



In this edition

CuATSM trial... Mullets for MND... Are you thinking about travelling?... Fungal neurotoxins and MND... Living Well with MND in Orange 20 February... Staying connected - Internet, email, text messages and verbal communication... Save the dates for Walk to d'Feet MND 2019... and more.

MND in the news - CuATSM (copper ATSM)

Australian media has recently reported on a poster presented at the 29th International Symposium on ALS/MND held in Glasgow in December that reported outcomes of a phase 1 Clinical Trial conducted in Australia. The phase 1 trial was designed to test the safety and dosage of the compound CuATSM and research funds donated to MND NSW have been part of the \$1.2million invested in trials of copper ATSM through the MND Research Institute of Australia.

CLT-26 Modification of ALS disease progression in a phase 1 trial of CuATSM
Dominic Rowe¹, Susan Mathers², Georgia Smith¹, Emma Windebank², Mary-Louise Rogers³, Kay Noel⁴, Craig S. Rosenfeld⁴
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Results presented in the poster support the establishment of a randomised, placebo controlled phase 2 study to further test CuATSM. You can read the poster pdf [here](#) (look for poster number CLT-26 which reports the results).

Although the results are promising CuATSM will need to be tested on more people in order to look at its effect on the progression of MND. We are

(Continued on page 2)



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hopeful that a phase 2 trial will commence later in 2019 and we will keep the MND community up to date as more information becomes available. Updates on this trial and other trials being conducted in Australia are listed on the [Clinical Trials](#) page on the MND Australia website and the [Australian Government Clinical Trials](#) website.

This [MND Research blog article](#) describes the context of the research findings and cautions against over-interpreting promising early data. It also explains that CuATSM is a specialised compound and is not the same as taking copper supplements, which can be poisonous in high doses. Other information of interest includes:

- update from the researcher Associate Professor Peter Crouch in the [MND Australia Spotlight on research: Update on copper-ATSM](#)
- [2GB interview](#) with Professor Dominic Rowe and Associate Professor Peter Crouch here
- a report from the [Channel 9 The Project TV show](#)
- [information on the development of copper-ATSM](#) and the work of Associate Professor Peter Crouch and his team to date

Living Well with MND Information Day

20 February at Orange

11 April at Newcastle

24 September at Berry

22 October at West Ryde

Living Well with MND is an informative day for people living with motor neurone disease, their families and friends.

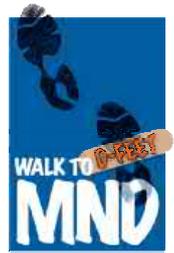
You will be provided with a range of strategies to live well with MND and to maintain independence. You will also have the opportunity to have your questions answered by health professionals with expertise in MND, and to meet others who understand what it is like to live with MND. There is no cost to attend the program but you need to reserve your place. [Find out more.](#)



2019 Walk to d'Feet MND

Save the date - registrations opening soon

Teams made up of family, friends, colleagues and individuals, regardless of age or fitness levels, walk to raise funds and awareness for research and support for people living with MND.



14
Apr

Walk to d'Feet MND Forbes *Supported by*
Lions Park
Forbes NSW



5
May

Walk to d'Feet MND Illawarra *Supported by*
Bulli Surf Club
Bulli NSW



26
May

Walk to d'Feet MND Hunter *Supported by*
Speers Point Park
Speers Point NSW



16
Jun

Walk to d'Feet MND Canberra *Supported by*
ACT



7
Jul

Walk to d'Feet MND Penrith *Supported by*
International Regatta Centre
Castlereagh NSW



2
Aug

Corporate Walk Sydney *Would your company like to support this event?*
More details soon

8
Sep

Walk to d'Feet MND Taree *Supported by*
More details soon



20
Oct

Walk to d'Feet MND Young *Supported by*
More details soon



3
Nov

Walk to d'Feet MND Sydney *Supported by*
More details soon



Support Service Update

It has been a busy start to the New Year for MND NSW. Our FlexEquip services have been swamped with new requests for equipment and are working to complete orders, speak with allied health workers and manage deliveries. So much so that we have added to this team with the appointment of Ben Whiffin, Equipment Assistant, who commenced in January. Ben is a very welcome addition and will help us to continue to improve our service to members.



I am also delighted to let you know that the new MND Advisor for the Far North Coast has also now started in the role. Sandra Woolnough is well known in the region and has worked within the community, aged and disability sectors for many years. We know she will be a great asset to our members and to the organisation. Sandra will be based in our Murwillumbah office.

The recent media attention around the CuATSM (copper ATSM) trial has caused a good deal of interest from our MND community. This trial is just one of a number of important studies taking place around the world, that give some glimmer of hope to finding a cure for MND. You can read more about the CuATSM phase 1 trial results on the front page of this edition of *e-news*. We understand that the research team hope to commence phase two of the trial from mid-2019. Understandably, we have had many enquiries from members wanting to access the phase 2 trial. We recommend that if you are interested that you speak with your neurologist about the study criteria and your suitability to participate. We will continue to monitor this and other research and provide updates as they come to hand.

Just a reminder that we will be running both Living Well with MND (for people living with MND, family and friends) and MND Aware (for service providers) in Orange over 20 and 21 February. You can find out more about the Living Well with MND program on page 2.

(Continued on page 5)

(Continued from page 4)

We have already commenced work on some new education and information programs which we hope to roll out in the first half of the year. They are designed specifically for new members and their families and we will provide more information in the coming months.

As always, please do not hesitate to contact me if you have any suggestions for how we can continue to improve our services.

Karen Martin
Manager

Wollongong's 2019 Citizen of the Year - Dr Justin Yerbury

Dr Justin Yerbury, MND researcher from UOW: University of Wollongong, Australia was named Wollongong's Citizen of the Year at the Australia Day Awards ceremony in January. For over a decade, Dr Yerbury has been actively involved in motor neurone disease advocacy, fundraising and research. Not only has he worked internationally, but has built a world recognised MND research group in the Illawarra. Photo: Illawarra Mercury.



Are you, or is a person in your family, an MND Genie?

MND Genies is a closed unlisted Facebook group for people, living in Australia or New Zealand, who have a motor neurone disease related genetic mutation, but do not have MND.

The aim of MND Genies is to provide a space where people can connect and share their experience of having an MND related genetic

mutation. MND NSW does not endorse comments or posts made by group participants.



To join MND Genies or for more information about the group contact Kate Maguire MND NSW at mndgenies@mndnsw.asn.au or ph. 02 8877 0902.

FlexEquip

FlexEquip is the equipment service provided by the Motor Neurone Disease Association of NSW. FlexEquip provides equipment to adults diagnosed with MND, who are over 65 years old and to adults diagnosed with MND who are NDIS participants living in NSW or ACT.



Care of equipment in the hot weather

With the extremes in temperature over the past weeks a reminder that extra care should be taken with equipment you may be using.

Cushions – Check the air pressure of air cushions, for example Roho cushions, at least daily. In extremes of temperature check the air pressure more frequently to ensure the air pressure that has been recommended by your occupational therapist, is maintained. In hot weather the air inside the cushion will expand. This causes the pressure inside the cushion to increase making the cushion firmer than it should be and can pop the cushion. In cold weather, the reverse is the case and the air pressure may be too low for use.

Wheelchair tyres – Although not all wheelchair tyres have inflatable inner tubes, those that do will need the correct air pressure. If your wheelchair does have inflatable tyres then the correct air pressure will be marked on the outside rim of the tyre. The tyres can be inflated with a portable air compressor or at a local service station.

Equipment in vehicles – Equipment should not be left in vehicles that are not under cover in the hot weather for extended periods of time as the equipment item can be easily damaged by the heat making it unsafe to use. This includes any equipment with batteries which should not be stored near any heat source and air cushions and wheelchair tyres which can overinflate.

Maree Hibbert

Team Leader - FlexEquip

Upcoming Support Service events

Click to find out more.

20
Feb **Living Well with MND**
Orange

26
Mar **Past carers lunch**
Gladesville

11
Apr **Living Well with MND**
Newcastle

11
May **Day of Hope and Remembrance**
Homebush

14
May **Care for Carers 14 May, 21 May, 28 May and 4 June**
Gladesville

12
Aug **Ask the Experts Forum**
West Ryde

17
Sep **Past carers lunch**
Gladesville

24
Sep **Living Well with MND**
Berry

10
Oct **Celebrating National Carers Week morning tea**
Pennant Hills

22
Oct **Living Well with MND**
West Ryde

7-8
Nov **Link and Learn**
Hunter

The Lap of Honour 2018 Raffle

A big thank you to Tony Calleja who raised \$1,390 from a raffle in support of MND NSW as part of his fundraising effort - 'The Lap of Honour 2018'. Thank you to everyone who supported Tony with a ticket purchase and congratulations to the winners! Pictured is Tony at one of his raffle ticket sale locations.



Mullets for MND

Thank you to the Kootingal Hotel and their amazing supporters who have raised over \$16,700 for motor neurone disease from their Mullets for MND event. The idea for the event was to raise awareness and funds, and to have some fun along the way. The months of mullet growing culminated in a day of family fun, live music and the mullet judging competition. Pictured right is chef Josh who went all the way! Thank you to the Kootingal community for your support.



Bunnings Sausage Sizzle at Eastgardens

A big thank you to Daniela Kacev, along with her family and friends, who raised \$1,450 for MND NSW from a recent Sausage Sizzle at Bunnings Eastgardens. The Sausage Sizzle was held in honour of a family friend who had died from MND.



Member library

Don't forget that members and carers have the opportunity to borrow MND-related books and DVDs for up to a month at a time, at no cost, from our member library. Contact the MND Info Line ph. 02 8877 0999 or email infoline@mndnsw.asn.au for details.

Christmas Appeal thank you

Thank you to all of our wonderful supporters who contributed to our 2018 Christmas Appeal. The appeal raised over \$40,000 and will assist us to provide the best possible care and support for people living with motor neurone disease.

‘Together we can!’



Community Calendar

Click to find out more.

23
Feb

5th MND Charity Concert

Grace Evangelical Church Auditorium - Glendale

5-11
May

MND Week 2019

Various across NSW and ACT

26
May

Run MND - Sutherland Shire

Sutherland

26
May

Run MND - Central Coast

Long Jetty Reserve

27
May

Hike for Health - Great Wall of China

Raise vital funds for MND NSW

18
Jun

Riddla MND Golf Fundraiser 2019

NSW Golf Club, La Perouse

12
Oct

Gundaroo Music Festival 2019

Gundaroo

Do you have a great idea for an event or activity that will raise funds for motor neurone disease care, support and research? <http://www.mndnsw.asn.au/get-involved/fundraise.html>

Are you thinking about travelling?

Although it takes a bit more organising, it is possible to find suitable accommodation and travel if you have MND. Here are some places to start.

Ideas

Ideas is a disability information organisation that provides information and assistance to people who are aged; have a disability, or are disadvantaged; their families, carers, supporters and service providers. Ideas provide a comprehensive list of accommodation and organisations that can support with accessible holidays. If you have an area or location in mind that you would like to stay then this will help narrow the search on the Ideas website - get started here [Accessible holiday accommodation](#) -

Trip Advisor

[TripAdvisor](#) is a large travel website. When looking for accommodation, you can change the accommodation search parameters to include 'accessible rooms' and 'wheelchair access', but double-check accessibility with the accommodation provider directly before finalising any payments.

Air BnB

Air BnB is an accommodation site where you can search for accommodation. For accessible accommodation searches you need to modify the search criteria/filters by following the [Air BnB instructions](#). You may also need to message the hosts to double-check they are able to meet your requirements.

Six-week Talk Link telephone support group starting February 2019

Are you caring for someone with MND in NSW? Would you like to be part of a telephone support group that focuses upon building your strengths as a carer? Through MND NSW's continued partnership with Carers NSW, their National Counselling program offers MND carers the Carer Well Being Talk-Link Program. The next program is commencing Tuesday 12 February 2019 and this six week telephone support group is free and suitable for anyone who is caring role. Find out more [here](#).

Are you caring for someone with MND? Do you want to increase your knowledge?

14 May, 21 May, 28 May and 4 June at MND NSW Centre Gladesville

Care for Carers is a supportive educational program for those caring for a family member or partner with motor neurone disease. Care for Carers runs once a week for four weeks and participants attend all sessions. There is no cost to attend the program but you need to reserve your place. [Find out more.](#)



Video from International Ask the Experts December 2018, Scotland, now free online

The full video of the International Ask the Experts session from the recent International ALS/MND meetings in Scotland can be viewed [free online on Facebook](#). Speakers include

- Professor Orla Hardiman, Director of the National ALS Clinic & Irish ALS Research Group on the subject of clinical trials in ALS/MND
- Professor Dame Pamela Shaw, from the University of Sheffield, on current key developments in MND research and looking to the future
- Dr. Arpan Mehta, from the University of Edinburgh, on stem cells and MND.



Bunnings Sausage Sizzle

Congratulations to Denise Morris and friends who recently held a sausage sizzle at Tuggeranong Bunnings raising \$1234 to support people living with motor neurone disease. What a great effort on a very hot day.



Thank you Berry Chiropractic and Berry Mixed Touch Football

A big thank you to the wonderful staff of Berry Chiropractic who recently held a MND Fundraising Garage Sale with \$3,454 raised. Berry Chiropractic said of the event, "We had a great day and were completely overwhelmed by the generosity and care of the Berry and wider community." Our thanks also to Berry Junior Mixed Touch Football for their generous donation of \$2,000 towards the event.



MND support groups and coffee mornings - 2019 calendar

MND support groups and coffee mornings provide the opportunity for people living with motor neurone disease to meet together regularly to chat and learn from each other. Regular meetings are held in the ACT, Campbelltown, Central Coast, Gold Coast, Illawarra, North West NSW (Tamworth), Northern Beaches and Northern Sydney. Meetings are also held from time-to-time in the Northern Rivers and Wagga Wagga/Albury areas. See the [full 2019 calendar online](#).



Accessible Telecoms

Accessible Telecoms is a nationwide disability telecommunications service that provides independent, up-to-date information on mainstream and assistive telecommunication products including fixed landline phones, mobile phones and accessories suitable for people with disabilities. This service also provides referrals for training, set-up, on-going support and equipment provision. The service is free and provided by Ideas Inc. It can be used by anyone, people with disability, their family & carers, service providers and advocates. [Find out more about Accessible Telecoms here](#).



Award for MND NSW

We are excited to announce MND NSW was selected as the winner of the Disability Services Consulting (DSC) 2018 Provider Awards in the category NDIS Transition for our proactive and progressive approach to solving NDIS challenges. Thank you to Karen Dempsey of Epic Rehab for nominating us and to DSC for this Award.



Newcastle Royals Korfball Club Trivia Night

A big thank you to the Newcastle Royals who recently held a trivia night to raise money for MND NSW as well as one of their founding members recently diagnosed with motor neurone disease. Korfball is a court sport with similarities to basketball and netball but played in mixed gender teams. The Royals Korfball Club trivia night received fantastic support with around 230 people in attendance. A donation of \$2,805 was made to MND NSW from the night. A special thank you to Rob Akers who coordinated the event, and to everyone who provided their support.



Advance December 2018

Advance is the newsletter of the MND Research Institute of Australia (MNDRIA) - the research arm of MND Australia. The Advance December 2018 edition reports on funds received and distributed in 2019 grants by the MNDRIA. It also explains the important function of the MNDRIA Research Committee which evaluates all grant applications using an extremely thorough peer reviewed process that supports the best research that has the greatest chance of changing the future of MND.



Illawarra Folk Festival

Since 2001 the Illawarra Folk Festival has supported charities and non-profit organisations from funds raised at their opening night concert. We were thrilled to be chosen as one of the charities to benefit from this year's festival. Thank you to our wonderful volunteers who attended the event, and the Illawarra Folk Festival for supporting MND NSW.



MND Australia International Research Update December 2018

MND Australia International Research Update is produced by the MND Research Institute of Australia - the research arm of MND Australia. This Update provides plain-English explanations of MND research developments. The December edition explores gene mutation research, cells and stress, MND-linked cell proteins and more.



Read the latest MND research news in the [MND Australia Research Update December 2018 edition](#).

Past Carers Lunch

26 March at MND NSW Centre Gladesville

This is a lunch and get together for people who have experienced bereavement during the last year. This occasion provides an opportunity for you to reconnect with old friends from MND NSW and to meet others who have cared for someone with MND. After lunch there will be a talk and discussion about some of the experiences of bereavement and possible ways to manage these.

There is no cost to attend the program but you need to reserve your place. More information here <http://www.mndnsw.asn.au/all-events/living-with-mnd.html>.



Together we can

Leaving a gift in your will to MND NSW will help us to provide support as needed for people living with motor neurone disease. Until there is a cure we need to make provision for the support and care required by our members and their families. For more information about making a gift for the future please contact Kym Nielsen, MND NSW ph. 02 8877 0912 or kymn@mndnsw.asn.au.

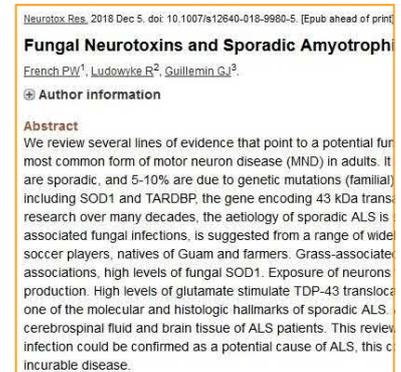
Newcastle Italian Film Festival

A very big thank you to Nick Moretti (pictured right with Graham Opie, MND NSW CEO) and his wonderful team from the Newcastle Italian Film Festival. This is the 5th year the Festival has supported the work of MND NSW with the most recent Festival raising \$14,000. A huge achievement.



Hypothesis about fungal neurotoxins and sporadic motor neurone disease in the news

A hypothesis adding another small piece to the MND jigsaw featured on the ABC radio AM program and on some news channels in Australia in December 2018. The story briefly explored a review article about fungal neurotoxins and sporadic motor neurone disease, published in December in the journal Neurotoxicity Research.



The researchers reviewed several lines of evidence for fungal neurotoxins as a potential contributing factor to the cause of MND concluding that if fungal infection could be confirmed as a potential cause of ALS, it could inform treatment strategy. The original article is here but access is limited

<https://www.ncbi.nlm.nih.gov/pubmed/30515715> and the story is here <https://www.abc.net.au/radio/programs/am/a-fungus-found-in-grass-could-be-behind-motor-neuron-disease/10633412>

Staying connected - Internet, email, text messages and verbal communication and MND. *Peteris Ginters (MND NSW member) shares what he has learnt along the way*

It has been approximately two years since I was diagnosed with motor neurone disease. In that time the strength in my arms and hands has gradually declined to the point where I have gone from being able to use a computer keyboard and mouse (and mobile phone) without difficulty, then with difficulty and now not at all. Obviously, this has had a significant impact on my ability to communicate and remain (semi-)independent and active.

From an early stage I started investigating options that would allow me to have access to a computer so I could use the Internet, send and receive emails and text messages and use of my mobile phone remotely et cetera.

I have also spent time investigating some of the voice recording/synthesis options that are available for people with MND. Although I don't need this type of assistance yet (or, hopefully, in the near future) all the information I read suggested it is better to "bank" your voice sooner rather than later.

I thought it might be useful if I shared my experiences with assistive technology that aids with communication when your ability to use your hands is limited or non-existent. (This article has been written using some of the equipment described below.)

At the outset though a note of caution. I have no particular expertise in the area of assistive technology/communication aids other than that which I have discovered through discussions with my speech pathologist and my own investigations. It would therefore be worthwhile for anybody who wants to look further into these matters to do so in consultation with their speech pathologist.

As my hand and arm strength declined I found a particularly useful way of being able to continue to access my computer was through the

(Continued on page 17)

(Continued from page 16)

use of Dragon voice activated software (which I use in combination with a microphone attached to my computer the Acoustic Magic VT-II.

I have had my tablet computer, microphone and mobile phone mounted on a Pentalock stand. A photograph of my set up is pictured right.

Without wishing to overly complicate the issue my speech pathologist also had me trial (and I ultimately purchased) gyroscopic mouse hardware and software known as Quha Zono. This allows me to control my computer cursor through a small gyroscopic mouse that I attach to my glasses. I use this equipment in combination with Grid 3



communication software to access and use all programs in the Microsoft Office suite as well as the Internet. In addition, I discovered a \$20 or so android phone app called Remote Phone Call that, when used with my android phone, Quha Zono mouse and Grid 3 software (mentioned above), allows me to send and receive text messages through my computer, and answer and make phone calls through my computer, without needing to use my hands.

About six months ago I also started investigating what is out there in terms of synthesised voice programs. This is because I was concerned I might ultimately lose my voice and, if that occurs, I want to be in a position where I can continue to communicate using 'my voice' rather than a generic computer-generated voice.

My researches have led me to discover there are various options out there, at various price points. Mention of some of these options can be found in an article in the May 2018 NSW MND newsletter.

(Continued on page 18)

(Continued from page 17)

There is one product from a British company known as CereVoice Me, the results of which you can see on a demonstration video (for what it's worth, the synthesised voice quality as shown on the video is quite good. However, the downside of this option is I understand it is you have to pay up front (£499) before you can begin the process of recording sentences to synthesise.

Recently a free software program developed through Project Revoice and an Australian company called Lyrebird was released. I spent a couple of hours reading and downloading the sentences provided with this program (I recall I read approximately 500 sentences, although you don't need to do nearly this many, but the more you do the better the accuracy). When I then went to the next stage and typed some text and played it back with my synthesised voice I was not overwhelmed with the result. The synthesised voice didn't really sound like mine. It may well be though that others will have better results with this software. As it is currently free for people who register it is certainly an option worth considering, particularly if cost is an issue.

The most realistic option I have found to date is produced by a European company called Acapela Group, with the software known as My Own Voice. With this system you can do the upfront work (recording sentences that appear on the screen), and you only have to pay for the product when you want to finally download and use it. That said, there is a capacity in the home page to log in using your login and type and have played back a sample of your synthesise voice for free. That is very useful.

The My Own Voice process involves reading back to the computer through a microphone approximately 500 sentences. Often these sentences make no sense. They are designed to create a digital recording of your voice that can be manipulated by the software to create new words. Of course, you don't need to record all 500 or so

(Continued on page 19)

(Continued from page 18)

sentences, but the more you do the greater the accuracy and clarity of the synthesised voice. To record the 500 sentences takes a minimum of four to five hours, as you need to do it in half hour to 45 minute blocks, otherwise you find your voice gets too tired.

The synthesised My Own Voice is very good. Indeed, it's a bit disconcerting at first (but in a good way) to hear an extremely close replica of your voice played back to you with a slight digitised/synthesised overlay.

Again, you get what you pay for and unfortunately the cost to download the final synthesised My Own Voice product is, as I recollect it, somewhere in the vicinity of €2000 to €2500, so it may be out of reach for many people. I guess it depends on how important it is for you to have your own voice as a means of communication through a computer if you lose your voice because of MND.

Finally, I should note, that an important selling point of the My Own Voice product is that it is compatible with, and therefore can be used in conjunction with, the Grid 3 communication software.

Peteris Ginters

Article link summary

| | |
|---------------------------------|---|
| Dragon voice activated software | https://www.voicerecognition.com.au/collections/dragon-professional |
| Acoustic Magic VT-II | https://www.acousticmagic.com/products/voice-tracker-ii-details/ |
| Quha Zono gyroscopic mouse | https://www.quha.com/products-2/zono/ |
| Pentalock stand | https://rehadapt.com/product/fs-pentalock-tele/ |
| Grid 3 communication software | https://thinksmartbox.com/product/grid-3/ |
| Remote Phone Call | https://www.justremotephone.com/ |
| Synthesised voice options | http://view.mndnsw.asn.au/mnd-nsw-e-news-2018-may/page/8-9 |
| CereVoice Me | https://www.cereproc.com/en/products/cerevoiceme |
| Project Revoice | https://www.projectrevoice.org/ |
| My Own Voice | https://www.acapela-group.com/voices/voice-banking/ |





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Admin Assistant NDIS

Brenda Smith

...and many valued volunteers