

MNDnews

The newsletter of the Motor Neurone Disease Association of Tasmania



MAKING A SPLASH IN OUR COMMUNITY

MESSAGE FROM THE PRESIDENT



Welcome to 2021 – the year 2020 was one of significant changes for everyone. On top of that have been the experiences of those who have had to cope with the new diagnosis of MND. If that's the case for you, be assured that we in the MND Tasmania community are all in this together with you. The Board of MND Tasmania is continuing to work with MND Victoria to provide the support and information service for all who are affected by MND in Tasmania.

Like everyone else, as an Association, we have learned to adapt to the changes caused by COVID-19 while pushing on with our core business of supporting people and their families in Tasmania who have MND.

A year ago, we held our AGM at the magnificent paranapple Centre in Devonport in March. At the time, we were oblivious to the fact that it was the last weekend before we learned about social isolation during a pandemic. We knew we were on the edge of change and so spaced the seating at the meeting, didn't touch each other, and used hand sanitiser sparingly as it was in very short supply! In fact, it was the last time that we had a face-to-face board meeting - we learned to Zoom after that!

2020 was the year where, for the first time, our MND Advisors had to tell our members they were unable to visit them. This was an emotional hurdle for many of us. But we learned about other forms of communication and the Association made sure that people would be given tablets and taught how to use them if necessary. Tablets have become vital communication tools rather than just medicine.

At the time of reading this newsletter, we will have held our AGM – this time in Hobart on March 21. You will be able to read the report about it in the June newsletter. During 2020, the Board has focussed on revising the Constitution and succession planning. Our fundraising almost stopped, however there were generous donors who continued to donate and our deficit at the end of the year was within the budget we had set in 2019. We are indebted to previous donors and foresighted Boards for the

resources we have in the Care Foundation so that MND Tasmania and the MND Advisor service can continue to operate during a pandemic.

MND Victoria operates the MND Advisor service on our behalf and their staff spent much of last year working from home. They also assist us with the administration, publishing and mailing of the newsletter. Since the Memorandum of Understanding between our Associations which commenced in 2007, the members of MND Tasmania have received the MND Victoria newsletter as well as our own every two months. This has changed in 2021. The newsletter will be published quarterly instead of bi-monthly, and MND Victoria, MND South Australia and MND Tasmania will be sharing content in a larger newsletter which will include State-specific content. Therefore, this edition is the first of this change. You will no longer receive the MND Victoria newsletter as the relevant content has been included in this larger newsletter.

So, what do you think of this new look newsletter? Please write and let us know at info@mndtas.asn.au or see our other contact details on the back page.

On behalf of MND Tasmania, I extend our heartfelt condolences to the family and friends of Thomas Baron, Graham Frankcom, Ingrid Van Zanten, Michele McCulloch, Carol Welbourne, Vivien Bruce, Byron Minty, Srimathi Ovans, Richard Barwick, Ricky Baldock, Dianne Rule and any other members who have recently passed away.

Michelle Macpherson,
President

MND TASMANIA SAYS THANK YOU



MND Research in Tasmania

We are very thankful and proud to have many local MND researchers who are among the world's best. One of these is Professor Anna King who works in the Wicking Centre of the University of Tasmania.

Anna, who has been a Guest Speaker at a previous MND Tasmania AGM, was also mentioned in our MND Newsletter in November/December 2019 after she was awarded a Fight MND grant for a pre-clinical trial of a potential new drug for MND. We thank Anna and her team for their valuable work on MND and have asked Anna to provide an update, which is provided below.

"My interest in MND research began in 2004 when I started my PhD to investigate the pathways by which the nerve cells degenerate in neurodegenerative diseases such as MND, supervised by Professors James Vickers, Tracey Dickson and Roger Chung. I now run a lab with a number of postdoctoral research fellows, students and technical officers, investigating how nerve cells degenerate in these diseases.

The lab has two goals; firstly, to identify and test drug targets that protect nerve cells and prevent the loss of motor function; and secondly, to develop tests that can detect when nerve cells are degenerating, so that we can intervene early on in the disease process, as well as determine if treatments are having an effect.

In order to achieve these goals, I have developed strong collaborations with a number of experts with expertise in different aspects of laboratory research.

Associate Professor Anthony Cook is an expert in using stem cell technology. His laboratory can take a sample of skin cells from any person and turn these cells into nerve cells (or any other cell type we want to investigate). This is a very powerful technique because it allows us to research and test treatments in human cells. We can use cells from people who have developed MND and compare them to cells from people who have not developed MND, which helps us understand how these cells behave differently.

Dr Sharn Perry undertook her research training in Sweden and joined the team in 2017. She is an expert on motor function and the nerve circuitry of the motor system, particularly in rodent models, and is integral to the testing of potential therapeutics before they enter clinical testing.

Dr Jacqueline Leung brings expertise in brain cells that support the nerve cells, including the cells that make myelin, a fatty substance important in insulating the nerves. The team also works with chemists, neurologists and drug discovery experts, as well as other researchers in Motor Neurone Disease at the University of Tasmania, nationally and internationally.

My team has three talented postdoctoral researchers working on projects related to MND.

Dr Jessica Collins is developing blood tests to detect nerve cell degeneration and loss. She also has a keen interest in examining nerve cell changes in human tissue, which is essential to guide our research.

Dr Rachel Atkinson is interested in the links between MND and the diseases that cause frontotemporal dementia, which share many pathways and genetics. She is currently examining the role of a hormone called leptin in these diseases, working with researchers in Spain, using animal and cell models as well as human tissue.

Dr Andrew Phipps recently joined the team after completing his degree in epigenetics. Epigenetics examines how the environment and lifestyle choices are recorded in our genes and Dr Phipps has expertise in analysing complex datasets. He will be taking a lead on a project to test a therapeutic drug in a number of models of MND to determine if it is promising to be taken to the clinic.

We look forward to keeping you updated with our research and introducing some of our students of the future!"

Professor Anna King
Wicking Dementia Research and Education Centre
University of Tasmania



MND Neurology Clinic

Our last newsletter featured an article on the wonderful news of the establishment of the above clinic at the Launceston General Hospital, led by Dr Lauren Giles. At the hospital, Dr Giles will be leading a clinical trial that explores potential treatment options for MND.

It will be the first multi-centre therapeutic MND trial to be undertaken in Tasmania. The following letter of thanks was sent from MND Tasmania President Michelle Macpherson to Dr Giles:

"The Board of the Motor Neurone Disease Association of Tasmania would like to thank you for making the first MND Clinic in Tasmania a reality.

Thank you too for the summary about the Clinic that you sent to Emma Forsyth, MND Advisor, which was published in the MND Tasmania November-December 2020 newsletter.

Together with the other members of the Neurological Alliance of Tasmania (NAT), MND Tasmania worked hard to influence the Tasmanian Government to provide a sustainable number of neurologists in our state. We were very pleased when you and your colleagues were appointed to your respective positions.

The MND Clinic is a huge step forward. The lives of people who have MND in Tasmania and their families will be enriched as it develops and grows to be more accessible and inclusive. Health professionals will also benefit from the hub of a continuous multidisciplinary team and the resulting expertise.

Best wishes as you work to establish and develop the MND Clinic in Tasmania. Please contact me if there is any way that MND Tasmania can assist you, your colleagues and the Clinic."

THANK YOU CAROL

MND Tasmania is a member of MND Australia which is the peak body for MND/ALS in Australia. We benefit from being able to participate and contribute as an equal with the other states on the board of this Association.

We also share in the impact of the knowledge and advocacy that MND Australia brings into the field of MND/ALS at an Australian and international level.

After 14 years as the CEO of MND Australia, Carol Birks has announced her retirement. We would like to



extend our thanks and gratitude to Carol for all of her hard work and dedication over the years. Her invaluable contribution and commitment to improving the lives of people impacted by MND has made the world a better place. We wish her well in her 'transition to retirement'.

PERSONAL STORY

For many, the MND journey can be a rollercoaster and, for Peter Chambers, his journey was no different. Pete had symptoms for around 18 months leading into his diagnosis in December 2019. And, as he explains, no stone was left unturned when investigating the cause of his symptoms.

"There were three or four things the neurologists were looking at and had to exclude. MND was always in the background, but it was never the likely diagnosis during that 18 month period," he says. "When it was finally diagnosed as MND, there were tears, but it didn't come as a complete and utter shock. I was kind of prepared for it, but when you hear those words, it's not what you want to hear".

Not wanting his diagnosis to define him, Pete has used it as the catalyst for his positive mindset and desire to help others.

"I wanted a legacy that is not negative. There's no way I want people to look at me and remember me as being someone who couldn't cope with this.

I looked at my kids and my wife, and I wanted the legacy of 'this is how you battle a disease such as this. This is how you face and cope with adversity'. I was driven by that really early on to say I know what the end result will be, but it's not going to get me. It's not going to define me."

MND Victoria have been with Pete every step of the way since his diagnosis, providing him and his family with care and support.

"We didn't know MND Victoria existed so, to find it really quickly, to make a phone call, and to receive a phone call back in a matter of hours, and then for Fran [his MND Advisor/Support Coordinator] to be on our doorstep 48 hours later, 3 days before Christmas back in 2019, was extraordinary. To know that you've gone from finding something that you didn't know existed to all this physical support really quickly is fantastic."

Pete has now started what he calls his 'MND Career'. He is using his voice to create a platform to advocate for others living with motor neurone disease.

"It means everything to me, that I can help others with my platform," he says. "You see all the positive responses come in and it's great to know people are thinking of you, but it also reinforces that what I'm doing is being seen by people, and people are seeing it as a really positive thing for the community in general."

"I want to make a commitment to give back for what I'm receiving. To be able to contribute in any way is not only an extension of what I'm doing, it's an extension of what's driving me to be an advocate for the work of MND Victoria and the recognition of the disease itself."

Part of his MND Career has included a recent appearance on Nick Bracks' podcast, "Move Your Mind", to discuss 'Dealing with Adversity'. Throughout the episode, Pete shares the life lessons that have come from learning to live with MND and focusing on the important things in life. "It was a tough gig at the time, but it's incredible how the mind works", he says. "I have my down times of course, but you've got support around you. MND Victoria look after me - I've got an Advisor, OT's, Physio and a support network of carers who do a wonderful job of taking the stress out of my life. It means I can get on with things and lead as normal a life as I can."

Pete has created his own campaign, Pete's Legacy, where you can follow along with his journey. Visit: www.mnd.org.au/campaign/2/petes-legacy

Like all other Australians living with MND, Pete receives services from his local MND Association. Please contact your local State Association for more details on the services they provide.



LIVING BETTER

Toilet Talk

One of the key areas that people express concerns about is their ability to use the toilet safely and independently. Using the toilet is typically a very private and personal affair; so when someone experiences problems with toileting, it can be stressful and impacts on confidence and dignity.

In this article, I would like to highlight some of the most frequently requested assistive technologies and other strategies that can be used to overcome practical difficulties and enhance safety and independence.

Issues with mobility and fatigue can interfere with a person's ability to:

- * get to and from the toilet
- * sit down and stand up from the toilet
- * maintain a stable sitting position
- * manage lower-body clothing
- * manage personal hygiene tasks



Grab rails: If you find yourself grabbing at furniture or fixtures to assist with getting on and off the toilet, then this is an indication you may need grab rails. Rails come in a range of shapes, materials and sizes and are used to provide assistance with lowering and standing. Drop down rails can be stored upright when not in use. Rails should be installed by a qualified tradesperson. An occupational therapist can advise on the type and positioning of rails to optimise their effectiveness.



Toilet surround: This is a height-adjustable frame that fits around most standard toilets. It provides armrests to grasp for assistance with lowering and standing. This can be a handy alternative to installing permanent rails.



Over toilet frame (OTF): Like the toilet surround, this provides armrests to assist with transferring. An OTF also has an in-built toilet seat which sits higher than a standard toilet seat.



Toilet seat raiser: As the name suggests, this raises the height for sitting. Some models have cutouts at the front and rear of the seat to enable easier access for cleaning. If raising the height of the toilet seat, ensure your feet are still able to reach the floor as this provides greater stability than if your feet are floating.





Toilet seat raiser with arms: This piece of equipment combines the use of a raised toilet seat with armrests to assist with transfers. The armrests can swing up out of the way if you need to transfer onto the toilet from the side. What I like about this item is that it keeps the floor clear of clutter.



Commode: Commodes can offer a higher level of support and come with a wide range of features to suit different needs. For wheelchair users, if there is not sufficient space to transfer between wheelchair and toilet, it can be more effective to transfer onto a commode and then wheel into position over the toilet. Commodes can also be used to sit on during showering. Dual-purpose items such as a commode can help reduce the amount of equipment required within the bathroom.



Urinal bottle: Urinal bottles are a portable option and come in styles for men and women. Some prefer to use urinal bottles overnight to avoid the disturbance of getting out of bed and to the toilet. These can be convenient for their reduced energy expenditure requirement.



Bidet: Bidets are becoming increasingly popular for automated cleaning and drying. They direct a gentle stream of water to assist with cleaning and can be operated with a control. These are particularly helpful for people with limited use of their arms and hands. Electric bidets require a power source and different models have particular installation requirements that should be considered before purchasing.

Other ideas:

- * **Flushing controls:** For someone with hand weakness, a lever may be easier to use than a button, or alternative controls can be integrated.
- * **Adapted clothing:** If managing your clothing is difficult, consider wearing clothing that is easy to remove and adjust (e.g. loose-fitting fabric, elasticated waistband, magnetic closures).
- * **Door:** If the toilet is located in a small space, consider changing the swing of the door so that it opens outwards, or switch to a sliding door if possible. This increases the circulation space available in the room and enables a helper to access the room if you were to have a fall behind the door.
- * **Remove trip hazards:** Ensure you have a clear path to get to the toilet. Avoid having a pedestal toilet mat as these can present a trip hazard.
- * **Lighting:** Ensure you have adequate lighting to guide you to the toilet. A night light or sensor light can be handy if you tend to get up in the middle of the night to use the toilet.
- * **Carers:** If you require a carer to assist with toileting tasks, it is important that you are afforded as much choice and control as possible. Carer assessment and education can be helpful to guide caregivers on dignified ways to support you to participate with as much independence as possible.

When assessing toileting skills, the main goal is always to respect a person's right to **dignity** and to optimise **privacy, safety and independence**. There are many factors to consider when selecting equipment, so it is recommended that you get in touch with a physiotherapist or occupational therapist who can provide assessment and advice on strategies and technologies to suit your individual needs.

Sophie Nunn,
Occupational Therapist,
MND WA

MND RESEARCH

CHCB Neck Weakness Research

Neck weakness is a symptom of MND that can have a big impact on the quality of life of the person living with MND. However, there is a lack of good quality research about the characteristics of neck weakness in MND or the best evidence-based strategies to help support the head and neck.

The Physiotherapy Department at Calvary Health Care Bethlehem (CHCB) in Victoria want to change this and have teamed up with MND Victoria to commit to further research into this subject.

What has been done so far?

At the 2019 Allied Professionals Forum in Perth, the Physiotherapy team presented about their experiences in helping people to manage neck weakness and head drop.

To help guide their research, they then conducted a survey with 33 of their patients who have developed neck weakness. They found that neck weakness occurs across all types of MND and typically results in the head dropping forwards, or a combination of forwards and to the side. The most common strategies these patients used were:

- * Postural support from their recliner chair or wheelchair
- * A neck collar (79% of the patients used some form of collar) – a soft collar or Aspen Vista collar were the most commonly used
- * For 43% of the patients who use a neck collar, the team had made custom modifications to their collars to improve comfort and tolerance.

Other strategies currently used were:

- * Pillows, cushions and rolled up towels
- * Specialist headrests for wheelchairs
- * Various forehead supports or straps

So.....what's next?

The team are now collaborating with MND Victoria in a new research study to look at:

- * How common it is to develop neck weakness in MND
- * At what time period neck weakness symptoms usually develop
- * How head support strategies may change over time
- * The relationship between neck weakness and respiratory function
- * The relationship between neck weakness and walking

All this research aims to develop evidence-based guidelines/framework to help people with neck weakness improve their quality of life, and their therapists to improve the quality of care.

The authors for the research (questionnaire) are:

Timothy Sheehy – CHCB, Karol Connors – CHCB and Dr Christine Wools – CHCB.

For the second project, the following people are involved:

Timothy Sheehy – CHCB, Trinh Nguyen – CHCB, Rosanne Gibb – CHCB, Stephanie Zhao – CHCB, Sally Mathieson – CHCB, Anna Smith – CHCB, Dr Christine Wools – CHCB and Prof Prue Morgan - Head of Physiotherapy School of Primary and Allied Health Care, Monash University.



UPCOMING EVENTS

Public Policy in ALS/MND Care – An International Perspective

Robert H. Blank | Springer

The above book provides perspectives and best practice on public policy regarding MND in various countries, and includes a chapter on Australia written by Aoun, Birks, Hogden, Mathers.

The Abstract of the book is below:

“Financial support, access to respite care, in-home support and assistive technologies, and access to specialist palliative care for MND patients vary between, and within, Australian States and the age groups of patients.

While care takes place mainly at home, proportions dying at home vary between 25-34%. MND multidisciplinary clinics operate in the capital city of each mainland State. Most States have statutory Advanced Health Directives, but voluntary assisted dying is only available in the States of Victoria and Western Australia to date. To improve care and advance research, improvements are needed at three levels: the Government, the workforce and the community. Public services need to be delivered in a more timely, efficient, integrated and equitable manner. In order to inform future planning and policies for solutions to the growing demand for family/informal care and the associated challenges encountered by family carers, it is essential to integrate family carers' needs into service planning.”

Further information is available at:

<https://www.palgrave.com/gp/book/9789811558399>



Devonport Community Support Dr. Bryn Parry

On 22 December 2020, hundreds of people from the Devonport community came together to support local GP Bryn Parry, who was recently diagnosed with MND, to raise much-needed funds for MND Research.

A fantastic fun day was held with hundreds attending to enjoy the cricket, ice bucket challenges, music, food and a classic car display. Libby Cohen, MND Tasmania Board member, spoke at the event, sharing the work of MND Tasmania and the importance of the MND Advisors.



North West MND Support Group

Junene Stephens has provided the following report. We have had an interesting year with COVID-19 and missed several meetings. We had a Christmas lunch at the Ulverstone RSL and, before our luncheon, had a meeting with Emma Forsyth, MND Advisor. It was good to hear about the work that Emma does with people with MND, the number of people she visits and other aspects of her work. Thanks, Emma, for coming - you certainly have a busy time.

We will also miss Michele McCulloch who passed away on January 1 after a long battle with MND. We will miss her lovely smile and her thumbs up, as well as Chewy, her assistance dog who came to a few of our meetings with her carer. Our thoughts are with Graham and his family. Michele raised money for MND by holding two big freezes at Ridgley. Money raised was donated to MND Tasmania as well as to the Menzies Centre for research into MND. We banked \$400 that was donated at Michele's funeral to the MND North West Support Group. Our thanks go to all those who donated in Michele's memory. Graham donated a suction machine as well as food that was surplus to their needs. The machine and food have been put to good use - thanks, Graham.

We would like to thank all the businesses and customers for placing the collection boxes in their premises. Below is how the money is used.

The MND group in Ulverstone gave \$1500 to Graham and Michele to contribute towards their ramp, as well as \$1500 to help Steve and Karen with their bathroom renovation.

The group also voted to donate \$250 twice a year to our group members who have MND.

If you know anyone who has MND, please advise them of our meetings. We have posters that are available to be placed around the North West Coast. These will be available at our next meeting.

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

Northern MND Support Group

This is an informal coffee and 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.

WHEN: Every second Tuesday at 10 am

WHERE: Selah Café at the Door of Hope, 50 Glen Dhu Street, South Launceston

CONTACT: Deb Beyer is the coordinator and can be contacted on 0418 462 369, 1800 806 632 (message) or email: info@mndatas.asn.au

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GIVING



Longford Primary School Does It Again!

In the MND Tasmania November-December 2020 Newsletter, we shared news of the tremendous fundraising activities of staff and students at Longford Primary School, who set a target of raising \$1500 over two terms.

The motivation for their fundraising was the news that a long term staff member had been diagnosed with MND. As celebrated in our last newsletter, \$1000 had been raised. We are thrilled to update readers ... by the end of the 2020 school year, \$1800 had been raised which is \$300 over their target - an ice bucket challenge being the final successful event. Sincere thanks again to staff and students at Longford Primary School for your commitment to advancing research towards a cure for MND.



Why Give

MND Tasmania is a volunteer organisation receiving no government funding. We are dependent on the generosity of our community and would like to acknowledge and sincerely thank our donors, including Geilston Bay 'Hands on Craft' Group and Fraser Christmas Lights, Ulverstone.

We have also gratefully received donations in memory of David Greenwood and Michele McCulloch.

Every single contribution made to MND Tasmania, regardless of its size, helps make a difference in the lives of people living with MND. **To show your support, visit <https://www.mndatas.asn.au/index.php/menu-donations>**

MND ADVISOR AND SUPPORT CO-ORDINATION SERVICES

In late 2020, MND Victoria appointed Janet Cowling to the new role of "Keeping Connected MND Advisor".

Janet is currently working from home and has an extensive health professional background. This role is primarily to offer support information and connection to services for people living with MND and Kennedy's Disease, who are over 65 years and are more slowly progressing with a stable condition. Currently in Tasmania, there are 4 people who will receive support and be contacted by Janet. Emma and Jenny can refer to the Keeping Connected program and Janet will make contact and develop a support plan with these people. Regular contact will be via phone/email/Zoom. As, and if, the situation escalates for these people, Janet can refer them back to Emma or Jenny for closer or face-to-face support.



Above: Emma Forsyth
Left: Jenny Fuller

Client Numbers

We are currently supporting 43 registered members:

North West Region Tasmania	8
North Region Tasmania	17
Southern Tasmania	18
TOTAL	43



**CURRENTLY
SUPPORTING
43
REGISTERED
MEMBERS**



**DELIVERED
654
HOURS OF
SERVICE**

MND Advisors and NDIS Support Co-ordinators

Northern Tasmania: Emma Forsyth (Mon, Wed, Thurs):
p: 0456 182 551 or e: eforsyth@mnd.asn.au

Southern Tasmania: Jenny Fuller (Tue, Wed, Fri):
p: 0412 599 365 or e: jfuller@mnd.asn.au

Team Leader: Eric Kelly (Mon-Fri.):
p: 0421 323 850 or e: ekelly@mnd.asn.au

FREECALL 1800 806 632

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.



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