasmania Board and my colleagues at MND Vic for such great support during my time in the role. I wish you all well and hope that you enjoy working with Jenny.

Jacqui Holland

SUPPORT SERVICES

We are in the process of recruiting to the MND Advisor and Support Coordination role that is based in the north/northwest of the state and hope to have some further news to report in the next newsletter.

MND TASMANIA FINANCIAL REPORT

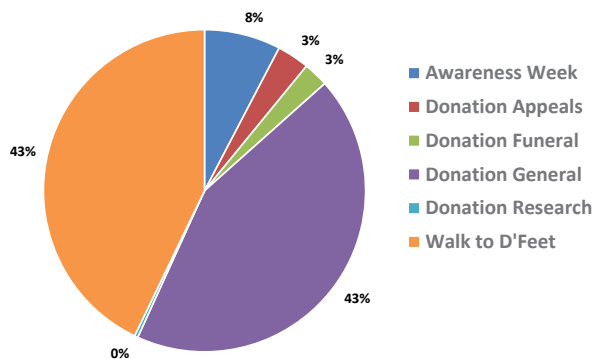
MND Tasmania is funded entirely by donations with no income from government. We have a volunteer Board and no staff. Our financial year is the calendar year and our AGM was held on March 17. The AGM and President's report are published in the May-June 2019 newsletter (available at www.mndatas.asn.au). Due to the lack of space in that issue, information about our finances was delayed until this newsletter.

Thanks to the generosity of many donors including MND Victoria, we posted a surplus of \$11,533 in 2018. This has enabled us to increase the size of the donation we have committed to MND Victoria for the MND Advisor service for 2019-2021. This service is operated on our behalf by MND Victoria through a Memorandum of Understanding. Income from government services such as NDIS and My Aged Care is expected to increase in the future but for the time being, the MND Advisor service will continue to run at a financial loss. Therefore our fundraising is vital in ensuring that our members can be assisted to find their way through the myriads of services that they will need at the rapid rate that MND dictates. We also provide funding

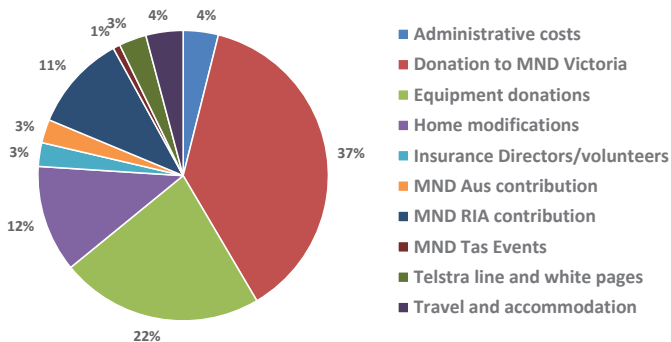
for our members to assist them with the purchase of assistive technology (AT) and home modifications.

The pie charts show the origins of the donations that support MND Tasmania and the allocation of these funds.

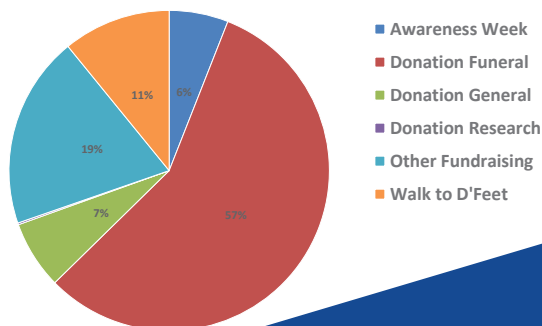
Income – Financial Year End 2018



Operating Expenses - Financial Year End 2018



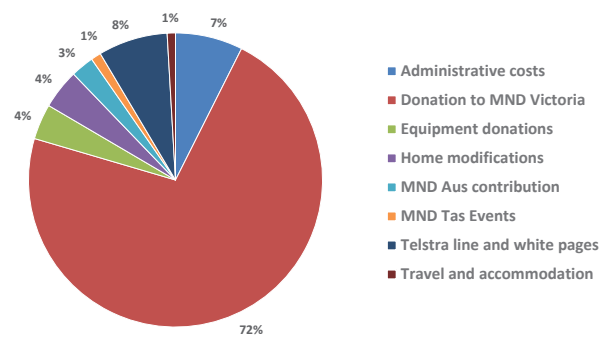
Income – 1/1/2019 – 17/6/2019



DONATIONS

Donations have been gratefully received in memory of Susan Bester. Thank you to members and other supporters who have sent a donation after receiving a newsletter or in response to the recent appeal letter. In addition to the donors mentioned in the Fundraising report, we really appreciate the donations deposited or sent in by others including the Lions Club of St Helens and the Marquis Hotel Motel. These funds enable MND Tasmania to continue to provide practical care for people with MND and their families in Tasmania.

Expenditure - 1/1/2019 – 17/6/2019



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 page 6. 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 Gisela Tauer, David Greenwood, Roy Barnes, Chris Shapter, David Flanagan, Brian Hardman, Mark Barrington, Wayne Fenton and any other members who have recently passed away.

WALK TO D'FEET MND SUNDAY, 20 OCTOBER!

Don't forget to mark it in your diary – Sunday, 20 October

It's starting again! Yep Walk to dFeet #03 is coming! Our mycause page is open so get in quick and register your team and start fundraising! We loved the t-shirts so much from last year that we have decided we will wear these again. We will still have the t-shirts available for early bird purchases (so get in quick if you don't have one) and for those that already have a t-shirt we will be gifting you an MND drink bottle to say thank you for your early registration, as this helps us plan for the day.

#walk2dfeet #beanearlybird

NORTH WEST TASMANIA MND SUPPORT GROUP

The NWSG lost three of our members just before the Walk to d'Feet MND held in Ulverstone in March. Our thoughts are with the families of Kerry Upchurch, Wendy Cox and Adrian Bonde. We will keep raising money until a cure is found for the beast of a disease.

We had a very successful first Walk raising \$12,381 for the MND Advisor support service. Thank you to all who helped make this a success and to those who walked, raised money, donated prizes. We have been asked by several participants if we are going to have another Walk next year.....

Our group welcomed two new members this year, Rhona and Greg. They both have MND.

We raised over \$1,920 from our boxes that we have around the North West Coast. Our group is grateful for the businesses that have our boxes on their premises and also for the public for contributing.

The money raised from the boxes and donations goes to our members who have MND and their families. \$300 plus a \$50 gift voucher have been handed to each this year to use in any way they wish.

We have had many different speakers at our meetings this year.

Dr David Sanger from the Mersey General Hospital (Latrobe) who is a Palliative care Doctor was telling us that there had been no change in the care of people with MND in the 15 years he has been at the hospital. We all valued Dr David's talk and question time; we could have listened to him all day.

Lionel Bonde who lost his son and nephew to MND promised his son Adrian that he would work towards having palliative care beds at the Mersey Hospital with 24 hour

care. This is needed for people who have MND, as of now family and friends take up the care, even in the hospital and nursing homes.

The North West Group is right behind Lionel in this quest. We need these beds NOW. The 24 hour care does not have to be fully trained nurses, just someone who can communicate what the patient needs as the patient has no way of communicating. With nurses over-stretched, there is a need for trained people who would be able to sit with the MND patients, get to know them and be able to call for the staff when needed.

We also request that the person whose partner, friend or relative has passed away from MND has a visit from a trained person who could help them with the minefield of Centrelink, etc. and also to talk, as often their home has been filled with people and suddenly there is no one around.

Please feel free to join our group on the first Tuesday of every month at 10.30am in the rear room at the Ulverstone Returned Servicemen's Club 21 King Edward St. Ulverstone.

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: August 6, September 3, October 1, November 5.

WHERE: Ulverstone Returned Serviceman's Club, 21 King Edward St., Ulverstone.

The contact person is Junene Stephens:

1800 806 632 (message) or email
info@mndatas.asn.au

WALK TO D'FEET MND — SUNDAY, 20 OCTOBER — SAVE THE DATE!



EQUIPMENT - LOW TECH COMMUNICATION

Someone experiencing communication difficulties can be assisted by a Speech Pathologist to find ways to improve communication. There are basic strategies anyone can try but an effective communication system is best designed to suit the person who uses it.

SPELLING BOARD

One simple strategy is to make a spelling board. To use this, the person will need to be able to spell effectively. Spelling out words can take time and be tiring so it is always good to include some common words and phrases on the board. The spelling board can have the letters set out alphabetically or in the qwerty layout, depending on what suits the person best. Making the board can be simple, using cardboard, pens and paper.

EYE-GAZE BOARD

A low tech eye-gaze communication board can be used by people who cannot point to letters, words or phrases on a board. This simple eye-gaze system requires a communication partner who is able to see where the person is specifically looking with their eyes. People who use a high tech device

may find that this is a good system to use whenever they are without their computer.

As with the spelling board, low tech eye-gaze boards can be designed using the alphabet or words and phrases.

An E-Tran board is a low tech eye-gaze board made of clear perspex. Speech pathology services in the Tasmanian Health Service has one of these boards in each region (North, North West, South) which may be available for trial or loan.

A Speech Pathologist or Occupational Therapist can help design these simple systems to best suit the person using them. Further information about making your own is available from the Independent Living Centre Tasmania (ILC Tas, 275 Wellington St., South Launceston, ph. 6335 9200).

For advice on how to contact the most suitable health professional or service, contact your MND Advisor (details below).

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.

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

Phone: 1800 806 632 (message)

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 23 August 2019.