



MND Research Network Newsletter

Winter 2021

Welcome to our Winter newsletter with the latest updates from the MND Research Network. June was MND awareness month, and we hosted a “Cuppa tea for MND” at the School of Biological Sciences in the University of Auckland. We raised \$450 for MND New Zealand. You can view photos of this event on our [Facebook page](#). If you are interested in raising funds and promoting awareness of MND, please contact [MND New Zealand](#) for information on how you can support.



We were excited to see so many people attend our first teleconference on 14th April 2021 with attendees from various backgrounds all with a shared interest in MND. The purpose of the MND Research Network is to facilitate the interaction between MND biomedical and clinical researchers, allied health professionals, and other researchers who will have an impact on MND in New Zealand. It was therefore fantastic to have professionals from all these disciplines including people with lived experience of MND attend. Thank you to everyone who joined, especially our presenters Dr Paige Thomas, Dr Michal Boyd, and Grace Chen. We received positive feedback from attendees who found the presentations informative and interesting. For those of you unable to attend, a recording, and a synopsis of each speakers presentation is available on the [MND Research Network website](#). Keep reading for more information about our next teleconference on 5th August.

In this newsletter you can read about:

- MND Research Network teleconference updates
- Publications
- Resources for researchers
- Research updates
- Upcoming national / international conferences

I encourage you to share this newsletter and information about our teleconferences within your networks. If you know anyone interested in MND research, please encourage them to connect with us via social media or email.

Warm regards,
Dympna Mulroy
NZ MND Research Network Manager

5th August Teleconference



The next teleconference is scheduled for Thursday 5th August from 10am to 11.30am. Please share information about this teleconference within your networks and to others who have an interest in MND. [Click here](#) to access the Zoom log in, and calendar link.

We are delighted to announce the following presenters for August, who both have a significant portfolio of experience in MND research.

[Dr Luke McAlary; Post-Doctoral Fellow, University of Wollongong, New South Wales](#)



Dr McAlary is a Post-Doctoral Fellow from the University of Wollongong. Dr McAlary's research involves targeting prion-like strains of TDP-43. Toxic proteins in MND are capable of spreading from cell to cell in the spinal cord and brain by recruiting normal healthy protein. This spread is controlled by the shape of the toxic protein, some shapes spread more readily than others. Advanced imaging technologies have been produced to see the shape of individual proteins. Dr McAlary plans to use these imaging technologies to define the shape(s) of toxic MND proteins and apply a broad set of drug discovery methods to identify the best drugs to target them.

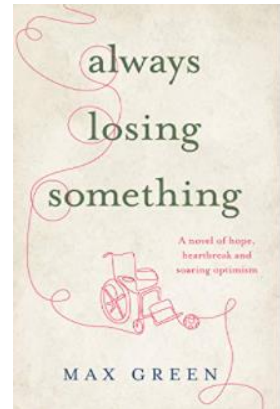
[Dr Emma Scotter; Head, Motor Neuron Disease Research Lab, Centre for Brain Research, University of Auckland.](#)



Dr Emma Scotter is head of the New Zealand Motor Neuron Disease Research Lab. Dr Scotter and her team research various aspects of Motor Neuron Disease, and in this teleconference, she will present an overview of research currently happening in the lab. This includes the nationwide MND genetics study, and insights from her labs program of human brain tissue and cell studies. In particular she will describe the route from identifying genetic changes in people with MND to understanding whether those gene changes have caused their disease or are simply normal variation.

Publications

New Zealander Marcus Gerbich, who has lived with MND since 2016, recently published 'Always Losing Something' under his pseudonym Max Green. Marcus is committed to raising awareness of MND and this fictional novel is based on his own personal experience and tackling the topic of what it might take to cure MND in 10 years. Marcus is also researching "The Global Economics of MND" in collaboration with MND New Zealand. "Always Losing Something", is available on [Amazon](#).



New Zealand Guidelines for Motor Neurone Disease Care

The MND Clinical Working Group (CWG) consists of 16 clinicians across multiple disciplines from New Zealand, who have an interest in improving care for people with MND and their families. The group are developing national guidelines for the assessment and management of MND. The draft "New Zealand Guidelines for Motor Neurone Disease Care" have been distributed to specialty medical and health professional organisations for feedback and endorsement. Once finalised the CWG aim to promote these guidelines at national conferences this year. It is hoped the guidelines will provide national consistency while remaining flexible and adaptable for local district health boards. They will be available on the MND New Zealand website, once they are finalised. The CWG are also writing a summary document for publication in the NZ Medical Journal. We will send a notification on our social media pages when the guidelines are published.

Resources



Amyotrophic Lateral Sclerosis online Database (ALSoD) collates information about genes and genetic variants connected to ALS. This includes genes and variants with a large effect on increasing MND risk, a small effect on increasing MND risk, and those for which an association has been shown but the evidence is currently weak. They also record information about genes and variants that may affect clinical aspects of the disease, for example how long people live after diagnosis. If you are interested in learning about the genetic variants connected to ALS you can read more about the different genes and categories on the [ALSoD website](#).



ARRIVE guidelines 2.0

The ARRIVE (Animal Research: Reporting of In Vivo Experiments) guidelines are a checklist of recommendations to improve the reporting of research involving animals. They have been revised to further support researchers in improving the reliability and reproducibility of their work through better reporting. Items within the guidelines have been organised into two sets to help researchers include the most important information within their manuscript. The guidelines can be viewed on the website www.arriveguidelines.org



New Zealand Association of Clinical Research

New Zealand Association of Clinical Research (NZACRes) is a professional association for clinical researchers in New Zealand. Membership is open to all those who have an interest in clinical research. Their goal is to promote and support clinical research within New Zealand through the provision of networking and educational opportunities, industry resources, and collaborations to address industry issues and create solutions. NZACRes also provides the clinical research community with a unified voice and a means for industry consultation. Membership is currently FREE until March 2022! Further information is available [here](#).

[Research news – clinical trials and studies](#)

News releases and research updates are posted on our website - [research news page](#) and social media page – [Twitter](#) and [Facebook](#). Follow us to keep updated on what is happening.

Understanding the genetics of MND



MND research is becoming increasingly focused on the role that genes play in the development of the disease and how gene therapies may provide more personalised treatment options for people with MND in the future. A recent international study by

access will be allowed for a subset of the SOD1-ALS population with the most rapidly progressive disease.

2. If results from the Phase 3 study indicate that tofersen is safe and effective, and if no further studies are required, Biogen will initiate an early access program for the broad SOD1-ALS population in countries where this is permitted by local regulations.

[Tofersen \(BIIB067\) Biogen; Presymptomatic Adults with SOD1 mutation.](#)

Leading on from the anticipated success of Tofersen (BIIB067) for symptomatic SOD1, a study for clinically presymptomatic adults with SOD1 mutation was recently announced. Individuals must have a protocol-defined rapidly progressive SOD1 mutation and be clinically presymptomatic for ALS and with plasma NfL levels less than the protocol-defined threshold. The development of drugs for presymptomatic adults of MND highlights the importance of current studies investigating the genetic causes and associations of MND and early identification of individuals with a genetic form of MND.

[Arimoclomol - ORPHAZYME](#)

It was disappointing to hear that the ORARIALS-01 pivotal trial of arimoclomol in ALS did not meet its primary and secondary endpoints to show benefit in people living with ALS. The randomized, placebo-controlled Phase 3 trial was conducted among 245 patients at 29 sites in 12 countries in North America and Europe. No important safety signals were reported in the trial. The completed data from the study will be published later this year.

[Conferences](#)

For a full list of upcoming conferences, webinars, and recordings of previous webinars please go to the events section on our [website](#). Below is a list of some upcoming conferences that are more accessible as travel restrictions remain ongoing.



[Brain Health Research Centre Conference | 8–9 July 2021 | Online or Dunedin](#)

The BHRC Annual Conference will feature a range of presentations across the field of neuroscience, and an Assistant Research Fellow and Speaker prize will be awarded on 8 July. This is a free conference, hosted by the University of Otago at their Dunedin campus. Zoom attendees are also welcome. More information is available [here](#).

Australasian Winter Conference on Brain Research | 29 – 31 Aug 2021 | Queenstown



Australasian Winter Conference on Brain Research (AWCBBR) encourages a multidisciplinary approach to neuroscience. This conference is New Zealand's premier annual Neuroscience conference attracting delegates from all over New Zealand and beyond. Early bird registration closes on Monday 19th July. [Click here for more information.](#)

MND Australia Conference | 3rd September 2021 | Online

The 10th National MND Australia Conference is scheduled to be held on Friday 3rd September. Due to changing COVID-related Australian travel restrictions the conference will now be online only. This National MND Australia conference is for clinicians, health professionals, and disability and aged care providers from across Australia and New Zealand who have an interest in and care for people living with MND. People living with MND, their family, and friends are also encouraged to register. Attendees will be updated with evidence-based clinical and practical information and will also have the opportunity to network with fellow practitioners, share expertise, and problem solve. [Click here for more information.](#)

32nd International Symposium on ALS/MND | 7 – 10 December 2021 | Online

Each year, the Symposium attracts over 1,000 delegates, representing the energy and dynamism of the global MND research community. It is the largest medical and scientific conference specific to MND/ALS and is the premier event in the MND research calendar for discussion on the latest advances in research and clinical management. Following the success of last year's first virtual Symposium and the ongoing challenges caused by the global pandemic, the MND Association's 32nd International Symposium on ALS/MND in December 2021 will once again be held online. [Click here for more Information.](#)

Allied Professionals Forum (APF) | 3 – 4 December 2021 | Online

The Allied Professionals Forum (APF) is an educational and training forum for allied health professionals who specialise in ALS/MND. This international forum offers healthcare professionals from around the world an opportunity to share ideas on good practice in the daily management of people with ALS/MND. The International Alliance of ALS/MND Associations will host a virtual Allied Professionals Forum spread over two days to accommodate time zones. Information about this forum is available [here](#).

MND Research Network Teleconference April – Synopsis

In April we were delighted to welcome Dr Paige Thomas, Dr Michal Boyd, and Grace Chen



who presented to our MND Research Network community. Some of you expressed interest but were unable to attend and a recording of this teleconference is now available on our website to watch in your own time. If you are limited on time a summary of each presentation is also available. [Click here to view.](#)

Dr Paige Thomas presented her PhD study on the impact of swallowing skill training protocol in patients with ALS.

This study investigated a new type of swallowing therapy using the Biofeedback in Strength and Skill Training (BiSSkiT) protocol with the aim of prolonging swallow and quality of life. Improvement was noted in two outcome measures which were of particular importance; 1. quality of life and 2. the degree of movement of the hyoid bone. Additional research with a larger cohort is warranted to determine if this therapy is of benefit to people with MND.

Grace Chen discussed her ongoing research and associations between occupational exposures and MND in New Zealand.

This is the first NZ population-based-control-study to investigate the associations between MND and occupational and environmental risk factors in New Zealand. Elevated risks were observed for agricultural, and construction occupations, and specific occupational exposures were also identified that can elevate the risk of MND.

Dr Michal Boyd discussed her study looking at the provision of end-of-life care in chronic illness, dementia, and cancer.

This study explored quality of death in residential aged care from staff, and family perspectives. Participants had a diagnosis of cancer, dementia, or chronic disease. Although they did not need a diagnosis of MND the results are still relevant to the MND community.

Want to see something in our October newsletter?

Please send any articles or contributions to

MNDresearch@auckland.ac.nz

*Until then we hope you can join us
on the 5th of August for our next teleconference!*

