



May - June 2017

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

✿ MND Week – 7-13 May 2017 ✿

Thank you to everyone who shook tins, distributed and collected boxes and held BBQ's and morning teas for MND in the North, North-west and South of the State. It has been wonderful to hear from our regular supporters of this event and "tins were shaken" in most of the usual places on Thursday May 4. John Hughes and Shane Chugg liaised with Southern Cross TV so that MND was featured yet again for two weeks.

As we know the aims of this Week are to raise awareness and much needed funds to support people living with MND in Tasmania. It creates opportunities for us to have conversations about our experience and share knowledge of this hurtful disease. Each and every one of these conversations raises awareness and takes us a step forward to achieving our goal of "a world without MND". We acknowledge and thank you for the very important role YOU play. A further report will be in the July-August Newsletter.



#LifeMeasuredinMoments: Trevor Newby shares how he continues to be a part of the surfing community thanks to the support of MND WA.

During MND Week MND Australia brought to life the tagline 'Living better for longer' via a "LIFE MEASURED IN MOMENTS" campaign. This includes a series of 90 second videos portraying personal stories, a sharing of their journey of living with MND and how this has impacted upon their life. You can view these stories on the MND Tasmania and Australia Facebook pages as well as the YouTube channel. Please help us raise awareness by sharing these videos amongst your social media network. #LifeMeasuredinMoments #MNDWeek17

Fund-Raising and Awareness-Building

Thank you to our generous fund-raisers and awareness-builders including the Lower Mount Hicks Indoor Bowling Club, Craig Machen's CMPT4MND team and Brayden Hayes and his team.

Run for a Cause

Some of you may have seen or read about "Run for a Cause" on our website, in the papers or on the TV but for those who haven't here is the story.

When Hobart Hurricanes looked like getting flogged by Melbourne Renegades, Brayden Hayes sent out a cheeky FB post announcing he would run from Hobart to his home town of Burnie in nothing but his undies – if the Hurricanes could come back and win!

Didn't he get a shock when the Hurricanes fought back and chased down that target using the last ball to win the game?? True to his word, Brayden said he would honour his post and he would run to raise monies for charity. He chose two charities close to

his heart, being Motor Neurone Disease (Tasmania) and Diddy's Day Out.

Well, he quickly got dubbed "Undie Boy" and with a small support crew, an army of followers and supporters and a few pairs of undies he made the run and smashed his target of raising \$20k by doubling that! He arrived at Wivenhoe Oval in Burnie between footy matches at about 2pm on Saturday April 1 and after having run 325 km from Hobart, he ran a lap of honour with the finishing line being under the RACT inflatable archway. The crowd included MND member Kirk Dicker, MND fundraiser Craig Machen and MND Tasmania directors Libby Cohen and Michelle Macpherson. What a MIGHTY effort. A huge thank you to Braydon and all those involved.



RACT Act of Royalty

Following Craig Machen's paddle around Tasmania known as CMPT4MND (refer to our March-April 2017 Newsletter and our Facebook page on our website), he nominated MND Tasmania for the RACT Community Act of Royalty funding program. MND Tasmania subsequently came FIRST after receiving the most votes from RACT members in the January-March 2017 quarter! RACT accordingly transferred \$3,000 into the MND Tasmania CBA account. Thank you Craig, RACT and all those who voted for MND.



Entertainment Books

An annual fundraising activity for us for many years has been to sell Entertainment Books. This is now well underway for the 2017/18 year and if you would like to get yourself some great savings and support MND Tasmania at the same time visit site link below or the MND Tasmania website to purchase yours. We would also be extremely happy for you to tell your friends and family about this too!! <https://www.entertainmentbook.com.au/orderbooks/24004m3>

Fundraising volunteers keep us going

Craig and Brayden's massive feats of endurance have resulted in many more people across Australia hearing about MND and their substantial donations will assist us to fund the position of the MND Advisor into the future and to assist members with the purchase of essential equipment.

If you would like to organise a fundraising event or be part of one of these events please contact me at info@mndatas.asn.au to register your interest.

Michelle Macpherson, Fundraising Coordinator

MND Advisor's Report

Hi everyone,

As some of you would be aware, each region of Tasmania now has bimonthly MND multidisciplinary team meetings, following the lead set by Hobart some years ago. At these meetings, health professionals working with people with MND discuss how to best support people they are working with, and get to know others on the care team. It's well established that having a well coordinated, well connected care team means better care for people with MND, so we are delighted that health professionals are committed to these new meetings. One of the roles of MND Advisors is to support your care team, and holding these meetings is one way to do this. If you have any questions about these meetings, or indeed anything else, don't hesitate to get in touch.

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



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 Susan Bester, Alan Burrell, Don Burleigh,

Deborah Costello, Mark Griggs and of our other members who have recently passed away.

Donations have been gratefully received in the memory of Jacqueline Barrow and Deborah Costello.

Renewal of membership

Thank you to all those who have renewed their membership of MND Tasmania and are therefore continuing to receive this Newsletter as well as mail from MND Victoria. Your support for people living with MND in Tasmania and their families is significant and appreciated.

Members of MND Tasmania are automatically registered as members of MND Victoria due to the Memorandum of Understanding between the two Associations. MND Victoria assists us by providing administrative support which is the reason for your Renewal of Membership form being sent from and needing to be returned to the MND Victoria office. We value such support from MND Victoria as MND Tasmania has a volunteer Board and lacks the resources to employ staff.

Research Information

Familial MND families – we want to hear from you

Around 10% of people with MND have familial MND, and two-thirds of these individuals will carry a genetic fault in a currently known MND gene, such as C9orf72 and SOD1. Once the genetic change causing MND in the family is identified, relatives can decide whether to have genetic testing to predict whether they are at risk of developing MND in future. Little is known about how individuals from these families decide whether to have genetic counselling, have genetic testing and undergo reproductive options. In fact, no Australian studies have been performed to date.

If you are from a family with familial MND and there is a known genetic fault in the family, you are invited to participate in an interview by telephone to discuss your experiences of familial MND, receiving genetic information, and any subsequent decisions made such as whether to speak to a genetic counsellor or have genetic testing. We are interested in hearing a variety of experiences, both positive and negative, old and new. It is hoped that information from this research can guide the MND care and genetic counselling community on best practice guidelines for familial MND.

Multiple family members are welcome to contribute by having an individual interview.

If you would like to participate or would like more information, please contact Ashley Crook by email (Ashley.crook@mq.edu.au) or phone (02 9812 3720). This is a 12-month project funded by the MND Research

Institute of Australia (MNDRIA) Graham Lang Memorial MND Research Grant 2017 that has been approved by the Human Research Ethics Committee, Macquarie University (Approval no. 5201600879).

Participation in drug trials and other research projects

We are often asked about access to drug and clinical trials for people in Tasmania who have MND. As one member said, "We contribute to research funding, so why don't we have access?"

The answer is multi-faceted. The MND Tasmania Board advocates for our members to be included in services available to people who have MND irrespective of where they live. We are also represented on the Board of MND Australia which is currently working on the inclusion of Australians as subjects in research projects conducted overseas.

We aim to provide as much information as possible about upcoming trials to our members but we often don't get this until a trial has commenced.

As there is usually a requirement that people can get to the location where the trial is being conducted for monitoring, measurement, health checks, etc., it is not just people in Tasmania who may be ruled out but people living in many different locations in Australia.

Researchers usually access participants via MND clinics and/or neurologists. We do not release our member/client information to researchers but we do offer to circulate their information to our membership.

The MND associations including MND Tasmania do not individually fund research trials and have no control over who is accepted. Research donations are sent to the MND Research Institute of Australia (MNDRIA) which is the research arm of MND Australia.

MND Australia has information on their website which is continually updated regarding the drug trials occurring in Australia and the eligibility criteria for being included.

Visit <https://www.mndaust.asn.au/Discover-our-research/Latest-research/Clinical-trials.aspx> and <https://www.mndaust.asn.au/Discover-our-research/Latest-research/Participate-in-research.aspx>

MND on the March for Science Day - April 22

An exciting breakthrough for the profile of MND occurred in Melbourne on April 22. Cure for MND Foundation Vice Chairman Neale Daniher (who has MND) announced new funding for research projects at the inaugural Cure for MND Foundation Symposium. The Foundation has

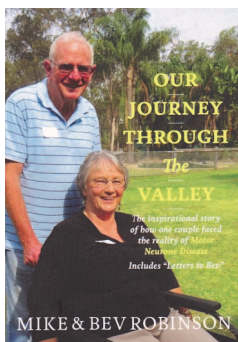
committed to \$12.55million in research in 2016/2017 with \$2.8million committed by the Australian Government.

Books

Our Journey Through the Valley (2016) by Mike and Bev Robinson

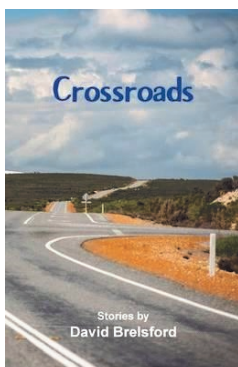
In 2000, Mike Robinson was diagnosed with Parkinson's Disease. After his wife Beverley was diagnosed with MND in 2013, they committed to keeping a journal of their experiences. Bev had been a Registered Nurse and Mike a Christian Pastor. Following Bev's death in 2015, Mike began writing "Letters to Bev" as a means of processing his grief. After his friends and family read the journal and letter extracts, they advised "These must be published!". Mike has published and circulated this book as a way of thanking "the MND Team for their amazing support during that period" and as a resource for the many "caring people" who are involved in providing for those who have MND.

Our Journey Through the Valley is available from the State Library at LINC Tasmania or can be purchased from Mike at mikebevfamily@bigpond.com for \$20 & postage.



Crossroads (2016) by David Brelsford

David Brelsford was featured in the MND Tasmania Newsletter of May-June 2011 (see the MND Tasmania website Newsletter archive) after he ran north-south and west-east across Tasmania for MND. He has now published a book of stories, the royalties of which will also benefit MND. David's book *Crossroads* can be purchased at Petrarch's Bookshop, 89 Brisbane Street, Launceston for \$16.95.



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:

Meetings are held from 11a.m. to 1p.m. on the fourth Monday of every second month. Meeting dates 2017: July 24, September 25, November TBA.

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.

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

Secretary: Michele Newton

Treasurer: Helen Fleming

Fundraising: Michelle Macpherson

Equipment: Libby Cohen

Social media: Shane Chugg

Ex-officio wisdom: John Hughes OAM

MND Advisor

Hayley Tristram, email: 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 June 28 2017.