



March - April 2018

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MND Tasmania 1986-2018: *supporting people living with MND in Tasmania for 32 years*

About us

This issue features three stories of people who are living with MND in Tasmania. They show a little of the breadth of difference of experience that we have among us.

MND Tasmania is about and for us who are living with and have lived with MND.

At the milestone event Walk to D'feet MND on October 21, we were there – people who are living with MND and those who have lived with it until recently or longer ago - husbands, mothers, grandchildren, sisters, partners, cousins, children, wives, friends, uncles, colleagues, fathers, neighbours, brothers. aunts. Health professionals, researchers and support workers too – as they are often touched by people with MND.

We have also gathered at many other fundraising events during the past year.

The Northwest Support Group meets monthly in Ulverstone.

The Board meets every one or two months.

We all know the intense concentrated grief of MND. When we say “MND”, we include Kennedy's disease (KD). People who have Kennedy's are often initially diagnosed with MND and MND Tasmania supports people living with KD as well as MND.

The Board held a strategic planning meeting on October 14 2017. We packed our morning teas and lunches and spent the day sharing our thoughts and ideas (and our food!) in a room in the Rosny Library. Darren Osborn of In2Change facilitated the workshop and expanded our knowledge and understanding of the rapidly changing world of not for profit organisations (the for purpose associations), disability and health services. Carol Birks, CEO of MND Australia, participated as our guest, gave us further information from her national experience of NDIS and myagedcare and extended our perspectives beyond Tasmania by sharing her extensive knowledge of MND in Australia and the world.



Unfortunately Willam Maguire, director, Hayley Tristram our MND Advisor and her manager Julie McConnell (Manager Support Services, MND Victoria) were unable to attend.

Outcomes from the workshop are a work in progress, have been presented at the AGM on March 18 and will be placed on the website and in future newsletters.

Annual General Meeting

The AGM was held in Launceston on March 18. As the final copy for this newsletter needed to be finalised before then, the report about the AGM and the past year will be in the May-June Newsletter.

Vale

We extend our heartfelt condolences to the families and friends of Jenny Hadley and of any other members who have recently passed away. Jenny was an active supporter of the Southern Support Group.

In Wendy's Words

by Wendy Cox who is a member of our MND NWSG

From when I was first diagnosed in October 2016, I knew that I would like to participate in all and any research into this Disease MND. So when my sister-in-law sent me a message about the new research program being carried out in Melbourne, I was very interested and registered immediately.

At the time I did not know when it would be happening, but sooner would be better. The process was that we arrived at the Calvary "Bethlehem" Hospital where we donate a small piece of tissue and blood. As it happened I managed to get into the first INTAKE of patients on the first day of testing. Unbelievably, so was Neale Daniher. He was the first person to donate that morning and my appointment was that afternoon.

Geoff and I arrived at the Hospital and were met by Head Scientists Dr Christopher Bye. He was so friendly and charming and told us how excited he and the team were to be doing this amazing NEW never been done before trial with a new robot that enables thousands of cells to be screened at one time. The cells would grow into thousands more and can survive for about 10 years. Those cells would be used to test and trial new drugs to fight MND. I then filled in and signed more paperwork, then went to have

bloods taken and a local anaesthetic before the small piece of tissue taken from my arm.

Having had communication with one of the Specialists from Calvary in a video conference with my GP some time last year, she came to meet and talk to me also.

The whole experience for me was very POSITIVE and worthwhile and if in the future they find a drug that slows or even better cures MND, I will have done all I could do to help not for ME, for all of US.

Life is what you make it

by Ellie, a Grade 10 student in Burnie who chose to write a life story on Michele McCulloch who was diagnosed with MND on Australia Day 2017

Michele is a family friend with a lighthearted personality, enjoying the company of friends and family, with a 'sparkling accomplishment'. She is the life of the party, putting smiles on everyone's faces, being a unique energetic human bean, making the best out of a day.

Michele Maree McCulloch was brought into the world on the 12th of October 1957 by Les and Barbara Beaumont. She was born in Burnie, moving to Rosebery, then Wynyard during her childhood. Michele had a step sister with an age gap of 30 years. She attended Rosebery District and Wynyard High to complete her education, that was somewhat difficult being dyslexic. After finishing school year 10, she went on working at Coles in the deli department.

In 1975 she married Graham and brought up their 3 girls in Ridgley, being greatly rewarded with 4 grandchildren. Michele went back to work after their children had grown up at Panorama Disability, where she worked for 32 years as a cook. Her job was something she deeply enjoyed becoming attached as they were a part of her. Unfortunately she is unable to work as a cook with her second family due to her motor skills going. When Michele has free time she makes the most of it walking, cooking, traveling, spending time with family and friends and enjoying watching television.

"Use your smile to change the world; don't let the world change your smile."

In January Michele was diagnosed with MND after returning returning from a caravan trip. She was diagnosed in Melbourne when doctors completed nerve conduction tests and spoke to neurologists and

brain surgeons. Michele had thought she had MND after watching a TV program, she wasn't surprised by the diagnosis, but didn't want to hear it was true. She had seen doctors, however they were unable to pick up on the disease having a different line of thought.

Michele's health before being diagnosed was fine, having nothing out of the ordinary. MND wasn't in Michele's family history. Michele's treatment is to keep active and busy keeping her mind sharp. Michele's goal that she sets out to achieve is, why it happened to her, and what the causes are, admiring Neale Daniher as he inspired Michele.

Michele wasn't aware of MND before being diagnosed, not knowing of anyone to experience the disease. She noticed symptoms occurring over the space of two years, starting with weakness in the hands and a cough that wouldn't disappear, eventually making swallowing a more difficult process, and collapsing muscles in her hands. Doctors conjectured it may have been carpal tunnel or a pinched nerve. Michele watched a program on the TV about Neale Daniher, a football legend with MND, she was fairly certain she had the disease.

Michele describes MND as being debilitating but she doesn't let it get to her, carrying on a normal life, experiencing tiredness often. Her doctor in Melbourne was shocked how well she was coping, keeping a positive mindset. Michele's voice wears out after talking for a while, normally towards the afternoon. She enjoys talking to anyone, and sometimes becomes frustrated when her voice is tired and struggles to be heard. Michele's motor skills are becoming more difficult to complete, making picking up small objects and holding a firm grip harder. She isn't at all scared of the disease, however worried when she loses her speech how she will communicate, being dyslexic. With her speech on the way out, it has driven Michele to make her message heard.

"While the muscle breaks down, the mind stays sharp." Michele strives to make more people aware of the disease and that's what she has set out to achieve. She used a local fundraiser that she played a large part in to learn about MND. She gathered information for others to read and understand, but also herself.

Michele and many others got together to organise a

family fun day to raise money and awareness. Her original idea was to hose nominated people down with a fire hose, however local business got on board and gave a helping hand. With the goal of creating a custom made big freeze like the AFL only in the country, they worked ideas. The turnout was a huge success having a big freeze, chocolate wheel, silent auction, raffles and much more, with a dollar from every drink purchased donated to MND. The slide was a large pipe running off the back of a truck into an icy pool. There were little amounts of chickens with approximately 50 people taking the challenge to freeze. The cost to nominate was \$10 and if they were to chicken out it cost them \$50. All money raised was donated to Menzies Research Hobart to find a cure for MND. The total count was \$13,000.



The terrific turnout surprised Michele, but meant the world. She succeeded as many more people are aware of the disease and the money raised helps a cure to be one step closer. "Live, not just survive."

Expressing her light hearted personality, Michele contains a fun adventurous lifestyle. She took her diagnosis on the chin, aware but not scared. Living day to day life in the moment, not wanting sympathy or to be treated different. Containing a positive perspective on life, valuing our world, and what it has to offer. Michele has inspired me. "No problem, is impossible to live."

Fund-Raising and Awareness-Building

Thank you to our generous fund-raisers and awareness-builders including the Ingenia Gardens Social Club, Claremont who sent us the proceeds of their residents' Christmas raffle. Sometimes we make a small change and wonder if anyone will notice.

Have you noticed that we have changed the postal cover sheet for the newsletter? Some people have! We have already received a number of donations accompanied by the cover sheet form from members. Thank you!

St Michaels Collegiate School: What a lovely surprise to find a deposit in our bank account from this wonderful group of grade 5 to 8 girls. Each year the school council selects a charity to fundraise for and in 2017 they generously chose MND Tasmania, raising a mammoth \$2460. Such kind-hearted behaviour and all done without expecting even a thank you! We couldn't let that happen though, and we have passed on our gratitude and let them know what their efforts mean to all of us.

Hash House Harriers Full Moon Red Dress Run: Oh what a day of comradery, sights and laughs! This terrific bunch took to the streets of Hobart to raise funds for our cause on February 3rd. Dressed all in red, dresses were definitely not off limits for either gender, actually the attire was encouraged for all and they were a sight to behold.

Shaking the "tin" as they made their legendary run around town they raised a whopping \$3100. We couldn't have been happier to cook a BBQ and share a drink or two with the crew when they arrived back at the Queens Head Hotel in North Hobart. This group certainly put the FUN in FUNdraising!

Beyond the River: On the 22nd February MND Tasmania hosted our first film screening. Inspired by the true story of Siseko Ntondini and Piers Cruickshanks, who together won gold in the 2014 Dusi, "Beyond the River" delivered a nail-biting adventure story about the triumph of the human spirit. An enjoyable night was had by all and we raised just over \$600. A special thank you to UTAS for donating



the use of their Centenary Lecture Theatre for the event and Charl Fourie for allowing us to screen this great film. A special thank you to all the helpers that promoted and worked in the background to make this event a success. **#togetherwecan**

Stick Fishing Trip: The annual Stick Competition is on again BUT this time they are sharing the fun and making the event public. If you like fun, fishing and fundraising get onboard and help Shane make this the most successful year to date. It's all to take place on the Macintosh Dam, Tullah on the 2nd June from 8am to 2pm. For full details or to get in contact with Shane go to the TJM Burnie Stick Comp facebook page or contact us at fundraising@mndatas.asn.au

Entertainment Books: Yes, it is that time again! The Early Bird release is underway and runs through until the end of April with the general release occurring during May. With a multitude of new offers this year, not to mention all the usual savings this book is awesome value. Check out our Website and FB page for the link and grab your copy today.

MND Week: This year MND Week will be held from Sunday 6th May through to Saturday 12th May. In years gone by we have had allocation of just one or two days to fundraise in public spaces, however, this year we have been fortunate enough to be granted permission to raise funds for the entire period. We need your help to make the most of this opportunity and welcome you to contact us ASAP to confirm your availability to volunteer and be part of this major fundraising and awareness building drive. **#togetherwecan**

What can I do to help I hear you ask? Do you have a fundraising idea? Would you like to help with an event? Do you know of a business that may be interested in supporting Walk to d'Feet MND 2018? Know someone that may like to buy an Entertainment Book? Can you help out during MND Week (6th to 12th May)?

If you answered YES to any of these questions please contact us at fundraising@mndatas.asn.au or contact us on Facebook.

Once again, a big THANKYOU to all our generous fund-raisers and awareness-builders, it is only through your work that we can continue to provide specialised care and support to the Tasmanian community. **#togetherwecan**

My blind date with MND

by Pat Stafford who wrote this verse soon after she was diagnosed with MND in 1992

My life was oh! so busy
 I had energy galore
 then I noticed there were changes
 my fingers wouldn't function
 the way they did before
 I couldn't do up buttons
 I dropped things upon the floor
 spasmodic tiredness took me by surprise
 my hand muscles disappearing
 right before my eyes
 tests and doctors' diagnosis
 indicated symptoms of MND
 motor neurone disease?
 never heard of that before
 couldn't imagine what was in store
 from MND foundation
 I sought more information
 I read it once I read it twice
 loss of body muscle, immobility
 it really wasn't very nice
 loss of voice, complete disability
 tears welled up into my eyes
 I shook my head in disbelief
 years of research but no relief
 it could be this it could be that
 no one knew for sure
 one thing that was certain
 there just wasn't any cure
 I cannot change the outcome
 but I savour every day I live
 I wish upon a star up in the Milky Way
 and if I don't last till a cure is found
 I really won't feel sore
 if money is found for research
 to help a million more.

On February 1 2018 Pat wrote to the Board - "A big thank you for your card and kind wishes on the loss of my man. Harry and I made it to 71 years married; it was not to be for Harry and I to share his 90th birthday this June ... My longevity with MND to me is my big question mark, living with who I now am, and not who

I was when in the fast lane past 20 years ago..."



MND Advisor Report

Hi everyone, for those of you who haven't had any contact with Specialist Palliative Care Services, I thought it might be worth touching on what they can offer for people living with MND. Palliative Care offer services in each of Tasmania's 3 regions, and offer multidisciplinary, team-based support for people with MND. They are integral members of our multidisciplinary case conferences held bi-monthly in each region.

Palliative care may be able to provide:

- Counselling
- dietary advice
- loan of equipment
- medical consultancy to the patient's GP
- Nursing
- occupational therapy
- opportunities for monitoring and review of symptom management
- Physiotherapy
- social worker services
- Respite
- support- pastoral, spiritual, bereavement
- support from trained volunteers

Sometimes, it can feel right to get introduced to the palliative care team early after diagnosis so you can find out who they are and how they work. For other people, it feels better to get in touch later. However you choose to do so, palliative care service is about working with you around your needs and your choices.

For more information, feel free to get in touch, or if there's anything else you might need assistance with.

Best wishes, Hayley

0412599365 / htistram@mnd.asn.au

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.

HELP NEEDED!

MND Tasmania Newsletter Editor

If you enjoy writing, reading and collating, would you please consider this vital role?

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 Tasmania. Information and contributions are collated and a draft document and attachments are sent to Heidi at the MND Victoria office 6 times a year. Heidi puts it all into Publisher and turns it into this colourful Newsletter which forms an archived history of MND Tasmania on our website. You will be coached, supported and assisted by the current editor and other members of the Board as needed.

If you think you could help in this way, please email Joyce Schuringa at 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 meetings are planned for 3 April and 1 May.

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 News

Please tell us your stories! Send them to the Editor at our postal or email address. The deadline for the next issue is 2 May 2018.

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 (to be changed at the AGM on March 18 2018)

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: 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.