

Advance

December 2024

mnd
Australia



Continuing to build Australian MND research

The best thing about the December edition of Advance is announcing the research projects we'll support in 2025. Once again, our focus is on emerging Australian researchers, with many new names among this year's grant recipients.

Funded projects include investigating environmental risk factors, developing genetic therapies, tracking disease progression, improving nighttime patient care, and managing cognitive changes. A total of \$2.55M will be allocated, thanks to the continued generosity of our MND community. To ensure the funds are used effectively, expert researchers review the applications, and our Research Committee finalizes the selections. This year, we were also pleased to include someone with lived experience in the final discussions, providing invaluable insight to guide our decisions.

Another marker of how our approach of funding early career stage researchers and new ideas to build world-class Australian MND research is the progression of projects through to larger grants. The recent FightMND grant announcement features many projects initiated with MND Australia funding that have moved through the development pipeline towards potential clinical use.

In June, 2024, MND Australia hosted a special event at Parliament House in Canberra, awarding lifetime achievement medals to 30 individuals who have made significant contributions to the MND community over the past 30 years, including many researchers and Janet Nash, who led MNDRA from 1984 to 2019.

We also hosted the highly successful 3rd Australian and New Zealand MND Research Symposium in Melbourne, with over 300 attendees. Highlights included presentations from people with MND, world-leading international researchers, groundbreaking Australian research, and lively debates.

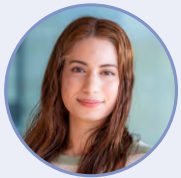
Globally, treatment options continue to expand. For updates on new therapies, including Biogen's SOD1 treatment, high-dose B12, Monepantel, and the Synchron Brain-Computer Interface, see the full version of this report at mndaustralia.org.au/articles.

Despite the challenges of the current economic climate, we continue to be inspired and humbled by the unwavering support of our community. Thank you.

Dr Gethin Thomas
Executive Director, Research

MND Research Grants commencing in 2025

MND Australia is incredibly grateful for the ongoing support of our donors, whose generosity has enabled us to allocate \$2.55 million to fund vital MND research across Australia. This essential funding is helping to drive increased understanding of MND.



The Bill Gole MND Postdoctoral Fellowship (2025-27)

Dr Azin Amin, The University of Melbourne

Development of an autophagy-inducing peptide as a therapy for MND



The MND Australia Postdoctoral Fellowship (2025-27)

Dr Nathan Pavey, The University of Sydney

Cortical Strength Duration Time Constant in the pathogenesis and evolution of MND/ALS



The Scott Sullivan MND Postdoctoral Fellowship (2025-27)

Dr Sophia Luikinga, The University of Queensland

Clinical validity of lipid dysregulation in MND



The Charcot Award, supported by Fat Rabbit

A/Prof Dominic Ng, The University of Queensland

Striking a sour note: Intracellular acidosis as a trigger for ALS pathomechanisms

Linda Elphick MND Research Grant

Yuval Gurfinkel, Murdoch University
Investigating the transcriptome of sALS patient fibroblasts after SOD1 suppression treatment

Peter Stearne Familial MND Research Grant

Dr Rita Mejzini, Murdoch University
Pre-clinical development of FUS targeted Antisense Oligonucleotides

Murray Geale MND Research Grant

Dr Eduardo Albornoz,
The University of Queensland
A Novel Patient-Derived Microglia-Brain Organoid Model to Accelerate Drug Discovery in MND

NTI MND Research Grant

Dr Lotta Oikari, QIMR Berghofer
Investigating the impact of TDP-43 pathology on blood-brain barrier integrity in ALS

Col Bambrick MND Research Grant

Dr Sonam Parakh, Macquarie University
Investigating the role of GABAA agonists as novel therapeutic against TDP-43 pathology

Paul Brock MND Research Grant

Dr Abigail Pfaff, Murdoch University
Examining the role of L1 retrotransposons in motor neuron disease

Jenny Simko MND Research Grant

Dr Andrew Phipps, The University of Tasmania
Protecting against axon degeneration in MND

Superball XVII MND Research Grant

Natalie Grima, Macquarie University
Investigating the molecular origin of a "C9orf72-like" patient subgroup of sporadic ALS

MonSTaR MND Research Grant

Neville Ng, University of Wollongong
Screening small molecules to promote innervation in a motor neuron disease neuromuscular junction patient stem cell model

Daniel Veysey MND Research Grant

Dr Saravanabavan Sayanthoran,
Macquarie University
Novel approaches to examining the environmental risks associated with ALS

Eileen Grace Bignall MND Research Grant

Prof. Peter Catchside, Flinders University
A novel mattress sensor device to improve MND care through comprehensive nightly movement and breathing assessments

To read more about the grants funded in 2025, visit: mndaustralia.org.au/currentresearch

Innovator Grants

Ian Sneddon Two Rivers Run MND Research Grant

Dr Grant Richter, Macquarie University
What's upstream of loss of nuclear TDP-43 function? The impact of phosphorylation on RNA binding

The Elizabeth and Peter John Cahill MND Research Grant

Dr Nirma Perera, The University of Melbourne
Unlocking the Potential of Astrocytic Autophagy: A Novel Approach to Extend Motor Neuron Survival in MND

MND South Australia MND Research Grant

Rebecca Francis, Flinders University
Families with MND as partners: Developing a joint approach to clinical discussions and management of cognitive and behavioural changes

Spotlight on research

by 2024 Bill Gole Fellow Dr Rachel Atkinson

When our core body temperature drops, our bodies activate a fascinating defence mechanism known as the 'cold stress response'. This response can protect our nervous system by safeguarding nerve cells and can also halt muscle wastage. It's a survival trick seen in hibernating mammals and in patients undergoing therapeutic cooling after stroke or spinal cord injury. Interestingly, it's also triggered in people who practice ice-bathing and cold-water swimming.

One key player in this protective response is a molecule known as RBM3, which is increased following cold stress. Imagine if we could harness the benefits of the cold stress response to treat MND. That is the exciting question driving my research.

In 2024, I was honoured to receive the Bill Gole Postdoctoral Research Fellowship to delve deeper into this potential breakthrough. Current treatments for MND often target single disease processes, but MND is a complex condition involving multiple pathways. To effectively combat it, we need to act upon several of these pathways simultaneously.

Our colleagues in Europe recently developed a drug that boosts RBM3 levels without the need for cooling.

This drug has already shown promise in reducing harmful changes in other brain diseases modelled in mice. With the support of the Bill Gole Fellowship, we aim to test this RBM3-enhancing drug to see if it can slow down disease progression and be protective in a mouse model of MND.

Additionally, we'll use our mouse models to explore the effects of

whole-body cooling on MND processes by using another drug that safely lowers body temperature. By combining these two approaches, we hope to uncover more about the therapeutic potential of cold stress in treating MND.

Stay tuned as we embark on this exciting journey to unlock new treatments for MND, inspired by the power of cold! Please contact me at Rachel.Atkinson@utas.edu.au if you would like to know more.



The National MND Lived Experience Network (LEN) was launched by MND Australia in August 2024. To date, we have had a total of 26 requests submitted by professional organisations/groups, wanting to connect with the more than 120 LEN members located across Australia, for a variety of purposes. Some of these requests have been related to research and it is great to see more lived experience voices getting involved in research. This includes participating in the grants process, joining advisory committees to inform & develop new research projects, or offering to act as a participant in current studies. So far, the feedback all round has been very positive. To read more about the LEN, visit mndaustralia.org.au/livedexperience



At our recent AGM, MND Research Australia and MND Australia agreed to a complete merger to form a single organisation—MND Australia. We remain committed to funding critical MND research through our dedicated grants program, ensuring that all donations earmarked for research are allocated exclusively for this purpose. Our robust grant review process will continue to be managed by our experienced Research Committee, supported by an expert Grant Review Panel. For more detailed information on this merge, please visit the news section of our website: mndaustralia.org.au/articles

2025 marks 20 years of the prestigious Bill Gole Postdoctoral MND Research Fellowship



To celebrate this milestone, we reflect on the profound impact this fellowship has had on the MND research landscape in Australia.

Bill Gole, who passed away from motor neurone disease in 2003, inspired a philanthropic friend to fund a PhD scholarship for Professor Steve Vucic in 2004. Professor Vucic has since become a leading Australian neurologist in the field of MND. Building on this, the philanthropist established the Bill Gole Postdoctoral Fellowship to further the legacy of Bill's impact.

The fellowship provides a three-year salary for emerging researchers to focus on MND research and advance their work. The first fellowship was awarded in 2005 to Roger Chung, who has become a prominent MND researcher and leader at Macquarie University.

Over the years, the Bill Gole Fellowship has become one of the most prestigious grants in Australian MND research. Many former fellows have risen to leadership roles, heading their own research teams and mentoring the next generation

of MND researchers. The list of past and present fellows reads like a "Who's Who" of Australian MND research: Roger Chung, Ian Blair, Julia Morahan, Anna King, Justin Yerbury, Shu Yang, Cathy Blizzard, Shu Ngo, Kelly Williams, Fleur Garton, Jennifer Fifita, Nirma Perera, Rosie Clark, Luke McAlary, Tom Shaw, Fiona Bright, Jeremy Lum, and Rachel Atkinson. These individuals have made invaluable contributions to understanding MND and have helped nurture a new wave of talent in the field, as we see with current fellows being mentored by former Bill Gole fellows. One such example is Luke McAlary who was mentored by the great MND researcher Justin Yerbury who himself passed away last year from MND.

Remarkably, the fellowship has been funded by the same philanthropist every year since its inception in 2005, demonstrating how one visionary idea can profoundly shape an entire field of research. The Bill Gole Fellowship has truly become a cornerstone of Australia's world-class MND research community.

MND Australia's research grants program 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

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