

Advance

December 2023



MNDRA Research Report

It has been another action-packed six months in the world of MND research. In positive news we have seen new treatments for MND make their way to Australia, however we have also seen the failure of some clinical trials. Some of these outcomes are disappointing however they demonstrate the hard work that is underway and it is just as important to know what doesn't work as well as what does!

I have had a busy 6 months and have been fortunate to attend a number of fantastic fundraising events. In September I also had the great experience of attending my first Pan-Asian Consortium for Treatment and Research in ALS (PACTALS) meeting, which was held in Malaysia. The meeting was a fantastic opportunity to

meet local MND associations from Asia. Interestingly, there was a strong representation from drug companies at the meeting demonstrating the increasing importance of the Asian region for clinical trials.

On a very sad note, the MND research community lost a giant of research and a staunch advocate with the passing of Professor Justin Yerbury in July 2023. Refusing to give in to this cruel disease that afflicted him and took many of his family members, Justin forged a brilliant research career leading an amazing team at the University of Wollongong developing new treatments for MND. As a mark of his legacy, we held the National Research Symposium in Wollongong and much of the

Vale Professor Justin Yerbury

best research being showcased at that meeting was coming from Justin's research team who are carrying on his work.

There's been a lot more happening at MNDRA and in the MND research space. Please take the opportunity to read my full report online: mndaustralia.org.au/articles.

Dr Gethin Thomas
Executive Director Research



We hope you like our simplified version of Advance. There are expanded versions of some of our stories online that you can read at mndaustralia.org.au/articles. We'd love to hear your feedback on our newsletter. Let us know what you think by taking this survey.

MND Research Grants commencing in 2024

MND Research Australia is immensely grateful to our donors, who have allowed us to allocate just over \$3.1 million to fund vital MND Research Projects around Australia in 2024.



The Daniel McLoone MND Research Prize (2024-25)

Dr Chien-Hsiung (Alan) Yu, University of Melbourne

Spatially Tracing Immune-mediated Neurodegeneration: a Guiding Map to Novel Discoveries (STING-MND)



The Bill Gole MND Postdoctoral Fellowship (2024-26)

Dr Rachel Atkinson, University of Tasmania

Freezing MND in its tracks



The Jim Zissimopoulos MND Postdoctoral Fellowship (2024-26)

Dr Nicole Sheers, University of Melbourne

Developing a new exercise therapy to improve breathing and cough in people living with MND



The David Deguara MND Postdoctoral Fellowship (2024-26)

Dr Thais Sobanski, The University of Queensland

Boosting sugar breakdown to halt the progression of MND



The Charcot Award, supported by MonSTaR

Dr Adekunle Temitope Bademosi, The University of Queensland

Investigating the role of synaptic proteins in MND neurodegeneration

To read more about these grants and the 17 additional Innovator Grants awarded for 2024, visit: mndaustralia.org.au/currentresearch

Daniel McLoone 2023 Major Research Initiative

In September we announced the two recipients of the Daniel McLoone Major Research Initiative. These research grants are jointly funded by MNDRA and FightMND. Each project will receive a total of \$1 million over four years.



Dr Thanuja Dharmadasa from the University of Melbourne and the Florey Institute of Neuroscience and Mental Health. *Exploring disease heterogeneity across MND clinical phenotypes using a multimodal, multicentre neuroimaging approach*



Professor Bradley Turner at the University of Melbourne and the Florey Institute of Neuroscience and Mental Health. *Australian Preclinical Research ALS (APRALS) Network: a roadmap for effective translation of therapeutics for sporadic MND*

MiNDAUS

There is still a lot we don't know about MND, including its causes and why it affects people in different ways. The MiNDAUS Registry is the name of the Australian Motor Neurone Disease Registry. A registry allows us to collect data about all those living with MND in Australia and get a picture of where they are, how their disease is developing and insights into potential causes and what treatments are working. For the registry to be at its most powerful, it is critical we engage as many participants as possible. The Registry is Australian, voluntary and highly secure and is open to all people diagnosed with MND in Australia. The registry allows people with MND to record information about themselves and their specific needs in the one place, via the patient registry. There is also an option to link to the clinical registry, which enables healthcare workers, clinicians and researchers to work together to achieve the best outcomes and develop evidence-based health policies for people affected by MND. It is free, quick and easy to join. You can register yourself or ask your MND clinic to help register you. mindaus.org

MND Connect

Whether you're living with MND, a caregiver, a family member, or a professional, MND Connect website has easy-to-understand information and resources on a wide range of MND-related topics.

Over the past few years, thanks to funding from an Australian Department of Social Services ILC grant, we've been hard at work developing the site and creating new and updated information. So why not head over and look for yourself.

Each page on MND Connect features a star rating widget at the bottom. Your feedback matters to us, so don't hesitate

to share your thoughts if you'd like to. mndconnect.org.au



Access to non-invasive ventilation in MND is an equity issue in Australia by Dr Marnie Graco, MNDRA 2022 Nancy Gray MND Postdoctoral Fellowship recipient

Motor neurone disease causes the muscles to weaken, including the muscles involved in breathing. Weakening respiratory muscles can lead to symptoms such as fatigue, difficulty sleeping and shortness of breath. Research has shown that using overnight breathing support or “non-invasive ventilation” (NIV) improves quality of life and can extend life for people with MND. In fact, NIV is currently the most effective treatment for extending life in MND.

However, data from the Australian MND registry

showed that from 2005 to 2015 just **one in five people** with MND in Australia tried NIV. Not everyone with MND will need or want to use NIV, but everybody should have the same opportunity to try it.

We have recently conducted a survey that has shown 25% of respondents had never discussed NIV with a health professional. Furthermore, using NIV was related to where people live (including their state and remoteness), their gender, who they live with, and whether they attend an MND multidisciplinary clinic.



'Dr Marnie Graco discussing NIV use with Natalie and Bruce'

This suggests there is inequitable access to NIV across Australia. We are delving deeper in this problem by interviewing people with MND, their families, and health professionals. Together, this information will help us to design solutions that address the problems we find to improve people's access to this effective treatment.

To read an expanded version of this story visit mndaustralia.org.au/articles

State of Play

Our State of Play webinars have continued throughout 2023 and will return again in 2024. To watch all previous editions and to sign up for upcoming webinars visit mndaustralia.org.au/stateofplay.



STATE OF PLAY
2023



Research Directions

Insights on Australian & international MND research by Dr Gethin Thomas, Executive Research Director

Have you heard about Research Directions? This monthly update is written by Dr Gethin Thomas and features insights on Australian and international MND research. Check out the news section on our website (mndaustralia.org.au) and follow us on Facebook (facebook.com/mndaustralia) to make sure you don't miss out.



We hope you like our simplified version of Advance. There are expanded versions of some of our stories online that you can read at mndaustralia.org.au/articles. We'd love to hear your feedback on our newsletter. Let us know what you think by taking this survey.



MND Research Australia relies on the generous support of donors to maintain its important MND research grants program. Please fill in the form below or visit mndaustralia.org.au/donatetoresearch

MY GIFT (donations over \$2 are tax deductible)

I would like to make a donation to MND Research Australia of:

\$50 \$100 \$200 \$500 \$

PAYMENT DETAILS

I enclose my cheque payable to MND Research Australia

I have made a direct deposit to MND Research Australia BSB: 062-152; Acc No: 00902053

Card number:

Name on card:

Expiry date: /

CVC:

MY CONTACT DETAILS (For receipting)

Name:

Address:

Suburb:

Postcode:

Ph:

Email:

Please contact me about including MND Research Australia in my will

To donate online or to sign up as a regular donor visit mndaustralia.org.au/donatetoresearch

Return this form in the reply paid envelope provided or:

Call us on **02 8287 4989**

Post to: **MND Research Australia**

PO Box 117, Deakin West, ACT 2600