



January - February 2019

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MND Tasmania 1986-2019: *supporting people living with MND in Tasmania for 33 years*

MND Tasmania – Annual General Meeting

1pm on Sunday 17 March 2019

At the Alma's Activities Centre Clarence, 17 Alma St BELLERIVE 7018 (The Centre has accessible facilities and parking)

All members, family and friends of MND Tasmania are warmly invited to attend the AGM at 1pm.

At 2pm there will be a presentation by invited speaker Jo Whitehouse, Manager Support Services MND Victoria & Tasmania.

Nominations for the Board

The term of office for Directors of MND Tasmania is one year. The election of nominated members of MND Tasmania to the positions of Directors is conducted at the AGM.

If you are a member who is unable to attend the AGM and would like to be nominated for a place on the Board and/or would like a proxy voting form, please contact Secretary Kate Todd via email at info@mndatas.asn.au

Fund-Raising and Awareness-Building

Walk to d'Feet MND 2019

10am Sunday 3rd March – Ulverstone Rowing Club Kings Parade



Francesca

Francesca is a local Tasmanian jewellery brand which supports different charities throughout the year by selling specially designed bracelets and donating \$20 from the sale of each item to the cause. They reported that the MND bracelets sold out within a week and they had to take backorders as they were so popular. All monies raised through this promotion will go research to help us find a cure. If you missed out on getting your bracelet keep your eye on our Facebook page as we will work to secure a second month of promotion later in the year!



Think BIG.....Think BIGGER



The guys at Grange Resources never do anything by halves. Recently they painted one of their trucks to help raise more awareness for MND and they have also been busily fundraising for us. We can thank the team at Grange Resources enough for all of their generosity and hard work.

Liz Ellis Memorial Run



Late last year Leah and her team from Health Revival Longford held a “Run” at Woolmer’s Estate in the North to honour the life of Liz Ellis and pay tribute to her lasting contribution to the local community. It was a great morning and we thank the people of Longford for their support by purchasing MND merchandise and donating so generously.

QUIZ NIGHT – SAVE THE DATE

We will be holding a quiz night at the Italian Club in North Hobart on Friday 22nd March. Peter Gee has agreed to take on the role of Quiz Master extraordinaire, so we are assured of a night full of fun and much laughter. There will be some awesome prizes up for grabs in recognition of your brilliance. Refreshments will be available at reasonable prices and a silent auction will be run to help assist with fundraising. For full details check out our Facebook page on how to get your tickets before they all sell out!!

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 MND Advisors for Tasmania who are also our NDIS Coordinators of Supports. Board members may also be contacted. The contact details are on page six. 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 families and friends of Kirk Dicker, Christopher Reeve and of other members who have recently passed away. Donations have been gratefully received in memory of Gary Alexander, Christine Boulter and Barbara Robertson. Donations received in the memory of a loved one enables MND Tasmania to continue to provide practical care and support for people with MND and their families in Tasmania.

Donations

Thank you to donors including the Collegiate Middle School, Margaret Eldridge and her Aquarobics group, members who have returned their Newsletter cover sheet with a donation, respondents to our Christmas appeal and the Kingborough Dog Walking Association whose donation was in honour of Dianne Fuglsang.

News from the Support Services team

Staff changes afoot in Tasmania!!

We are sad to advise that Hayley Tristram who has been our MND Advisor and Support Coordinator in Tasmania since June 2015 has resigned. Hayley was our inaugural MND Tasmanian based Advisor and has done some great work in raising the awareness about MND and supporting clients and their families/carers. Hayley is finishing on 25th January, so by the time this goes to print she will have left, but hopefully many of you will have had chance to say goodbye to her.

It’s not all bad news!! Jacqui Holland is commencing as a new MND Advisor and Support Coordinator on 14th Feb. She will be based in Hobart and will work 2 days a week. Jacqui has been working in Melbourne as a speech pathologist for many years and is

relocating to Tasmania with her family. Jacqui (photo below) has a wealth of experience in working with people with neurological conditions including MND and has experience in both the Aged Care and NDIS space.



As this goes to press we are looking at recruiting to fill Hayley's position and hopefully will have news in the next newsletter!

We currently have 40 registered clients in Tasmania –

North region – 11

North-west – 13

South -16

Jo Whitehouse, Manager Support Services

MND Advisors

Hi everyone,

As we start 2019, I wanted to touch on an issue that a number of people have raised with me and that is exercise, and the role of physiotherapists.

As MND affects the nerves in the brain and spinal cord that control how muscles work, muscle groups can become weak and joints can become stiff and muscles tight, sometimes making daily activities more difficult and painful.

A physiotherapist can offer guidance and exercises to help. Once the motor neurones that control a particular muscle have weakened, the muscle can't be repaired by exercise or anything else. However, exercise can help to keep weakened muscles as strong as possible. Strengthening healthy muscles that have not yet been affected also helps to compensate for the muscles that are no longer working properly. Regular exercise can also help



maintain muscle elasticity.

Physiotherapists can:

- develop a tailored exercise programme suitable for your particular needs and abilities
- advise on different ways to do things to compensate for loss of movement and how to conserve energy, including the use of equipment
- provide guidance on breathing and techniques to help you clear your chest and how to conserve energy
- give advice on posture and positioning
- show your carer how they might help you with your exercises and advise them of safe movement and handling techniques.

If you have any questions about this topic, or would like help with a referral, please get in touch.

Best wishes, *Hayley*

Equipment

Assistive Technology – Communication

The advances in Assistive Technology allow people with MND to optimize their function and independence even as their physical function declines. Timely assessment, with trial and prescription of 'equipment' addressing the needs of a person is essential for this.

The Communication Equipment Library was established to give people living with MND access to a range of communication devices. It is planned that future acquisitions will broaden the scope of the library.

A simple but useful device is a voice amplifier. It may be useful where speech is clear but it is difficult to project the voice (i.e. only the volume of speech is affected). These devices can enhance voice volume by providing additional amplification.

People with MND experiencing problems with speech may benefit from using a device that converts text to speech. Typed text is converted to synthesized speech. Specialized devices as well as smart phones, tablets or laptops can do this with the appropriate software installed. These devices can also be used to access the internet for communication with friends and family via email and social media.

People who are not able to use a physical keyboard or touch screen keyboard might be able to use devices that offer alternative access using switches,

head tracking or eye-gaze control. This is very specialized equipment.

Early referral for assessment, to a Speech Pathologist or Occupational Therapist with expertise in 'Communication' is important when a person with MND is experiencing difficulty with speech.

The MND Tas Communication Equipment Library was established in 2017 in collaboration with Fight MND. It is managed by ILC Tasmania, a statewide organization. For further information on accessing the library, contact the MND Advisor or your referring health professional.

Libby Cohen, Equipment coordinator

HELP NEEDED!

What are your plans for 2019?

Do you enjoy reading, collating, writing? Would you like to have a vital role for MND?

The editing of our newsletters involves about 3-4 hours every 2 months and being part of a team of people who want to make a difference for people living with MND in Tasmania.

A draft document is sent to Heidi at the MND Victoria office 6 times a year. She turns it into a colourful Newsletter which forms an archived history of MND Tasmania on our website and in the State Library.

You will be coached, supported and assisted by the MND Tasmania Board. If you think you could help in this way, please email the Editor at info@mndatas.asn.au

Research news

**14th MND Australia Research Conference—
9 November 2018 - Melbourne**

MND Australia's annual Research Conference was held at the Florey Institute of Neuroscience and Mental Health with a full day of presentations and posters from Australia's MND researchers.

The team of MND research scientists from the Menzies Centre in Hobart was well represented by Professor Tracey Dickson, Dr Catherine Blizzard and 5 young researchers who featured their work on posters.

Dr Blizzard (photo, top right) was a keynote speaker with her presentation "Investing in Innovation: supporting researchers at all stages of their careers".



She said that every discovery leads to more questions which need to be answered and thus long term funding is vital for the progression of knowledge and discovery. As a young scientist, she was interested in the field of acquired brain injury but after she was awarded the Bill Gole MND Post-Doctoral Fellowship 2011-2014, she changed her research focus to MND. She then had the honour of being the first recipient of the prestigious Betty Laidlaw Prize for an outstanding mid-career MND researcher in 2017, and was followed in 2018 by Associate Professor Justin Yerbury from Wollongong who has MND and has been featured twice in the ABC's Australian Story in 2018.

Dr Rosemary Clark from the University of Tasmania was awarded the Bill Gole MND Post-Doctoral Fellowship 2019-2021.

Professor Tracey Dickson, Dr Catherine Blizzard and their students have often presented their research findings at MND Tasmania AGM's and Health Professional Forums.

MND Australia has been funding, fostering, developing and promoting MND research and researchers for over 31 years. MND Tasmania is a member of MND Australia and donates annually to its MND Research Institute (MNDRIA) which has funded a significant amount of the Menzies Centre's MND research.

MND care and best practice

Professor Samar Aoun is Professor of Palliative Care at La Trobe University and also serves on the Boards of MND WA and MND Australia and on the MNDRIA Research Committee. On December 6 2018 she was awarded the Senior Vice-Presidential Medal from the European Society for Person Centred Healthcare for



Learn from the MND experts at our MND Health Professionals Forum in Launceston on Friday, 1 March 2019 at Launceston Convention Centre.

This forum is for health and community professionals and all those who have an interest in MND or have MND.

Keynote speaker is Dr Helen Castley, Staff specialist in neurology, Royal Hobart Hospital.

Presentations by key MND experts from Calvary Healthcare Bethlehem.

The Program:

9am Tea and Coffee upon arrival

9.30am Welcome—Joyce Schuringa, President, MND Tasmania

9.40am Personal Perspective—Person with MND

9.55am Keynote speaker—Dr Helen Castley, Staff Specialist in Neurology, Royal Hobart Hospital

Morning Tea

11.15am OT for people with MND—Sarah Solomon, Calvary Health Care Bethlehem, Victoria

11.45am Secretion Management in MND—Marian McCarron, Calvary Health Care Bethlehem, Victoria

12.15pm Adapting to Communication Changes that occur in MND—Sarah Solomon & Marian McCarron, Calvary Health Care Bethlehem, Victoria

12.45pm Assistive Technology for Communication for people with MND—Dennis Lo, Independent Living Centre, Tasmania

Lunch

1.45pm Dr Christine Edwards, Staff Specialist in Palliative Medicine, Tasmanian Health Service

2.15pm Panel Discussion—all speakers

3.15pm MND Advisor & MND Information Service—Eric Kelly and Alison Jones, MND Victoria

3.35pm Personal Perspective—Carer

3.50pm Closing address—Joyce Schuringa, President, MND Tasmania

Afternoon tea upon departure

Please book your tickets online at: www.trybooking.com/BAABU

For further information, please contact: 1800 806 632 or email: info@mnd.asn.au



(from page 4) **Photo: Professor Samar Aoun** her research on a person-centred approach to MND care encompassing quality of life, quality of care and quality of death. Her published paper can be found in the European Journal for Person Centred Healthcare Vol.6 No.2 (2018).

The principles underpinning the MND Support Service provided by the MND Associations in Australia is in accordance with her research.

In Tasmania, this world's best practice model of care is funded by philanthropic donations and your fundraising! NDIS is now also becoming a funder through the role of our MND Support Coordinators.

MND research trials

The MND Australia website lists the current trials in which people who have MND may participate.

As the MND community in Australia is relatively small, participants may need to travel to interstate centres if they are eligible to participate in a trial. For information, visit the MND Australia website or follow the links from the MND Tasmania website or Facebook page.

Northwest Support Group

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: March 5, April 2, May 7.

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

The contact person is Junene Stephens at 1800 806 632 (message) or email info@mndatas.asn.au

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 22 February 2019.

MND Tasmania 1986-2019: supporting people living with MND in Tasmania for 33 years

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: Libby Cohen

Secretary: Kate Todd

Treasurer: Julie Driessen

Public Officer: Shane Chugg

Fundraising: Michelle Macpherson

Logistics: Dr Andrew Moy

Ex-officio support: Chris Symonds



MND Advisor & NDIS Support Coordinator

Jacqui Holland phone 1800 806 632 (message) Email: jholland@mnd.asn.au

Support Service

MND Tasmania and MND Victoria work together to provide the MND Advisor service and NDIS Support Coordination services which provide 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.