

MNDnews

The newsletter of the Motor Neurone Disease Association of Tasmania

A T-20 Cricket Match in Memory of Allan Jones!



MESSAGE FROM THE PRESIDENT

We hope you had a safe and happy holiday period. We finished off the year with a cricket match to raise funds for Allan Jones, a local Tasmanian who we lost to MND last year.

The event is covered on Page 1 of this newsletter. Thank you to everyone involved, and particularly to Hydro Tasmania for their significant contributions to the event.

We have held our Annual General Meeting for 2023 which took place on March 19th at the Menzies Centre in Hobart and online. The Board of MND Tasmania always love the opportunity to catch up with our members, and to discuss recent research updates from people at the Menzies Centre.

When preparing for our AGM we always reflect on the achievements and many learnings from the previous years, and I want to take this opportunity to thank our broader MND community. To those living with MND who show great courage and dignity as they face the challenges of this disease, you truly inspire us to do what we do. To our voluntary board, who give their spare time to organise and guide the efforts of the organisation. To our amazing advisors, Jenny and Emma, who provide so much love and support to our members. To the family and friends of



our members, who show-up to support and help their loved ones. And, of course, to our financial supporters for always making it all possible!

The collective efforts of our MND Community contribute to the success of MND Tasmania and helping those living with MND in our state. Thank you to all involved in our AGM. A full report from the AGM will be available in our next newsletter (Winter 2023).

We welcome new members to the MND Tasmania family in 2023. We are here for you and will support you on the journey ahead. Please reach out to us through the Board and through our wonderful MND Advisors.

We love to hear from our members, so please write and share your stories, opinions, questions, or any thoughts about this newsletter. Write to me at info@mndatas.asn.au and see our contact details on the back page.

Kate Todd
President

MND TASMANIA SAYS **THANK YOU**

A Wonderful Afternoon of Cricket!

Hydro Tasmania, Tas Networks, and Marinus Link joined efforts to honour the legacy of Allan Jones and to raise funds for MND Tasmania. Allan worked for the Hydro for over twenty years, making significant contributions to the energy sector in Tasmania. He is fondly remembered by all of his colleagues for his dedication, intelligence, positive attitude, and for being a real people person.

Allan was a big cricket fan, and we are very grateful to Cricket Tasmania for allowing us the use of Blundstone Arena and its facilities, as well as for donating amazing prizes to be raffled. We had more than 20 players from across all organisations, and around 80 people attended the match.

Caption: Prajit Parameswar (pictured right) came up with the idea to honour the memory of his dear friend and colleague for many years, Allan Jones, with an annual T20 Memorial Match.

It was a beautiful November afternoon of sunshine, barbecue, and excellent cricket being played. They raised more than \$10,000 in funds for MND Tasmania after auctioning off some great prizes and selling raffle tickets.

Thank you so much to all of the volunteers, players, spectators, and everyone who donated, to make this event so special. We are so very touched by everyone's generosity!



William Fraser's Christmas Lights Tradition



Keeping up with 17 years of tradition, William Fraser planned and executed another beautiful Christmas lights display! William, who is almost 92 years old, does the entire display himself, and also gives away hundreds of toys to children.

Funds collected from those who come to see his lights are donated to MND Tasmania.

We are so thankful for his remarkable efforts, and for his continuous support of MND Tasmania!

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 (see contact details on the back page). The MND Advisor service is managed on our behalf by MND Victoria, with MND Advisors who travel State-wide as required to support our members on a needs basis.



Parry to Pinnacle

Dr Bryn Parry, who was diagnosed with MND in 2020, always wanted to complete the world-famous 'Point to Pinnacle' half marathon. So his family and friends rallied behind the beloved Devonport GP to make his dream come true!

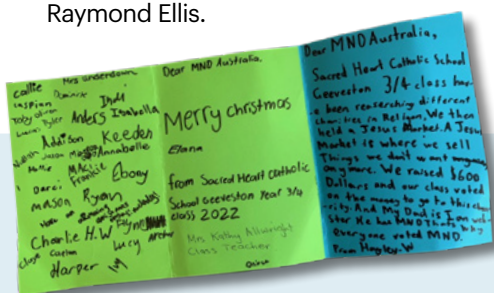
A team of 10 tackled the 'world's toughest half marathon' all while pushing Bryn in a specialised wheelchair, a total weight of 120kg.

The team, led by Bryn's sons, Lucas and Dave, have raised more than \$40,000 for the Clifford Craig Foundation in Tasmania. Lucas said it was a mammoth effort from all involved and thanked everyone who got behind the cause.

Thank you for your support!

We are grateful for the support we received from Pamela Stout, Sacred Heart Catholic School Geeveston, Hobart Pathology, Luke Moure, Wendy Burbury, Latrobe Primary Big Chill, and the continued support we receive from Margaret Eldridge, Pamela Greenwood, and Kevin Burgess.

We have also received donations in memory of Colin Anthony Raison, Lynette Gobbey, and Carlyle Raymond Ellis.



Professor Tracey Dickson the new director of Menzies Institute

Our own Board Member, Professor Tracey Dickson (pictured right), has been named as the new Director for the University of Tasmania's Menzies Institute for Medical Research.



Caption: In late 2022, Tracey gave some of our Board Members a tour of the Menzies Institute, showing off the state-of-the-art laboratories and facilities.

She's the first Tasmanian to be appointed to the role, and she says she hopes to develop the Institute's reach into the north of the state, where she started her own science studies. Tracey has been involved in the MND Community through her research and her role on the MND Australia Research Committee since 2010.

Having Tracey as one of our Board Members is an incredible privilege!

Margaret Jingles

Margaret Eldridge, a long-time supporter of MND Tasmania, has written a new book. Margaret has been writing jingles for many years and it has become part of her persona. She is inspired by a variety of things and, sometimes at the request of others, she writes moving and captivating jingles!



She wrote this book with the help of her friends, Minh Hien Thi Tran and Farshid Anvari. She dedicates the book to her dear friends who have succumbed to MND: Dr Kate McPherson, Doreen Walker, Gloria, and Minh Hien's dear mother. All funds raised from the sale of the book are donated to MND Tasmania.

You can buy a copy directly on Amazon Australia - visit www.amazon.com.au/Jingles-Me-Margaret-Eldridge/dp/099460288X/ or scan the QR code above. You can also reach out to us at info@mndatas.asn.au and we can organise to send a copy to you.

Thank you for everything Margaret - you're wonderful!

The Sacred Heart Catholic School Year 3/4 class of 2022 held a Jesus Market where they sold arts and crafts raising funds for MND Tas. Thank you, Hayley and classmates!



Join MND Victoria's Larapinta Trek to help provide and promote the best possible care and support for people living with motor neurone disease.


Over six days, you'll discover the rich history of Australia's First Peoples, exploring scenic landscapes along well-worn, red dirt tracks. At night, you'll camp under a blanket of stars and fall asleep to the nocturnal sounds of the desert.


Best of all, with every step you take, you'll raise vital funds to support Victorians and Tasmanians living with MND and those who will be diagnosed in the future.

Highlights


- ◇ Discover the Australian Outback on one of the world's premier walking treks
- ◇ Immerse yourself in the rich history of Australia's First Peoples, following red dirt tracks across the West MacDonnell Ranges
- ◇ Camp under star-studded skies and fall asleep to the nocturnal sounds of the desert
- ◇ Raise vital funds to provide care and support to people living with MND

 9-14 August 2023

 Moderately challenging (3/5)

 Fundraising target: \$3,000

Travel package: \$3,121
Land only and subject to change

 Twin-share in 4-star hotel and at comfortable campsites

#MNDVICLarapinta2023

Register now:

 www.inspiredadventures.com.au/event/mndvic-larapinta-2023

LIVING BETTER



Mindfulness for Carers

By Carmela Quimbo



Mindfulness is a mental training practice that teaches you to slow down racing thoughts, let go of negativity, calm both your body and mind, while cultivating compassion and friendliness towards yourself.

In this article, Carmela discusses the free 5-week Mindfulness for Carers Program that she is running which began at the start of March. You are more than welcome to join any of the upcoming sessions, regardless of whether or not you attended any previous sessions.

If you are unable to make any sessions but would like to learn more about mindfulness, you can view a recording of a previous session Carmela ran, which includes 3 mindfulness exercises. You can view this session at <https://vimeo.com/730195649/bdb5a1c79e> or by scanning the QR code above right.

Hello everyone.

My name's Carmela Quimbo and I am one of the Keeping Connected Advisors at MND Victoria. I'll be leading a 5-week online Mindfulness for Carers group beginning on Thursday 9 March at 2pm. The practice sessions will run for 45 minutes. They're free of charge, and you are welcome to attend one, all, or any number of the sessions.

Each Thursday for 5 weeks, we at MND Victoria would like to encourage family and friends of people who have been diagnosed with MND to come together and experience how mindfulness practices can support people by cultivating an inner state of kindness, peace and wellbeing in the midst of all of life's array of circumstances ... including the often difficult and sometimes heartbreaking challenges of caring for someone diagnosed with MND.

The practices we will do together are an invitation to explore the effects of bringing non-judgmental attention, curiosity and friendliness to all aspects of our daily lives. With practice, we begin to discover that the inner quality of mindfulness can be a reliable, loving and wise companion as we navigate the fullness of a human life.

I've heard people say that they "can't do mindfulness" because their minds are too distracted, or that they can't stop thinking, or that they can't sit still, or that they are too anxious or they don't have enough time. But the great gift of the quality and practice of mindfulness is that it can be present and attentive to all the distractions, all the discursive thoughts, all the physical sensations, all the emotions, and all the busyness of our lives.

Mindfulness practices are not aimed at changing the content and circumstances of our lives. The wonderful and powerful shift that occurs is in how we relate to our life's circumstances. We begin to see ourselves, our families, our friends, our community, our work, our

environment, our world, and all of the experiences of our bodies and minds with more clarity and spaciousness.

As I sit here typing these words, I am becoming aware of a wish to have this article finished and submitted. I am starting to feel anxious that I am not going to reach the 600 words I promised by tomorrow. So, I intentionally pause and notice there is worry right now, there is a thought that I won't be able to get this done. I'm not trying to change this experience, I'm not trying to fight it or ignore it, I'm allowing it to be there. I notice where the worry is alive in my body, a tightness in the shoulders, a clenching in the stomach, a dryness in the mouth. I allow those too. I stay with myself, the way I would stay with a beloved friend, sitting on a chair at my kitchen table, typing, breathing, thinking, worrying. And, in this staying with my present moment experience of worry, with mindfulness, kindness and curiosity, I can see it more clearly. I can see that it is not permanent and that, in fact, it is already ceasing.

So now, I can bring this article to a close with a sincere and warm invitation for carers of people who have been diagnosed with MND to join me in the practice of mindfulness. You can register your interest by emailing info@mnd.org.au or calling MND Victoria on 1800 777 175. If you have any questions, or would like to talk with me about it, please feel welcome to call me on 0479 039 402 or email on cquimbo@mnd.org.au

MND RESEARCH

Cough medicine to be trialled for MND treatment

By Professor Brad Turner

Researchers at the Florey Institute will lead a world-first clinical trial of Ambroxol as a potential treatment for MND. Ambroxol is a generic drug found in cough syrup and has been used to treat respiratory conditions for over 30 years with an excellent safety profile. Ambroxol is a mucolytic agent (drug that helps to clear mucus from the respiratory tract) which helps break down phlegm and acts as a cough suppressant.

Now, research led by Professor Brad Turner at the Florey Institute, University of Melbourne, has discovered a novel action of Ambroxol for MND. His group has shown that Ambroxol works by reprogramming metabolism inside motor neurons, leading to stronger physical connections between motor neurons and muscles. These connections are thought to be disrupted early in MND, leading to characteristic muscle weakness and wasting. Accordingly, Ambroxol treatment improved disease in models of MND across different laboratories, supporting its potential for slowing down MND progression.

This Phase 2 trial called AMBALS will launch in March 2023. This clinical, multi-centre trial will recruit 50 MND patients across Australia for treatment with escalating oral doses of Ambroxol for 6-months with an option for a 6-month open label extension. Participants will receive either Ambroxol or a placebo treatment. The effectiveness of Ambroxol will be measured using clinical rating scores, questionnaires, electrodiagnostic tests and blood biomarkers of disease progression.

Professor Turner said, "We are excited to lead this trial which represents five years of extensive research across an international team of collaborators. Ambroxol is an ideal drug candidate for MND. It is a safe drug, taken orally as a syrup and readily enters the brain. We will repurpose Ambroxol for MND for the first time. We look forward to working with the MND community in this trial."



The AMBALS trial is funded by FightMND and the Australian Government. Patient recruitment for this trial opens February to September 2023 at 5 clinical sites, including Calvary Health Care Bethlehem, VIC; Concord Hospital, NSW; Brain and Mind Centre, NSW; Flinders University Medical Centre, SA; and Launceston General Hospital, TAS. The expected trial completion will be late 2024. Please speak with your neurologist if you are interested in participating in this trial. of collaborators.

PERSONAL STORY



Something *to* Say

By Marilyn Martyn

Marilyn volunteers for MND Victoria in our Life Stories Program, helping people living with MND to record, transcribe and prepare stories of their life for printing, so that the stories of their life can be recalled, celebrated and shared.

The time has come to put my grief aside and share my experience with people facing the same situation.

I first heard of MND in the mid-eighties when a colleague's wife suffered from this insidious disease. My colleague was distraught, feeling helpless and without a lot of support.

I remember thinking I could not face that situation. I could never cope.

Thank goodness we have no idea what is ahead of us.

Sol was my second husband. We met in our fifties, both of us experiencing the despair of a broken marriage. We had rebuilt our lives and were busy and content (well, sort of).

A mutual friend arranged for us to meet for dinner before we went to her daughter's wedding. I was not a romantic at heart but thought it would be good to have someone with whom to attend the wedding.

Sol was in the kitchen when I arrived for dinner. I was expecting to see a short, rotund, middle-aged man. I turned around to face the door as this tall, slender, attractive man entered the dining room and introduced himself. He also had this deep, melodic voice. I fell in love at first sight! It was a mutual attraction. After a two-year friendship, we decided to live together. After twelve years, we decided to get married.

Marriage was something I wanted.

We were in our sixties and knew that we had to make the most of the time that we had left. We were committed to marriage and were the best of friends. I am a mother of two sons, and motherhood was a joy. I learned that my love for my husband was just as strong.

One day I noticed Sol's voice had changed. It had lost its depth. Initially, I thought it was because he was a man in his seventies. He also appeared withdrawn. Sol started to experience odd symptoms. In retrospect, his doctors knew what they indicated but they wanted to be sure before giving us a formal diagnosis. Sol passed away from MND on the 2nd of May 2017. I think of him every day and miss him enormously, but I am grateful that he is free from this dreadful disease.

I faced the situation and coped. Why? Because I didn't face it alone. I experienced the courage and fortitude of one man and how caring human beings can be for one another.

Sol displayed courage, sensitivity, and a practical attitude; I am sure he felt fear as I did. He announced that he could no longer drive his car, and he accepted the wooden walking stick which he needed and then the walker. But he wasn't too happy about the wheelchair!

Continued on page 7

MOVE FOR MND

Continued from page 6

I had to call the ambulance when he couldn't breathe. He wanted to go home when we both knew that he couldn't. When he could no longer speak, he wrote, 'the situation must be difficult for you!' He indicated how he was feeling. I didn't have to guess. I knew what he wanted, and he didn't argue if it wasn't possible. He showed me the gracious and loving man I knew him to be.

We appreciated the support from MND Victoria and Bethlehem Hospital, our church community and medical attendants. A loving family and friends also cared for us.

I have a joyous memory. Sol was a meticulous man. I saw that he needed an electric shaver.

"I am going to 'The Good Guys' to get you an electric shaver. I will bring it in the morning," were the last words I said to him. Supported by nurses, he nodded and gave me his V for victory sign. Sol passed away that night.

I am still associated with MND Victoria. I have the privilege of working with people recording their life stories, the perfect legacy to leave a family.

I received a beautiful card from my niece. On it was a quote from Kahlil Gibran:

"Ever has it been that love knows not its own depth until the hour of separation."

I have experienced this to be true.



During the month of February, our wonderful community joined efforts for the 'Move for MND' fundraising event. They walked or ran a distance of their choosing while supporting a worthy cause.

**We thank our main fundraisers:
Emma Lovegrove, Amanda Barrett, and
Brittany Walker for all the effort dedicated
to this amazing cause!**

They achieved their goal and donated over three thousand dollars to MND Tasmania.

UPCOMING EVENTS

Carer Wellness Programs

Carer Wellness Programs give carers the opportunity to take some time off, connect with other carers, and learn some skills for caring for someone living with MND and for themselves.

We recently held one of these Programs in Launceston over the 15th and 16th of February, with attendees using words such as 'warm', 'caring', and 'relaxing' to describe the experience. 11 carers came together, along with Emma Forsyth and Jenny Fuller (MND Advisors), and Andrea Salmon (MND Carer Support Program Coordinator) to participate in a number of sessions.

Mimi Churchill (OT) and Lauren Giles (Neurologist) spoke to the group, and encouraged them to learn more about MND, get support to navigate the system, manage their own health, make some changes, try something new, and be kinder to themselves. They also enjoyed a relaxing guided art activity, ate lovely meals they didn't have to cook, slept late, and took a stroll along the Riverside Walk.

A beautiful aspect of the program was the Carers Pamper Packs which were given to everyone who attended. These contained relaxing tea, chocolate, a Sukin hand cream, a makeup pack, sleep handout, and scented candle.



The carers who attended were partners, daughters and granddaughters of people diagnosed with MND. When asked for their feedback, they said:

- It was a varied program and catered for a warm, non-threatening environment.
- Simply having 24 hours of not having to decide what to eat, shop, cook, and take care of someone else was brilliant. Especially the option to stay overnight in a gorgeous relaxing hotel. Loved the paint activity and the walk. It was also excellent to just have "free time".
- Loved that it was all in the one venue so you didn't have to think, just leave your room 5 mins before the next activity started.
- It was nice to meet with others with partners who have MND in a lovely atmosphere.

MND Tasmania AGM

By the time you receive this newsletter, MND Tasmania will have held our AGM. This was our first hybrid AGM, hosting the meeting both in person and online. The AGM took place at the Menzies Institute for Medical Research, on Sunday March 19.

The MND Tasmania AGM is always a great opportunity to meet our Board Members, find out more about our work, meet other members in attendance, and hear from a specialist researcher in the field of MND. During the meet, we reported to members on the Association's performance during 2022 and our plans for the coming year. You will be able to read a report on this in the next edition of MND News (Winter 2023).

If you wish to attend in the future, please do not hesitate to contact us via email to info@mndatas.asn.au. We always post our updates and upcoming events on our website and Facebook page, so please stay tuned!



MND Support Groups

The MND Support Groups in Tasmania are independently run by community members for community members. We appreciate their willingness to devote their time and volunteer for such a worthy cause.



North West MND Support Group

The NWSG in Ulverstone invites all MND Tasmania members and supporters to its meetings.

WHEN: At 11 am on the first Wednesday in the month, except January

WHERE: Ulverstone Returned Servicemen's Club Back Room, 21 King Edward Street, Ulverstone

CONTACT: Junene Stephens is the secretary and can be contacted on 0428 252 763 or email: jstephens@berendsen.net.au

Northern MND Support Group

This is an informal catch-up style group, where members come together to talk all things MND and Kennedy's Disease, as well as share experiences and helpful tips. The group have currently ceased in-person meetings and are instead communicating via a private Facebook group. You can request to join at www.facebook.com/groups/337315731509176 or scan the QR code below.



MND ADVISORS AND NDIS SUPPORT COORDINATORS

Client Numbers

We are currently supporting 46 registered members:

North West Region Tasmania	10
North Region Tasmania	17
Southern Tasmania	19
TOTAL	46



**CURRENTLY
SUPPORTING
46
REGISTERED
MEMBERS**



**DELIVERED
967
HOURS OF
SERVICE
in the last quarter**

MND Advisors and NDIS Support Co-ordinators

Northern Tasmania: Emma Forsyth (Mon-Thur):

p: 0456 182 551 or e: eforsyth@mnd.org.au

Southern Tasmania: Jenny Fuller (Tue, Wed, Fri):

p: 0412 599 365 or e: jfuller@mnd.org.au

Team leader: Kim Hamilton (Tue - Fri):

p: 0422 149 445 or e: khamilton@mnd.org.au

FREECALL 1800 777 175

This number is at the MND Victoria office (Monday - Friday, 9 am - 5 pm). To assist the volunteer receptionist, please say that you are calling MND Tasmania. If you wish to speak to a Board member or an MND Advisor, you will be asked for your contact details and your call will be returned by that person as soon as possible.

*Right: Emma Forsyth
Below: Jenny Fuller*



MND Tasmanian Board Members:

MND Tasmania has a volunteer Board and no paid staff.

President: Kate Todd

Senior Vice President: Tracey Dickson

Vice President & Public Officer: Chris Symonds

Secretary: Lucy Polizzi

Treasurer: Julie Driessen

Member Support: Elisa Howlett

Fundraising: Saga Hassinen

Ordinary Directors: Steve Isaac



We acknowledge Aboriginal and Torres Strait Islander peoples as the Traditional Custodians of the lands in which we live, work, and learn. We recognise and respect the enduring relationship they have with their lands and waters, and we pay our respects to Elders past, present, and emerging.

MND TASMANIA

PO Box 379, Sandy Bay,
TAS 7006 Australia

Freecall: 1800 777 175

Charity ABN: 21877144292

✉ info@mndatas.asn.au
🌐 www.mndatas.asn.au
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