

**FIGHT
MND.**
IT TAKES PEOPLE

2023 Cure & Care Booklet



FightMND to invest \$20.2 million in MND research and care in 2023

FightMND are proud to announce we will invest a further \$20.2 million into Motor Neurone Disease (MND) research and care initiatives for people with MND in 2023.

WE'RE INVESTING \$20.2M INTO MND RESEARCH AND CARE

FIGHT MND.
IT TAKES PEOPLE

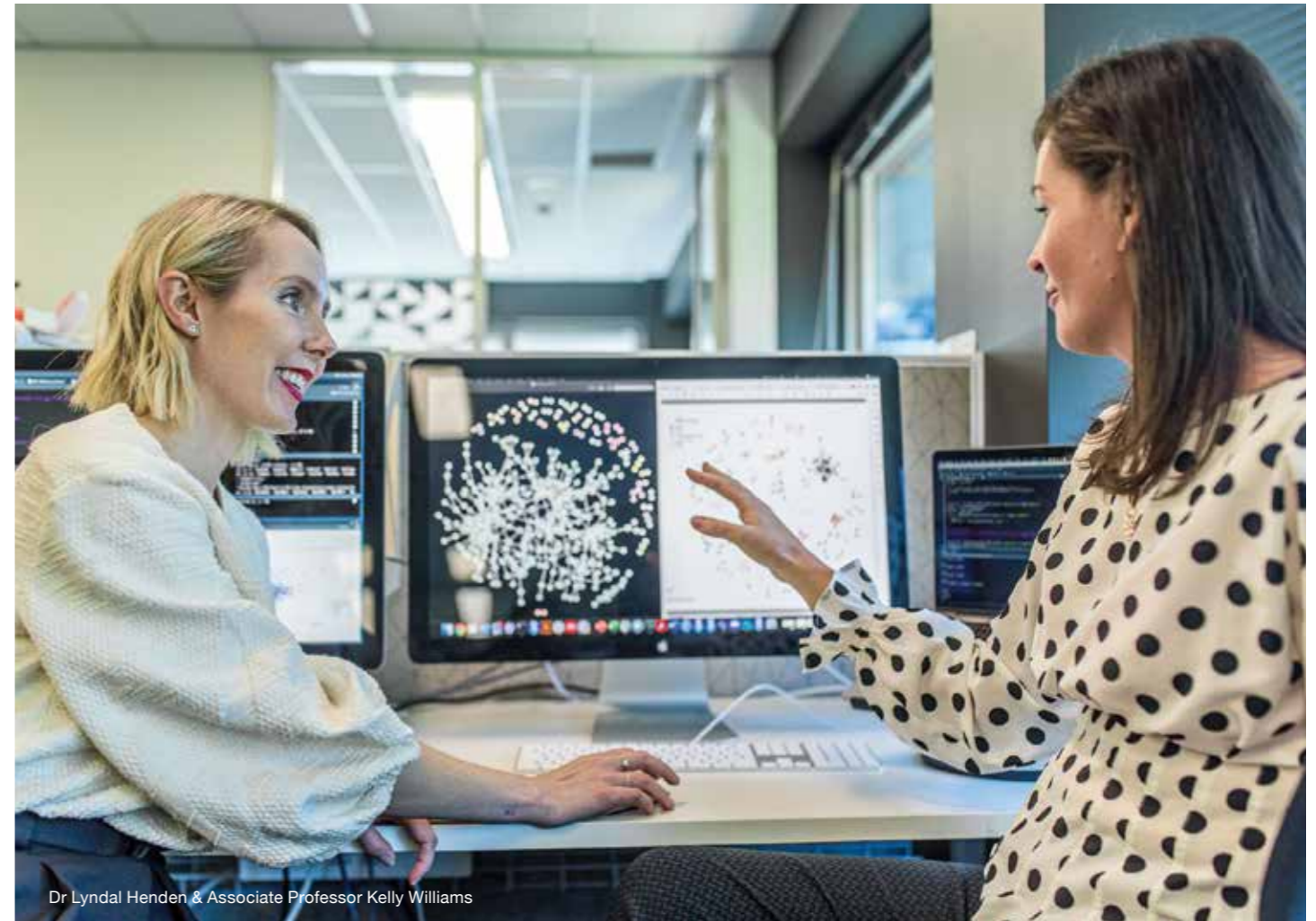
 **\$16.54M**

into research projects so we can get closer to defeating the Beast

 **\$3.67M**

into care projects to support people living with MND and their families

Thank you for being **ALL IN** with us, together we are **changing the future** for people with MND.



Of the \$20.2 million, FightMND will commit \$16.5M into MND Research, including support of 23 projects and 6 career development awards:

- 1 Clinical Trial
- 7 Drug Development Projects;
- 4 Discovery Projects;
- 7 IMProving and Accelerating Translation (IMPACT) Projects;
- 1 Clinical Investigator award;
- 2 Mid-Career Research Fellowships;
- 2 Early Career Research Fellowship; and
- 1 Angie Cunningham PhD Scholarship and Grant-in-Aid

Additional funds invested in 2023 include:

- 2 Daniel McLoone Major Research Initiatives – co-funded with MND Australia;
- Other research initiatives (Victorian Brain Bank, Massey Park grant, COVID-19 Impact support funding)

FightMND will also commit a further \$3.67 million into 22 MND Care Support projects for Australians living with and affected by MND. This funding will support projects that:

- Provide equipment, technology and at home needs;
- Support the development and delivery of MND education initiatives; and
- Support the establishment and growth of support groups in the MND community

CURE Investment

1 x Clinical Trial

Clinical trials test promising new drugs, or drugs already approved for other diseases or conditions in people with MND. Phase 3 trials are studies that test the safety and effectiveness of drugs in a large group of people living with MND. Phase 2 trials are studies that test the safety and effectiveness of a drug in a smaller number of people living with MND. Phase 1 trials are safety studies to assess whether a drug is safe to administer to people, and in particular, people with MND.

CLINICAL TRIAL /

PROJECT /

Phase 2/3 Clinical Trial – A randomized, phase II/III trial on the biological and clinical effects of acetyl-L-carnitine in MND /

PROJECT LEAD:
Professor Steve Vucic
(The University of Sydney, NSW)

AMOUNT FUNDED:
\$1,799,816

SUMMARY:
This phase 2/3 clinical trial conducted in Australia and Italy tests a re-purposed drug called ALCAR in 250 MND patients. ALCAR showed early promise by slowing MND progression and prolonging survival in smaller studies, and this new trial will provide definitive data on ALCAR's potential to advance as an MND therapy.



"This trial provides real treatment hope for patients living with MND"



CURE Investment

7 x Drug Development Projects

Drug Development projects focus on advancing promising new drugs or therapies through the final stages of testing in preparation for their progression to clinical trials for MND patients.

STAGE 1 /
DRUG DEVELOPMENT PROJECTS (MAX \$550,000) /

PROJECT /
Discovery of STING inhibitors for the treatment of Motor Neuron Disease /

PROJECT LEAD:
Professor Peter Crack
(The University of Melbourne, VIC)

AMOUNT FUNDED:
\$549,515

SUMMARY:
Professor Crack will lead a team to screen a library of drugs to find the most promising candidates to treat inflammation in MND, a major driver of disease progression. Professor Crack is a first-time recipient of FightMND funding.

“We aim to modulate the neuroinflammatory response and potentially slow down or halt the progression of MND”



Professor Peter Crack

**STAGE 1 /
DRUG DEVELOPMENT PROJECTS (MAX \$550,000) /**

PROJECT /
Selective blockade of microglial Kv1.3 with HsTX1[R14A]
as a novel approach for the treatment of Motor Neurone Disease /

PROJECT LEAD:
Associate Professor
Joseph Nicolazzo
(Monash University, VIC)

AMOUNT FUNDED:
\$549,638

SUMMARY:
Increased inflammation in the brain is thought to contribute to the death of motor neurons in MND. This project tests if a new drug can block a key inflammatory pathway to reduce inflammation and prevent loss of motor neurons in MND.



Above: Associate Professor Joseph Nicolazzo |
Below: Team

“Our research group wholeheartedly thanks donors and supporters of FightMND who have made it possible for FightMND to back local researchers to hopefully make a difference for individuals with MND”

**STAGE 1 /
DRUG DEVELOPMENT PROJECTS (MAX \$550,000) /**

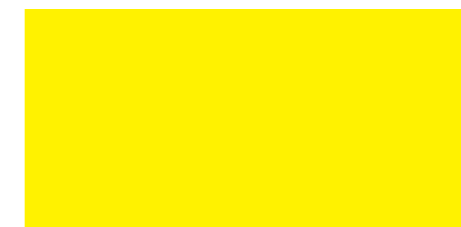
PROJECT /
A blood-brain barrier permeable DHODH inhibitor for treating MND /

PROJECT LEAD:
Associate Professor Peter Crouch
(The University of Melbourne, VIC)

AMOUNT FUNDED:
\$475,085

SUMMARY:
Associate Professor Crouch and team will test if a new treatment developed for brain cancer can also slow disease progression in preclinical models of MND. Because this drug can reach and act on brain areas affected in MND, positive outcomes from this study may fast-track its advance to a clinical trial for MND.

“Because of your donations and support, you’re in the lab with us every day”



Associate Professor Peter Crouch (left) & team

**STAGE 1 /
DRUG DEVELOPMENT PROJECTS (MAX \$550,000) /**

PROJECT /
Novel axonal regenerative therapy using antisense oligonucleotides for sporadic and familial MND /

PROJECT LEAD:
Dr Dunhui (Oliver) Li
(Murdoch University, WA)

AMOUNT FUNDED:
\$549,537

SUMMARY:
This project tests a new strategy to repair and protect dying neurons and wasting muscles in MND using a gene therapy approach, hoping to improve function and survival outcomes in patients.

**STAGE 1 /
DRUG DEVELOPMENT PROJECTS (MAX \$550,000) /**

PROJECT /
Development of next-generation blood-brain barrier penetrating SOD1-targeting antisense therapy /

PROJECT LEAD:
Dr Fazel Shabanpoor
(The Florey/The University of Melbourne, VIC)

AMOUNT FUNDED:
\$547,406

SUMMARY:
Dr Shabanpoor's team is designing an advanced way to deliver gene therapies for treating MND. They aim to improve on the amount of gene therapy that can reach motor neurons and reduce the invasiveness of current methods. The team will test how effectively their new design reduces a form of a protein called SOD1, that is harmful to motor neurons.

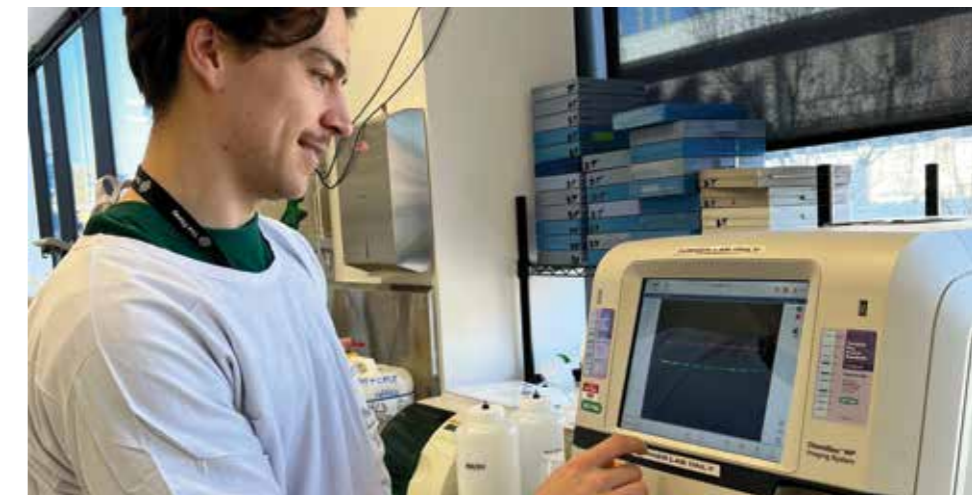
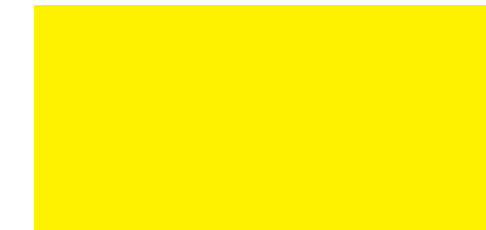
“Our study will assess the feasibility of developing an innovative axonal regenerative treatment for both sporadic and familial MND”



Above: Dr Dunhui (Oliver) Li | Right: Team



“By directly targeting the root cause of MND in patients harboring SOD1 mutations, this approach will prevent the degeneration of motor neurons”



Left: Dr Fazel Shabanpoor | Right: Research in the lab

**STAGE 1 /
DRUG DEVELOPMENT PROJECTS (MAX \$550,000) /**

PROJECT /
Validation of NC-B8 anti-CD38 antibody safety
and efficacy using human MND samples /

PROJECT LEAD:
Dr Damien Toulorge
(ENCEFA, France)

AMOUNT FUNDED:
\$505,583

SUMMARY:
This project will gather evidence in preclinical models of MND to support the advance of a drug called NC-B8 to a clinical trial for MND. NC-B8 has a number of mechanisms of action to tackle MND in multiple areas.



“Our research projects aims to further validate the efficacy and safety of our MND treatment”



Left: Dr Damien Toulorge | Above: Research lab



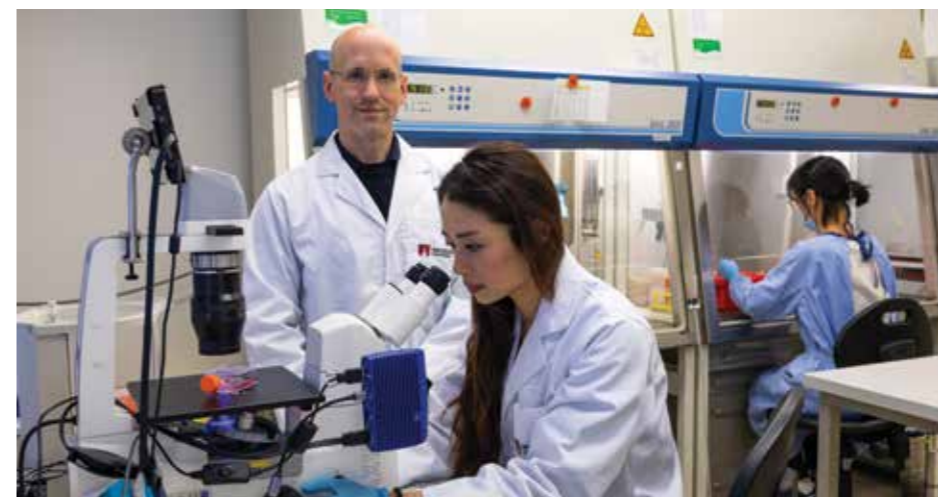
**STAGE 2 /
DRUG DEVELOPMENT PROJECTS (MAX \$1,200,000) /**

PROJECT /
Translating a novel gene therapy for MND towards clinical testing /

PROJECT LEAD:
Professor Lars Ittner
(Macquarie University, NSW)

AMOUNT FUNDED:
\$1,200,000

SUMMARY:
This project will test the safety and effectiveness of a new gene therapy targeting TDP-43, a key protein in MND that accumulates in motor neurons and makes them unhealthy. Successful outcomes will bring the gene therapy closer to a clinical trial for MND. Professor Ittner is a first-time recipient of FightMND funding.



Professor Lars Ittner (left) & research team



“Gene therapies offer the opportunity for long-term therapeutic effects from a single administration”



CURE Investment

4 x Discovery Projects

Discovery projects aim to resolve one or more current unknowns in the MND research sector, focused on discovering why MND occurs and what contributes to its progression. Outcomes should significantly advance our understanding of MND, and substantially increase the likelihood of accelerating the development of more effective treatments or cure for MND.



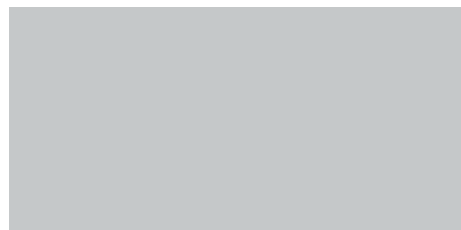
**DISCOVERY PROJECTS /
INVESTIGATING NEURONAL SUPPORT CELLS
AND THEIR DYSFUNCTION IN MND /**

PROJECT /
Oligodendrocytes and TDP-43 pathology in MND /

PROJECT LEAD:
Dr Adam Walker
(The University of Queensland, QLD)

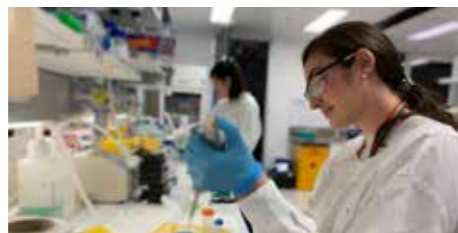
AMOUNT FUNDED:
\$1,000,000

SUMMARY:
Dr Walker received the 2022 Bill Guest Mid-Career Fellowship. This project is part of his broader research program to understand the role of the MND-linked protein, called TDP-43, in MND.



Left: Dr Adam Walker | Right: Lab

“This is a completely new project bringing together researchers from Brisbane, Melbourne, Hobart and Auckland to tackle an important under-studied area of MND”



**DISCOVERY PROJECTS /
UNDERSTANDING THE EARLIEST SIGNS OF MND DEVELOPMENT /**

PROJECT /
ACORN (Australian C9orf72 National Study) /

PROJECT LEAD:
Dr Thanuja Dharmadasa
(The Florey/The University of Melbourne, VIC)

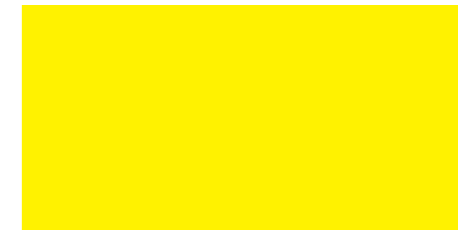
AMOUNT FUNDED:
\$999,294

SUMMARY:
Dr Dharmadasa is a first-time recipient of FightMND funding. This project will harness collaborations between clinical researchers in Australia and the UK who will study MND in people before symptoms emerge, to understand the earliest signs of disease and to enable treatment for MND to begin much earlier than is currently possible.



Left & right: Dr Thanuja Dharmadasa | Centre: Research team

“The successful development of future therapies in MND depends on a better understanding of the very early, presymptomatic phase of the neurodegenerative process”



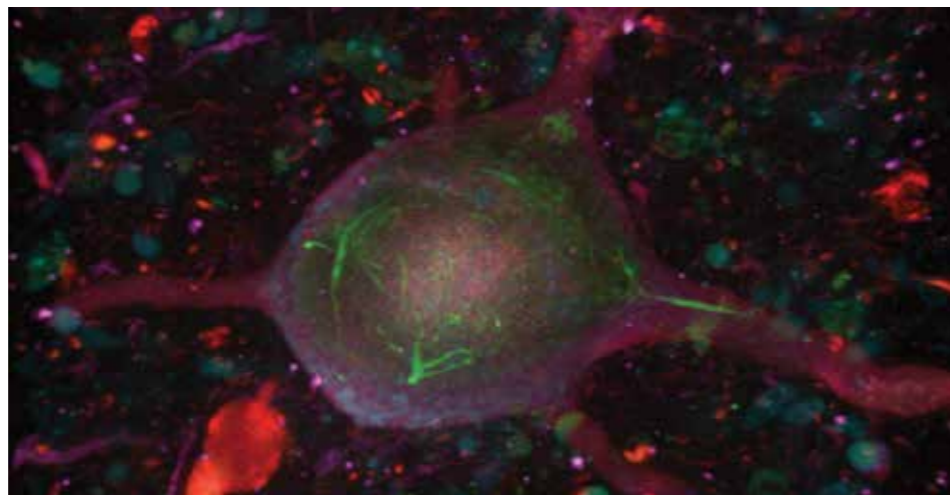
**DISCOVERY PROJECTS /
UNDERSTANDING HOW TDP-43 REGULATES GENES IN MND /**

PROJECT /
Deciphering the role of TDP-43 regulation
of cryptic exons in MND pathogenesis /

PROJECT LEAD:
Professor Roger Chung
(Macquarie University, NSW)

AMOUNT FUNDED:
\$997,931

SUMMARY:
This discovery project seeks to understand some of the fundamental molecular causes of motor neuron death and MND. It will study how a protein called TDP-43, that becomes harmful in MND, alters the make-up of genes in motor neurons, and how this genetic change causes MND.



Above: Professor Roger Chung |
Right: Motor neuron under the microscope

“We look forward to reporting on the outcomes of this research, and advancing knowledge towards development of treatments for MND”

**DISCOVERY PROJECTS /
RETROVIRUSES AND MND /**

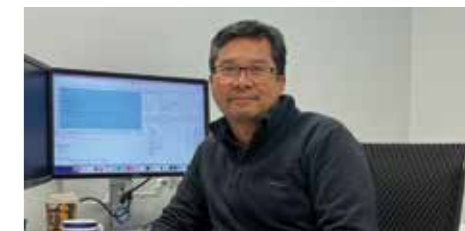
PROJECT /
How Does Human Endogenous Retrovirus Cause MND? /

PROJECT LEAD:
Associate Professor
Mary-Louise Rogers
(Flinders University, SA)

AMOUNT FUNDED:
\$999,157

SUMMARY:
Anti-retroviral therapy used to treat HIV is also showing promise as a potential treatment for MND in clinical trials. This project will seek to advance our understanding on how retroviruses may cause MND, and how therapies targeting retroviruses may slow progression of the disease.

“We will answer critical questions around what causes MND that are unanswered”



Above: A/Prof Mary-Louise Rogers (right) & research team | Below: Co-Investigator A/Prof Beben Benyamin

CURE Investment

7 x IMPACT Projects

IMProving and ACcelerating Translation (IMPACT) projects support key areas of research focused on overcoming some of the hurdles and challenges in MND research that contribute to failed drug development or clinical trials. Outcomes from these projects will include:

- improvements in drug design and delivery
- treatments that target disease causing genes
- improved understanding of the variability in disease characteristics between individuals with MND
- the development of molecular markers to help diagnose MND, or predict if a drug is effective
- better models for studying MND in the laboratory

IMPACT PROJECTS / DISEASE HETEROGENEITY /

PROJECT /

Delving deep into the MND genome to reveal somatic mosaicism /

PROJECT LEAD:

Dr Lyndal Henden
(Macquarie University, NSW)

AMOUNT FUNDED:

\$300,000

SUMMARY:

This innovative project will perform an analysis of blood and brain samples from MND patients, searching for brain-specific genetic defects to help uncover new genetic causes of MND. Dr Henden is a first-time recipient of FightMND funding.



Dr Lyndal Henden

“Finding the genetic causes of MND remains critically important for diagnosis and for understanding how the disease works”



**IMPACT PROJECTS /
DISEASE BIOMARKERS /**

PROJECT /

Lower Motor Neurone excitability as a new, and specific, biomarker of disease progression /

PROJECT LEAD:

Associate Professor Gabriel Trajano
(Queensland University of
Technology, QLD)

AMOUNT FUNDED:

\$220,468 (co-funded with MND
and Me Foundation)

SUMMARY:

Associate Professor Trajano is
developing a non-invasive technique
to measure neuronal activity in MND
patients. Successful outcomes will
deliver a new and accurate way for
clinicians to assess the progression
of MND in patients. Associate
Professor Trajano is a first-time
recipient of FightMND funding.



Left: Associate Professor Gabriel Trajano |
Right: Research

“We are proposing a new biomarker of disease progression that is painless, non-invasive, and easy to be implemented in clinical practice”

**IMPACT PROJECTS /
DISEASE BIOMARKERS /**

PROJECT /

Lipid dysregulation underlying MND –
a new scope for biomarker development /

PROJECT LEAD:

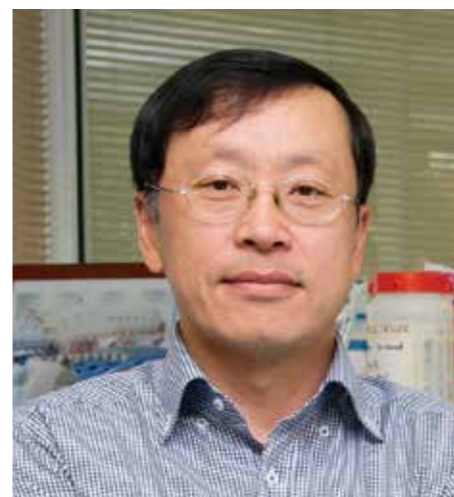
Associate Professor Woojin Kim
(The University of Sydney, NSW)

AMOUNT FUNDED:

\$299,687

SUMMARY:

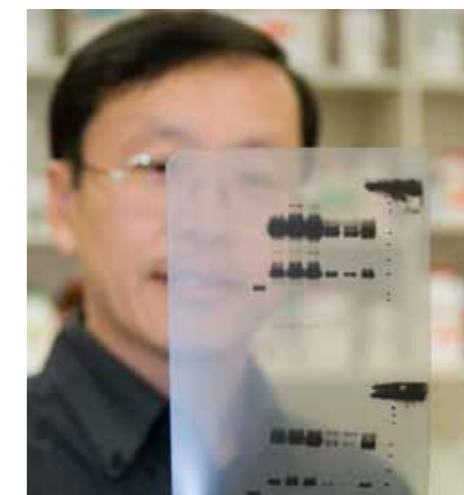
Associate Professor Kim is a first-time recipient of FightMND funding. This project will seek to develop a blood-based lipid test to diagnose MND more rapidly, accurately monitor disease progression and measure if treatments are successful.



Associate Professor Woojin Kim



“Our pioneering study into understanding lipid dysregulation in MND will reveal novel insights into an under-recognised perturbed pathology in MND”



**IMPACT PROJECTS /
GENE THERAPIES /**

PROJECT /

Developing novel gene expression control mechanisms for MND gene therapies /

PROJECT LEAD:
Professor Roger Chung
(Macquarie University, NSW)

AMOUNT FUNDED:
\$299,668

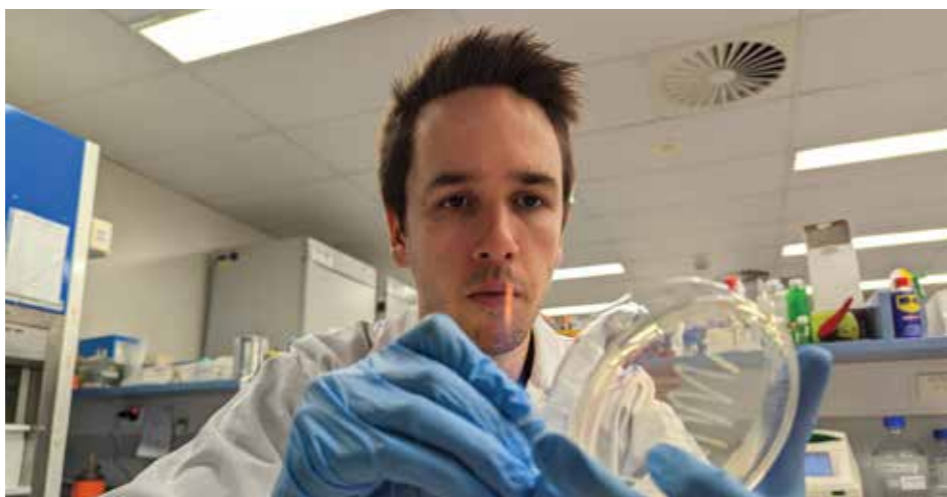
SUMMARY:
This project aims to fill a key gap in gene therapy, by developing a gene therapy that activates only when unhealthy forms of proteins are present in motor neurons.



“Your fundraising efforts are the catalyst for enabling us to undertake these innovative research projects”



Above: Professor Roger Chung | Right: Research



**IMPACT PROJECTS /
GENE THERAPIES /**

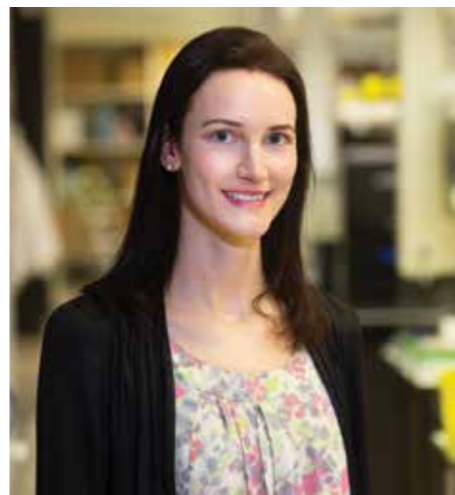
PROJECT /

ASO-mediated reduction of UBQLN2 for X-linked MND /

PROJECT LEAD:
Dr Emma Scotter
(The University of Auckland, NZ)

AMOUNT FUNDED:
\$300,000

SUMMARY:
This collaborative project brings together teams from New Zealand and Australia to explore a gene therapy approach for treating a rare familial form of MND caused by a defect in the UBQLN2 gene.



“This collaborative project brings together teams from New Zealand and Australia to explore a gene therapy approach for treating a rare familial form of MND”



Above: Dr Emma Scotter | Right: Research team



**IMPACT PROJECTS /
DISEASE MODELS /**

PROJECT /

Generation of inducible and MND-sensitive genetic models for both basic research and drug discovery /

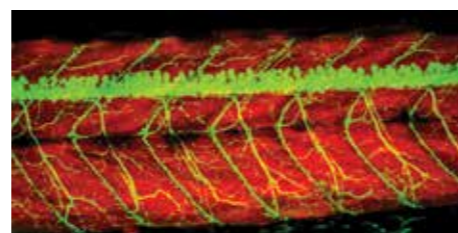
PROJECT LEAD:
Dr Jean Giacomotto
(Griffith University, QLD)

AMOUNT FUNDED:
\$299,791

SUMMARY:
This project will develop innovative preclinical models to advance studies in genetic causes of MND. The preclinical models will also be powerful tools for drug screening and the discovery of potential treatments for MND. Dr Giacomotto is a first-time recipient of FightMND funding.



"We are tremendously honoured to receive the support of FightMND"



Above: Zebrafish growing |
Centre: Dr Jean Giacomotto |
Right: Zebrafish motor unit



**IMPACT PROJECTS /
DRUG DELIVERY /**

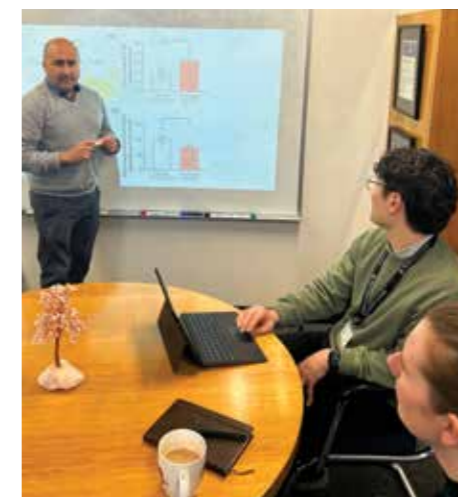
PROJECT /

Developing blood-brain barrier penetrating inhibitors of fatty acid binding protein 4 to reduce microglia-mediated neuroinflammation in Motor Neurone Disease /

PROJECT LEAD:
Associate Professor
Joseph Nicolazzo
(Monash University, VIC)

AMOUNT FUNDED:
\$299,940

SUMMARY:
Associate Professor Nicolazzo will create and test a series of modifications to a promising drug targeting inflammation in MND. The team aims to improve the drugs ability to reach motor neurons in the brain and enhance its therapeutic potential for MND.



Above: Associate Professor Joseph Nicolazzo |
Right: Team



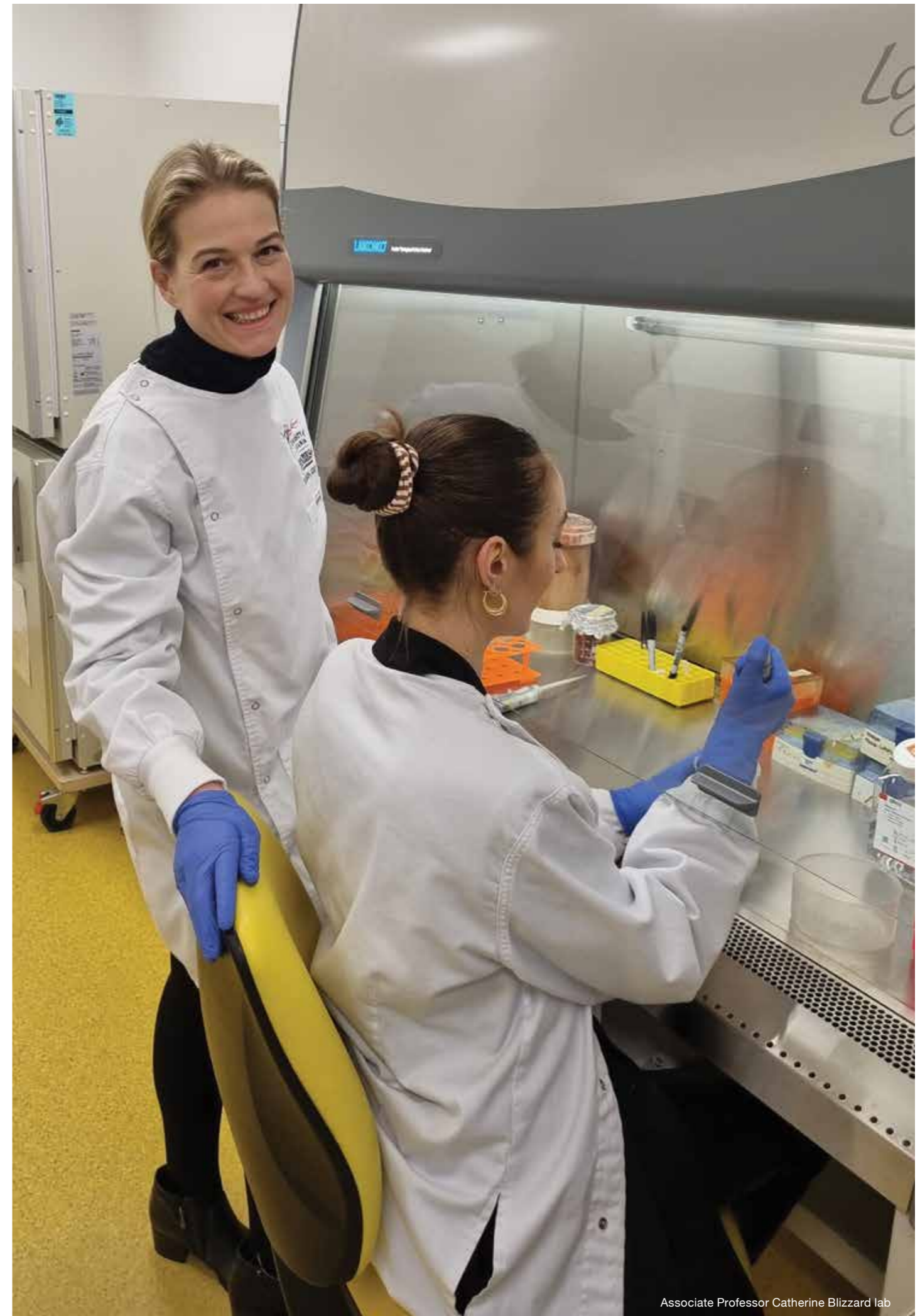
"The findings from this research project will identify a new target that contributes to the inflammation occurring in the brains of individuals with MND"



CURE Investment

2 x Mid-Career Research Fellowships

FightMND Mid-Career Research Fellowships encourage outstanding researchers to choose or to continue to focus on MND as their primary area of research. The 4-year fellowship provides the opportunity for mid-career researchers to strengthen their research team and independent programs, build collaborations and embed themselves as key players in the MND research sector. The fellowship's research program is focused on causes of MND and elucidating disease mechanisms, with the ultimate goal of developing more effective treatments, and a cure, for MND.



BILL GUEST MID-CAREER RESEARCH FELLOWSHIP /

PROJECT /

Comprehensive disease gene discovery across familial MND, sporadic MND & MND twins /

PROJECT LEAD:

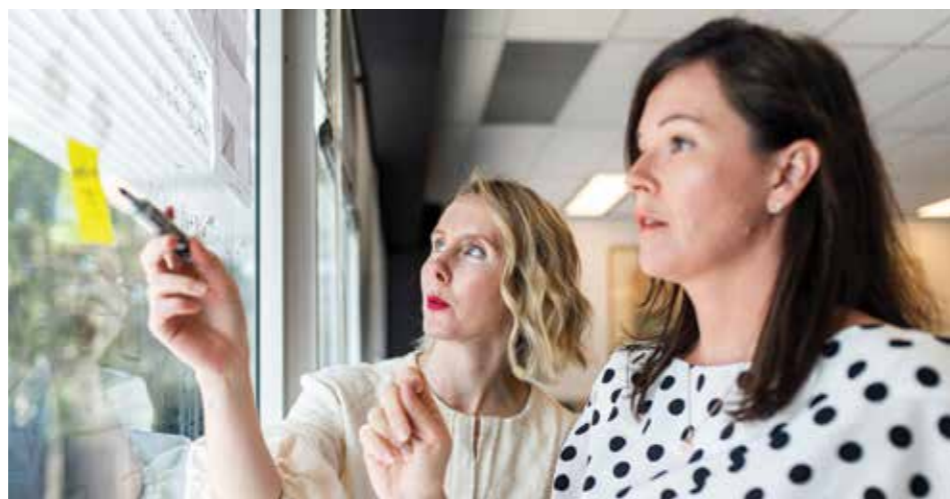
Associate Professor Kelly Williams – Bill Guest Mid-Career Research Fellow (Macquarie University, NSW)

AMOUNT FUNDED:

\$680,000

SUMMARY:

Associate Professor Williams is awarded the Bill Guest Mid-Career Research Fellowship in 2023, named in honour of inaugural FightMND board chairman Bill Guest AM. Associate Professor Williams will lead a team to uncover new genetic causes underlying familial and sporadic MND.



“Understanding the genetic defects that contribute to disease can transform our understanding of MND and provide critical impact in patient care, clinical genetics, preclinical drug discovery and clinical trial design”



Above: Associate Professor Kelly Williams | Right: Research team

MID-CAREER RESEARCH FELLOWSHIP /

PROJECT /

Can we tailor excitation therapy for MND? /

PROJECT LEAD:

Associate Professor Catherine Blizzard (University of Tasmania, TAS)

AMOUNT FUNDED:

\$680,000

SUMMARY:

Associate Professor Blizzard is a first-time recipient of FightMND funding. Associate Professor Blizzard will lead a team to identify why motor neurons become overactive in MND, and map out how this overactivity spreads through the brain and spinal cord as MND progresses.

“I hope to design a pioneering, precision medicine treatment strategy ready to take to the clinic”



Centre: Associate Professor Catherine Blizzard | Right: Team

CURE Investment

2 x Early-Career Research Fellowships

FightMND Early-Career Research Fellowships encourage researchers with outstanding ability to focus on MND as their primary area of research. The 4-year fellowship provides the opportunity for early-career researchers to establish their own independent research programs, build collaborations and further themselves as an MND researcher. The fellowship's research program is focused on causes of MND and elucidating disease mechanisms, with the ultimate goal of developing more effective treatments, and a cure, for MND.



EARLY-CAREER RESEARCH FELLOWSHIPS /

PROJECT /

Genetic markers and antisense oligonucleotides to restore axonal health in MND /

PROJECT LEAD:

Dr Frances Theunissen
(The University of Notre Dame/
Perron Institute for Neurological
and Translational Science, WA)

AMOUNT FUNDED:

\$580,000

SUMMARY:

During this fellowship, Dr Theunissen will work with mentors at the Perron Institute in WA and The Florey in VIC to identify genetic signatures that define subtypes of MND, and test new potential genetic therapies.

“This work will help us to determine if we can use genetic markers to identify subgroups of patients with a faster disease progression”



Dr Frances Theunissen



EARLY-CAREER RESEARCH FELLOWSHIPS /

PROJECT /

Improving the likelihood of translation of novel degrader technology for the treatment of MND /

PROJECT LEAD:

Dr Stephanie Rayner
(Macquarie University, NSW)

AMOUNT FUNDED:

\$580,000

SUMMARY:

Dr Rayner will work to design and test a new type of MND therapy that seeks out and destroys unhealthy proteins which are damaging motor neurons, whilst ensuring healthy proteins remain intact. Dr Rayner is a first-time recipient of FightMND funding.

“We are immensely grateful to the generous donors and supporters of FightMND”



CURE Investment

1 x Angie Cunningham PhD Scholarship

The FightMND Angie Cunningham FightMND PhD Scholarship and Project Grant-in-Aid Award honours the life and qualities of Angie Cunningham wife of FightMND founder Pat Cunningham who died from MND in 2016.

ANGIE CUNNINGHAM PHD SCHOLARSHIP /

PROJECT /

Identification and characterisation of RNA-protein interaction in pathological aggregates of TDP-43 in MND /

PROJECT LEAD:

Dr Albert Lee
(Macquarie University, NSW)

AMOUNT FUNDED:

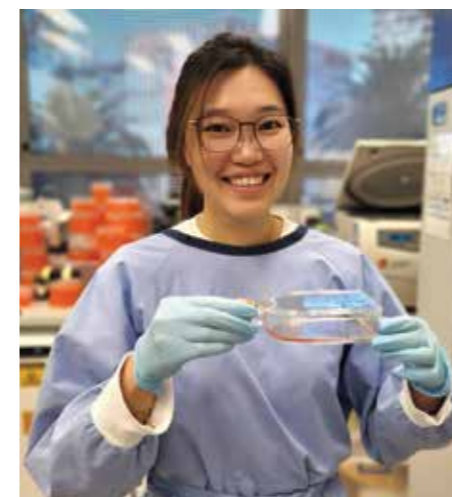
\$236,670

SUMMARY:

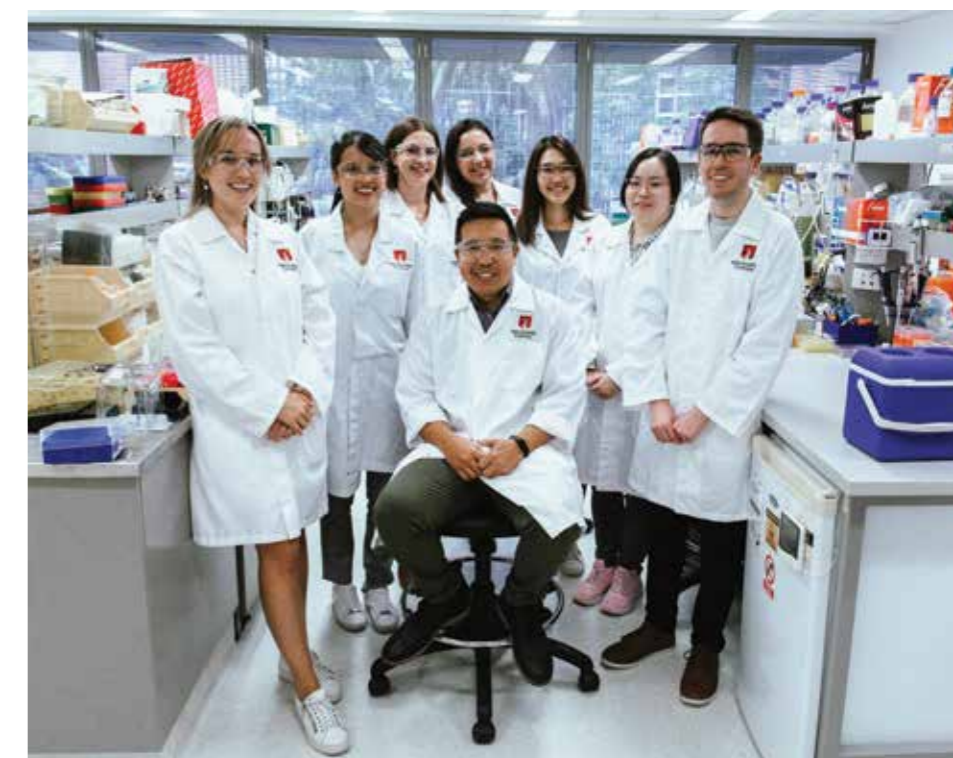
The 2023 Angie Cunningham PhD scholarship is awarded to Ms Flora Cheng, working under the mentorship of Dr Albert Lee at the Centre for Motor Neuron Disease Research, Macquarie University. Ms Cheng will map out how known defects in TDP-43 cause it to misbehave in MND patients.

PhD CANDIDATE:

Ms Flora Cheng



"I want to extend my gratitude to all the donors and supporters who have granted me the chance to be a part of this battle, striving towards a world where MND no longer poses a threat"



CURE Investment

1 x Clinical Investigator Award

This is the first year FightMND are offering Clinical Investigator Awards. Offered for a term of 1 year, these awards aim to assist an early-career clinical fellow to transition into a research appointment.

CLINICAL INVESTIGATOR AWARD /

PROJECT /

Unravelling the early cortical signature of MND in vivo /

PROJECT LEAD:

Dr Thanuja Dharmadasa
(The Florey/The University
of Melbourne, VIC)

AMOUNT FUNDED:

\$99,813

SUMMARY:

Dr Dharmadasa is a first-time recipient of FightMND funding. This project will use advanced imaging techniques to study “split limb syndrome”, one of the earliest clinical signs of MND. Study outcomes may lead to the development of imaging biomarkers that detect and diagnose MND.



Dr Thanuja Dharmadasa



“This project focuses on unravelling the brain changes that are linked to the development of the earliest clinical phenomena in patients living with MND”



CURE Investment

2 x McLoone Research Initiatives
(Jointly funded with MND Research Australia)

The Daniel McLoone Major Research Initiative (MRI) aims to support an outstanding innovative and collaborative project that has the capacity to make a significant impact on Australian MND research. This award is a MND Research Australia initiative and this year two projects were selected that are jointly funded by FightMND and MND Research Australia.



Professor Bradley Turner performing an experiment in the lab

**MCLOONE RESEARCH INITIATIVES
(JOINTLY FUNDED WITH MND RESEARCH AUSTRALIA) /**

PROJECT /

Exploring disease heterogeneity across MND clinical phenotypes using a multimodal, multicentre neuroimaging approach /

PROJECT LEAD:

Dr Thanuja Dharmadasa
(The Florey/The University of Melbourne, VIC)

AMOUNT FUNDED:

\$1,000,000
(co-funded with MND Australia)

SUMMARY:

This project will combine advanced brain images of MND patients with their clinical assessments to identify patterns or markers that can separate them into clinical subgroups. Study outcomes will allow clinicians and researchers to identify which subgroup a patient fits into (e.g. fast-progressor or slow-progressor), lead to better prediction of MND progression, and provide an earlier and more informed understanding of how best to manage the person's disease.

“For people living with MND, this project will lead to better prediction of disease spread and, earlier implementation of management strategies”



Dr Thanuja Dharmadasa



**MCLOONE RESEARCH INITIATIVES
(JOINTLY FUNDED WITH MND RESEARCH AUSTRALIA) /**

PROJECT /

Australian Preclinical Research MND (APRALS) Network: a roadmap for effective translation of therapeutics for sporadic MND /

PROJECT LEAD:

Professor Bradley Turner
(The Florey/The University of Melbourne, VIC)

AMOUNT FUNDED:

\$1,000,000
(co-funded with MND Australia)

SUMMARY:

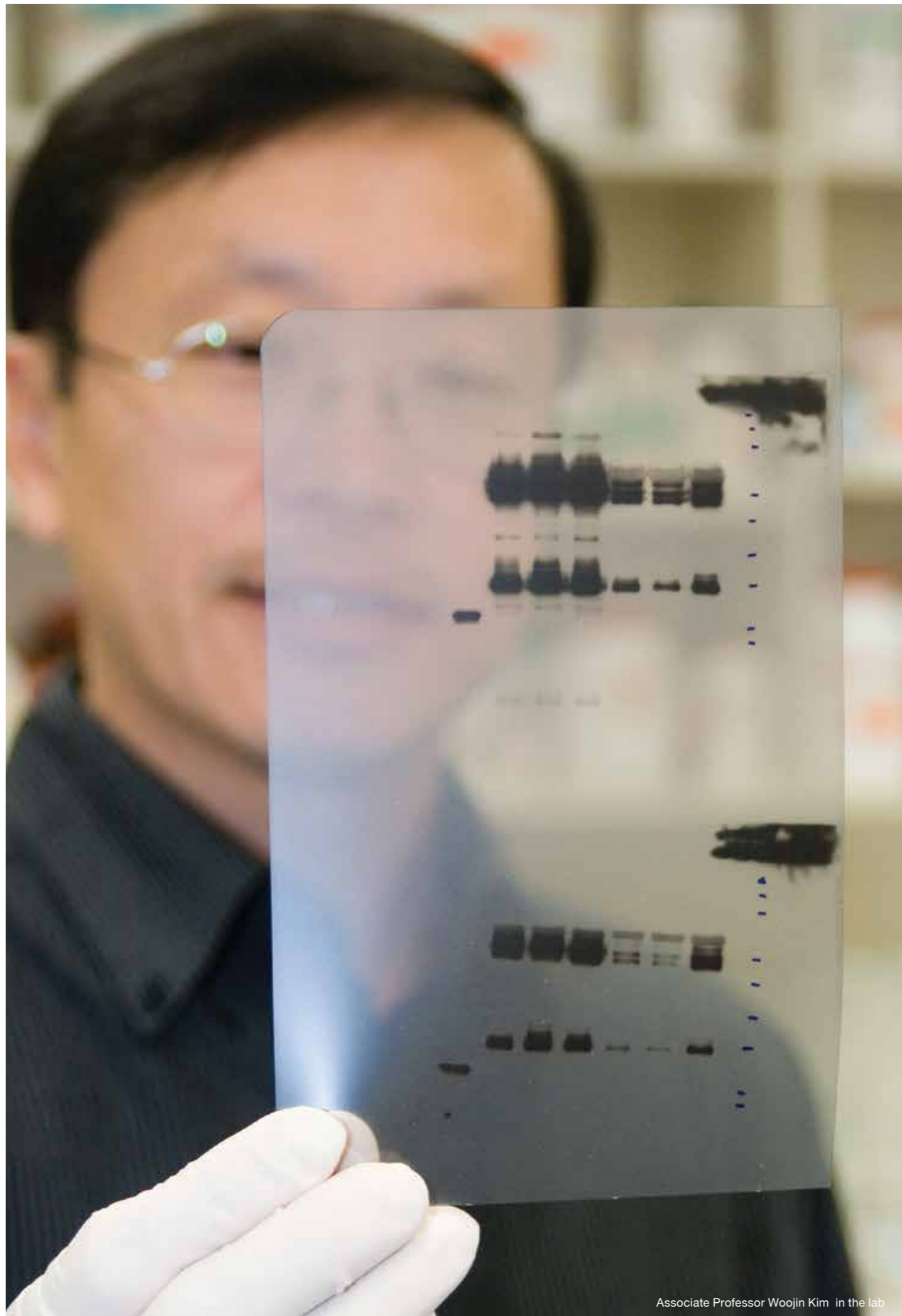
This project will establish Australian Preclinical Research ALS (APRALS), a national collaborative network of expert MND laboratory researchers, to fast-track the development and testing of potential new treatments for people living with MND.



Professor Bradley Turner

“This project will launch Australian Preclinical Research ALS (APRALS), a national collaborative network which aims to accelerate the development of new treatment candidates towards clinical trials in MND”





Associate Professor Woojin Kim in the lab

OTHER RESEARCH INITIATIVES /

PROJECT /

Victorian Brain Bank /

PROJECT LEAD:

Professor Catriona McLean
(The Florey/The University
of Melbourne, VIC)

AMOUNT FUNDED:

\$82,118

FightMND will provide support to strengthen operations of the Victorian Brain Bank. The Victoria Brain Bank is an important resource for Australian researchers, providing them with access to well-characterised post-mortem brains and clinical data that may give clues to why MND occurs and improve diagnosis.

"This funding allows us to continue to support the MND research being conducted, not only today, but into the future"



Professor Catriona McLean

CARE – Support Projects

9 x Equipment technology and at home needs projects

These projects are aimed at improving the quality of life for people living with MND, and allowing them to maintain their independence for as long as possible.

EQUIPMENT TECHNOLOGY AND AT HOME NEEDS PROJECTS /

These grants will enable the purchase of essential care equipment and improve access to care services, to support the day-to-day needs of people living with MND across Australia /

PROJECT /

MND equipment pool /

ORGANISATION:

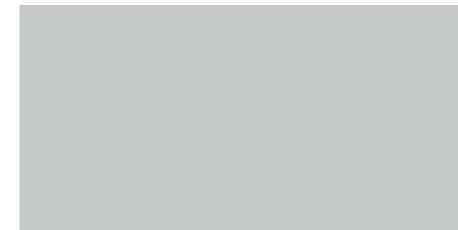
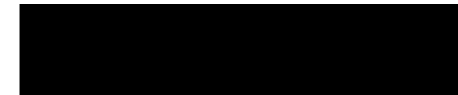
Barwon Health

AMOUNT:

\$99,395

SUMMARY:

Access to assistive care equipment in regional Victoria is limited, Barwon Health MND clinic will establish a pool of equipment to trial and loan for at-home use, providing much needed aids to people living with MND in Victoria.



This one-stop-shop would allow MND clients (and their families) in regional Victoria to have all their needs met in the one place, including the prescription, trial and loan of equipment

Above: Zoe Waters, Executive Director, Barwon Health | Right: Patient



EQUIPMENT TECHNOLOGY AND AT HOME NEEDS PROJECTS /

These grants will enable the purchase of essential care equipment and improve access to care services, to support the day-to-day needs of people living with MND across Australia /

PROJECT /

Driving for a Better Life /

ORGANISATION:

Cavalry Health Care Bethlehem

AMOUNT:

\$98,496

SUMMARY:

Management of end-of-life care for MND patients at home is currently difficult. Cavalry Health Care Bethlehem will purchase two vehicles to transport allied health professionals to care for patients at home and offer the transport of patients to visit their loved ones or to a memorable location. This will provide support for the care of terminally ill patients across Victoria to delay the difficult transition into palliative care.



The grant will enable Cavalry Bethlehem staff to provide services within Victorian MND patient's homes making their care more comfortable in familiar surroundings



FIGHT MND.

EQUIPMENT TECHNOLOGY AND AT HOME NEEDS PROJECTS /

These grants will enable the purchase of essential care equipment and improve access to care services, to support the day-to-day needs of people living with MND across Australia /

PROJECT /

Make Aged Care fair /

ORGANISATION:

Motor Neurone Disease Association of QLD

AMOUNT:

\$150,000

SUMMARY:

If a person is diagnosed with MND over the age of 65 they are no longer eligible for NDIS funding and whilst they can apply for My Aged care packages these offer only a fraction of the financial support provided by the NDIS and are subject to long wait times. This project will address the inequity in funding and accessibility by providing (30) care support packages for people living with MND in Queensland who do not receive NDIS funding.



Left: QLD man living with MND with mobility equipment | Right: Stacey Thorpe, CEO, MND QLD

This will ensure that older Queenslanders with MND can still access expert services and the equipment they so desperately need



FIGHT MND.

EQUIPMENT TECHNOLOGY AND AT HOME NEEDS PROJECTS /

These grants will enable the purchase of essential care equipment and improve access to care services, to support the day-to-day needs of people living with MND across Australia /

PROJECT /

Providing Equipment Services to People with MND /

ORGANISATION:
Motor Neurone Disease
Association of South Australia

AMOUNT:
\$248,244

SUMMARY:
This project will support the continued provision of specialised and critical equipment to people living with MND in South Australia and the development of new online resources and training programs for clients and carers.

EQUIPMENT TECHNOLOGY AND AT HOME NEEDS PROJECTS /

These grants will enable the purchase of essential care equipment and improve access to care services, to support the day-to-day needs of people living with MND across Australia /

PROJECT /

Electronic equipment library /

ORGANISATION:
Motor Neurone Disease
Association of Tasmania

AMOUNT:
\$150,000

SUMMARY:
This project will support the continued running of the MNDA Tasmania electronic equipment loan library to purchase new equipment for MND patients, provide technical training and support for effective use of complex equipment and circulate webinars to upskill local allied health professionals.

New investment in augmentative and alternative communication (AAC) will allow MNDSA to provide an expanded specialist communication service focused on the needs of older people



Centre: Client visit with speech pathologist |
Right: Karen Percival, CEO, MND SA



Above: Neater Eater equipment |
Right: 2023 MND TAS Board



EQUIPMENT TECHNOLOGY AND AT HOME NEEDS PROJECTS /

These grants will enable the purchase of essential care equipment and improve access to care services, to support the day-to-day needs of people living with MND across Australia /

PROJECT /

Empowerment and Quality of Life through Assistive Technology /

ORGANISATION:

Motor Neurone Disease Association of Victoria

AMOUNT:

\$250,000

SUMMARY:

Assistive technology is a core need for people living with MND. This project will support the continued provision of specialised assistive mobility equipment to people living with MND in Victoria.

EQUIPMENT TECHNOLOGY AND AT HOME NEEDS PROJECTS /

These grants will enable the purchase of essential care equipment and improve access to care services, to support the day-to-day needs of people living with MND across Australia /

PROJECT /

Equipment provisions for people with MND /

ORGANISATION:

Motor Neurone Disease Association of Western Australia

AMOUNT:

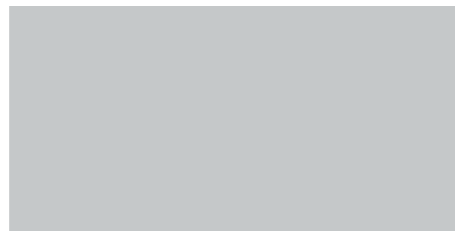
\$250,000

SUMMARY:

Assistive equipment is a core need for people living with MND. This project will support the provision and timely access of free assistive technology for people living with MND in Western Australia who do not have access to appropriate government funding.



Above: Kate Johnson, CEO, MND VIC |
Right: Patient in power wheelchair



The power wheelchairs assist people with MND to remain independently mobile for as long as possible



Our equipment program ensures that people living with MND have access to timely and appropriate physical supports, adaptive and mobility equipment, and assistive technology, so they can live as safely and independently as possible at home and have an enhanced quality of life

Above: Equipment program | Right: Courtney D'Mello, CEO, MND WA



EQUIPMENT TECHNOLOGY AND AT HOME NEEDS PROJECTS /

These grants will enable the purchase of essential care equipment and improve access to care services, to support the day-to-day needs of people living with MND across Australia /

PROJECT /

Improved access to Assistive Technology /

ORGANISATION:

Motor Neurone Disease NSW

AMOUNT:

\$248,175

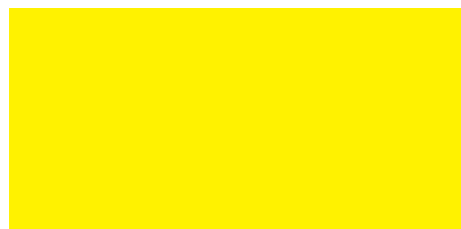
SUMMARY:

Assistive technology is a core need for people living with MND. This project will support the continued provision of a comprehensive range of assistive equipment to people living with MND in NSW, NT and ACT.



Left: Armchair | Right: Red leitner

Access to a light weight, portable wheelchair has enabled improved independence and social interaction for people with MND as they can independently use their wheelchair within the community



EQUIPMENT TECHNOLOGY AND AT HOME NEEDS PROJECTS /

These grants will enable the purchase of essential care equipment and improve access to care services, to support the day-to-day needs of people living with MND across Australia /

PROJECT /

MND overwhelm reduction via technology /

ORGANISATION:

MND and Me Foundation

AMOUNT:

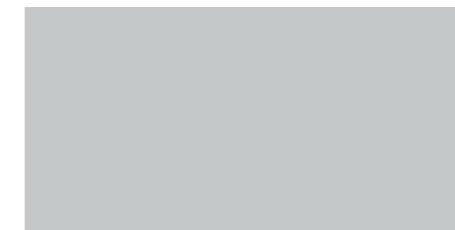
\$125,000

SUMMARY:

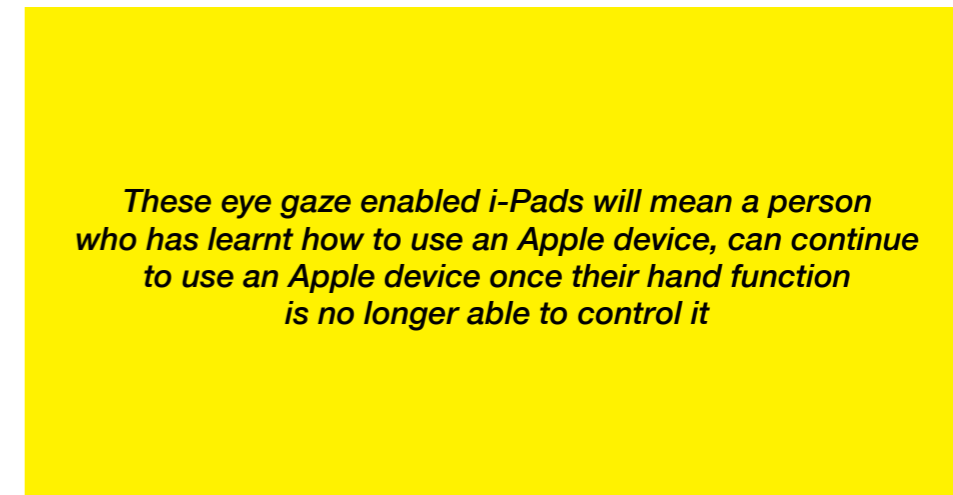
As MND progresses, patients can lose the ability to speak. This project will support the continued provision of specialised communication devices designed for people living with MND, including new eye-gaze technology, so that patients can communicate effectively with their multidisciplinary team and loved ones.



Jane Milne, CEO



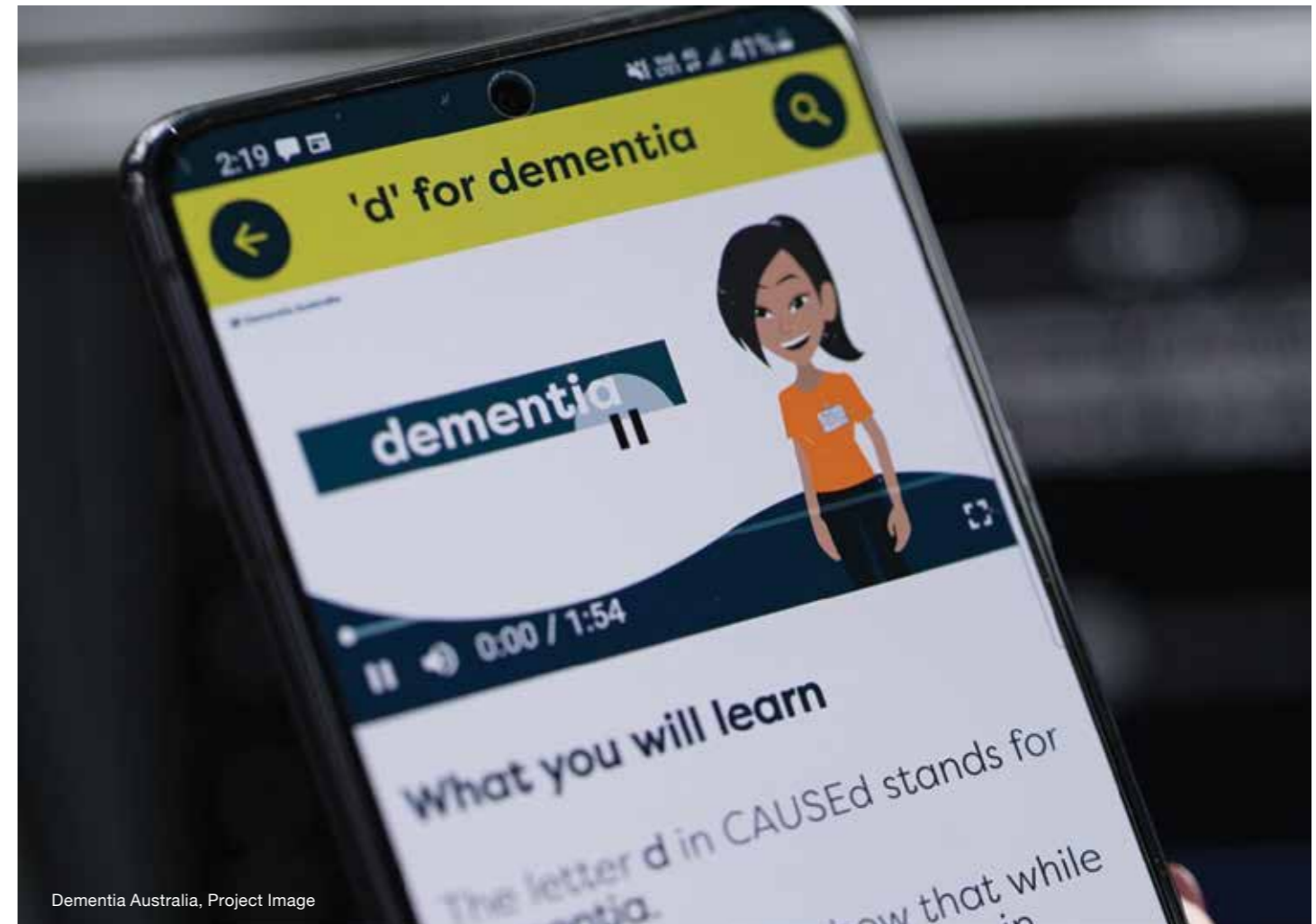
These eye gaze enabled i-Pads will mean a person who has learnt how to use an Apple device, can continue to use an Apple device once their hand function is no longer able to control it



CARE – Support Projects

10 x Education initiative projects

These grants will provide funding to support the design and development of care-focused informational resources for the MND community, in the form of online resources and/or workshops.



Dementia Australia, Project Image



Education Program, MND WA

EDUCATION INITIATIVE PROJECTS /

These grants will provide funding to support the design and development of care-focused informational resources for the MND community, in the form of online resources and/or workshops /

PROJECT /

Innovative immersive mobile education to improve the quality of life for people living with Motor Neurone Disease (PlwMND), their families and carers /

ORGANISATION:
Dementia Australia

AMOUNT:
\$244,000

SUMMARY:
Access to MND care across Australia is highly variable and services, particularly in remote areas, can be inadequate. Dementia Australia will develop and launch a free educational app available to all Australians, that will support and teach best practice care for patients with MND through highly engaging learning experiences.



The modules' animation care-worker 'Annie' will provide learners with simple practical strategies for best practice in care and immediate critical on-the-job practical skills for caring for people living with MND, and MND/dementia



Left: Ask Annie App | Right: Dr Tanya Petrovich, Business Innovation Manager



EDUCATION INITIATIVE PROJECTS /

These grants will provide funding to support the design and development of care-focused informational resources for the MND community, in the form of online resources and/or workshops /

PROJECT /

"Game on with MND": Improving quality of life for people living with Motor Neurone Disease (MND) through more fun and accessible digital games /

ORGANISATION:
Motor Neuron Disease Association of Australia

AMOUNT:
\$146,696

SUMMARY:
Current gaming platforms do not meet the physical and social needs of people living with MND. This project will engage with MND patients to understand the social and technological challenges playing digital games and create new interfaces to improve access to games and the overall gaming experience for people living with MND.



Above: Game On with MND | Right: Ben O'Mara, Information Resource Development Manager

We hope to ease the boredom, stress and isolation that many people with MND experience



EDUCATION INITIATIVE PROJECTS /

These grants will provide funding to support the design and development of care-focused informational resources for the MND community, in the form of online resources and/or workshops /

PROJECT /

Carers' Can Project /

ORGANISATION:
Motor Neurone Disease
Association of Victoria

AMOUNT:
\$150,000

SUMMARY:
Carers are an essential part of the multidisciplinary team that cares for people with MND, but they are rarely given the support that they need. MND Victoria will develop a series of self-management support videos for carers aimed at providing practical guidance to increase confidence and understanding on how to manage and support people living with MND.

EDUCATION INITIATIVE PROJECTS /

These grants will provide funding to support the design and development of care-focused informational resources for the MND community, in the form of online resources and/or workshops /

PROJECT /

MND Community Capacity Building /

ORGANISATION:
Motor Neurone Disease
Association of QLD

AMOUNT:
\$250,000

SUMMARY:
People impacted by MND in Australia do not always receive the same support and the advice given by healthcare professionals can be unsuitable and ineffective. This programme will offer educational learning resources and workshops in metropolitan and regional QLD to train and educate healthcare professionals on the complex needs of MND patients and empower clients and carers to feel well-informed on managing the disease and supported in periods of grief and bereavement.

The videos aim to increase confidence to apply initial strategies to manage symptoms, identify when expert advice is needed, and identify who to ask about symptom management challenges



Above: Volunteers |
Right: Stacey Thorpe, CEO MND QLD



Both our educational and volunteer programs will bring our community together, empower individuals through increased knowledge and widely share the experience and expertise that exists within the community



EDUCATION INITIATIVE PROJECTS /

These grants will provide funding to support the design and development of care-focused informational resources for the MND community, in the form of online resources and/or workshops /

PROJECT /

Caring for people with motor neurone disease: Education and training /

ORGANISATION:
Motor Neurone Disease
Association of Western Australia

AMOUNT:
\$150,000

SUMMARY:
People impacted by MND in Australia do not always receive the same support and the advice given by healthcare professional can be unsuitable and ineffective. This programme will develop and deliver three educational workshops in WA, to upskill and educate healthcare professionals and carers about the complex needs of MND patients and advise on the current MND and care strategies, to build capacity in the MND healthcare sector in WA.



Upskilling and building the capacity of the Western Australian community to respond to the needs of people with MND will ensure that people living with MND receive best-practice and appropriate care



EDUCATION INITIATIVE PROJECTS /

These grants will provide funding to support the design and development of care-focused informational resources for the MND community, in the form of online resources and/or workshops /

PROJECT /

Increasing Support Capacity /

ORGANISATION:
Motor Neurone Disease NSW

AMOUNT:
\$95,500

SUMMARY:
People impacted by MND in Australia do not always receive the same support and the advice given by healthcare professional can be unsuitable and ineffective. This programme will develop and deliver two educational workshops, to upskill and educate healthcare professionals and carers about the complex needs of MND patients and build capacity in the MND healthcare sector across NSW, ACT and NT.

The workshops will improve the the provision of formal and informal supports for people living with MND



EDUCATION INITIATIVE PROJECTS /

These grants will provide funding to support the design and development of care-focused informational resources for the MND community, in the form of online resources and/or workshops /

PROJECT /

MND Massive Open Online Course (MOOC) Development /

ORGANISATION:
Multiple Sclerosis of Queensland

AMOUNT:
\$250,000

SUMMARY:
Access to MND care across Australia is highly variable and services, particularly in remote areas, can be inadequate. MS Queensland will develop a web-based interactive learning course available to all Australians, that will provide in-depth information on the MND journey, from diagnosis to end of life care, and will help guide those impacted by MND to make informed decisions about MND care.



Above: Professor James Vickers, UTAS & MS QLD |
Right: David Curd, MS QLD



The course will address the knowledge gap about MND on a mass level, and is designed for many people to participate in and can be accessed from anywhere in the world

EDUCATION INITIATIVE PROJECTS /

These grants will provide funding to support the design and development of care-focused informational resources for the MND community, in the form of online resources and/or workshops /

PROJECT /

A national person-centred approach to family carer needs assessment and support in MND community care: Translation into practice /

ORGANISATION:
Perron Institute for Neurological and Translational Science

AMOUNT:
\$153,285

SUMMARY:
The practical, physical and emotional needs of family carers of people with MND are often overlooked. Researchers at the Perron Institute will develop and implement a web-based system 'Carers Alert Thermometer' in Australia that is responsive to the changing needs of family carers and coordinates with service providers to resolve these issues in a timely manner.



Above: Samar Aoun, Project Lead |
Right: Family carer online support and information toolkit

The project will support the wellbeing of family carers by reducing their burden, empowering them and building their capacity to care and keep their loved ones as long as possible at home and out of acute and residential care settings.

www.mndawa.asn.au/family-carer-support



EDUCATION INITIATIVE PROJECTS /

These grants will provide funding to support the design and development of care-focused informational resources for the MND community, in the form of online resources and/or workshops /

PROJECT /

A Roadshow of Care – Improving regional capability in MND care /

ORGANISATION:

Royal Brisbane and Women's Hospital Foundation

AMOUNT:

\$110,200

SUMMARY:

Access to specialist care in regional, rural and remote settings for people living with MND is often not available and it can be difficult for people to travel to metropolitan areas to receive this care. This project will support a multidisciplinary team of MND experts to deliver a roadshow of tailored workshops and educational sessions in disadvantaged areas of regional-rural QLD targeted at allied healthcare professionals, carers, GPs and nurse practitioners working in hospital, community or aged care facilities.



The roadshow of care will take specialist care and experience information sharing out to regional QLD, and is the first step in delivering equitable access to information and care for all Queenslanders living with MND



Above: Professor Henderson with his patient Cameron McPherson and carer Mahtab Soroush, at our recent MND research showcase | Centre: Palliative care trip to Longreach | Right: Nicole Hutchinson RBWH

EDUCATION INITIATIVE PROJECTS /

These grants will provide funding to support the design and development of care-focused informational resources for the MND community, in the form of online resources and/or workshops /

PROJECT /

Enhancing support for pabMND and upskilling psychological workforce on the needs of plwMND and pabMND /

ORGANISATION:

The Australian Psychological Society

AMOUNT:

\$98,000

SUMMARY:

There are currently very limited resources in Australia focused on the psychological health and care needs of people living with, or affected by, MND. To address this, the Australian Psychological Society will develop a clinical practice guide for psychologists and allied health professionals that provides evidence-based recommendations on psychological care for people living with MND. In parallel, they will develop a webinar to support the psychosocial care needs and mental health of people impacted by MND throughout the disease journey.



These resources will provide clinicians with evidence-based information to support consistent and multidisciplinary care in this area



Dr Zena Burgess, CEO

CARE – Support Projects

3 x Building support groups
in the community

These grants will provide funding to help build support groups in the MND community across Australia.

BUILDING SUPPORT GROUPS IN THE COMMUNITY /

These grants will provide funding to help build support groups in the MND community across Australia /

PROJECT /

Development of a national lived experience model for people living with MND in Australia /

ORGANISATION:

Motor Neuron Disease
Association of Australia

AMOUNT:

\$205,859

SUMMARY:

There is a significant lack of involvement of the MND lived experience in targeted resources, policies and research for MND care. MND Australia will collaborate with the MND community to co-design a new initiative that will incorporate the patients voice in the development of new frameworks and structures that better represent people living with MND.

*The framework will ensure people living with MND
are at the centre in identifying opportunities,
developing information and influencing advocacy work*

BUILDING SUPPORT GROUPS IN THE COMMUNITY /

These grants will provide funding to help build support groups in the MND community across Australia /

PROJECT /

Building Capacity of MNDSA's Volunteer Program /

ORGANISATION:

Motor Neurone Disease Association of South Australia (MNDSA)

AMOUNT:

\$149,798

SUMMARY:

Volunteers provide essential support for the MND State Associations in Australia, however since the pandemic there has been a noticeable drop in the number of regular volunteers. This project will focus on improving the recruitment, training and retention of volunteers to support critical services provided by the MND Association of SA.

BUILDING SUPPORT GROUPS IN THE COMMUNITY /

These grants will provide funding to help build support groups in the MND community across Australia /

PROJECT /

A Friend's Place – specialist grief and bereavement care service for families impacted by MND (Pilot Program) /

ORGANISATION:

National Centre for Childhood Grief

AMOUNT:

\$54,309

SUMMARY:

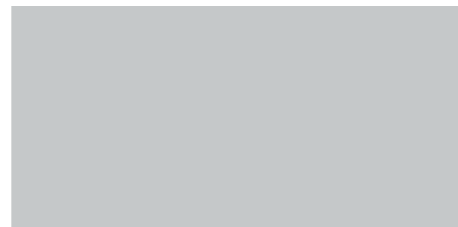
Children are highly vulnerable to developing life-long psychological challenges after living with and losing a parent to MND. This project will develop a grief and bereavement counselling programme to support families with children under 18 years of age who have a parent diagnosed with MND.



Above: MND SA Building |
Below: Karen Percival, CEO, MND SA



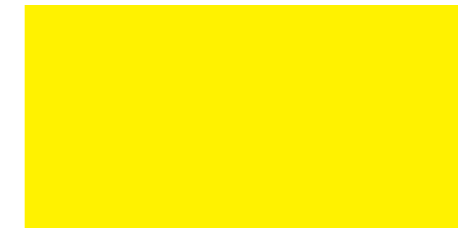
The increased volunteer capacity will allow cost effective expansion of the programs that MNDSA provides to clients and their families across South Australia



FIGHT MND.



Above: Dr Liz Mann, Clinical Director |
Below: Counselling Team |
Right: Education Group



Participating families will receive specialist counselling and support to navigate the impact of the physical and personal changes caused by MND to their loved one



FIGHT MND.

fightmnd.org.au