FIGHT MND.
IT TAKES PEOPLE

2024 CURE & CARE INVESTMENT

A MESSAGE FROM DR BEC SHEEAN

FightMND Director of Cure Research and Programs

I am thrilled to announce that in 2024, FightMND is investing $18.89 million into research and care initiatives for people with motor neurone disease (MND). This brings our total investment to over $115.78 million since our inception in 2014.

When FightMND was founded a decade ago, Australians had very limited access to clinical trials, and awareness of the disease was minimal. Support for the small but passionate MND research community was also lacking.

Today, Australia stands as a central hub for MND research, with our dedicated researchers playing a crucial role in the global effort. We now understand some of the genetic mutations and biological events that may cause MND. Moreover, Australians living with MND have more opportunities than ever to participate in research and clinical trials.

The projects and initiatives receiving funding in 2024 will continue to build on the incredible work done so far. I encourage you to explore the various projects and initiatives being funded this year. Each one highlights the diverse efforts needed to understand MND and find effective treatments.

Our investment is powered by our iconic Big Freeze Beanies and our amazing community, who tirelessly raise awareness and vital funds for our cause. To everyone involved in research, caring for the MND community, purchasing a Beanie, donating, and more – thank you.

Your support has laid a solid foundation in our battle against this relentless disease. While we still have a long way to go, your efforts ensure we are making significant strides in this fight.

WE'RE INVESTING $18.89M INTO MND RESEARCH AND CARE

$3.45M

into care projects to develop national MND clinical care guidelines and support people living with MND

$15.44M

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

Thank you for letting your actions speak louder than words.
Together we're changing the future for people with MND.

CURE
INVESTMENT

At FightMND our investments are driven by our core values of integrity, urgency, efficiency, boldness and community. Our values guide our efforts to advance research and support the MND sector both in Australia and globally.

Our commitment to finding a cure is built on four key pillars:

FUNDING WORLD CLASS RESEARCH

We invest in top-tier research through a rigorous and competitive grants program aligning with the National Health and Medical Research Council (NHMRC) grants process.

CAPACITY BUILDING

We enhance the capacity and capability of the MND research workforce through scholarships and fellowships.

INFRASTRUCTURE

We make targeted investments in critical infrastructure that supports MND research in Australia.

KNOWLEDGE EXCHANGE

We facilitate the sharing of knowledge across the national and international MND community.

These investments ensure that MND research in Australia remains competitive and world-leading, driving us closer to better treatments and a cure for MND.

$100.67M TOTAL INVESTED IN MND CURE RESEARCH

15 clinical trials

5 drugs progressed from the lab to clinical trial

34 Drug Development projects in the pipeline

10 clinical trial sites

600+ patients access to trials

BUILD

- **8** sites collecting data for the national genetic database
- **150** stem cell samples banked from MND patients

GROW

- **18** research fellowships
- **3** PhD scholarships
- **1** clinical investigator award

CONNECT

- **45+** delegates attend Global MND Research Roundtable
- **23** scientific seminar series presentations

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.

Four drug development projects received funding in 2024. Drug Development Grants support early-stage projects aimed at identifying or developing drugs targeting critical biological pathways affected by MND. These grants also fund initial pre-clinical studies to test the drug's potential benefits for treating MND.

PROJECT: Preclinical development of complement C5a receptor 2 modulators for MND

PROJECT LEAD: Prof Trent Woodruff

INSTITUTION: The University of Queensland, Qld

AMOUNT FUNDED: $549,920

PROJECT SUMMARY:

Inflammation is a key player in MND, and reducing the burden of inflammation may be a promising therapeutic avenue. Prof Woodruff's team have identified a key protein that drives inflammation and motor neuron damage. This project tests if a drug that blocks this protein has potential to advance to clinical development.

> **"Australian researchers are at the forefront of developing therapies targeting the immune system for neurodegenerative diseases like MND."**

PROJECT: Upstream Protein Clearance Pathway Activators for MND Treatment

PROJECT LEAD: A/Prof Adam Walker

INSTITUTION: The University of Queensland, Qld

AMOUNT FUNDED: $550,00

PROJECT SUMMARY:

A protein called TDP-43, which misbehaves in 97% of people living with MND, often forms clumps within motor neurones that are harmful. This project is testing if a drug that activates the body's natural ability to clear these harmful clumps improves the health of motor neurones.

A/Prof Adam Walker is a current FightMND Bill Guest Mid-Career Fellow.

PROJECT: Pathway to Precision: Developing Specific TDP-43 Degraders for MND

PROJECT LEAD: Prof Yazi Ke

INSTITUTION: Macquarie University, NSW

AMOUNT FUNDED: $550,00

PROJECT SUMMARY:

TDP-43 is a key protein in MND that becomes harmful to motor neurones in almost all individuals living with MND. Prof Ke's team is developing a drug treatment that selectively seeks out and destroys harmful TDP-43 in motor neurones and ensures only healthy TDP-43 remains. The team will test if this drug slows or stops MND.

Prof Ke is a first-time recipient of FightMND funding.

PROJECT: Development of a combination therapy for targeting protein aggregation and neuroinflammation as a next generation therapeutic for MND

PROJECT LEAD: A/Prof Fazel Shabanpoor

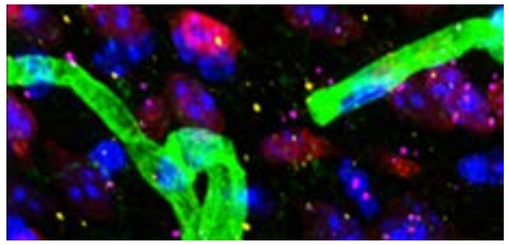
INSTITUTION: The Florey / The University of Melbourne, Vic

AMOUNT FUNDED: $549,537

PROJECT SUMMARY:

A/Prof Shabanpoor's team is designing a dual-targeting therapy for MND – one that targets a harmful protein called SOD1 in motor neurones and one aiming to lower damaging inflammation in the brain. They will test if this combination approach is more effective at slowing MND.

"I would like to express my gratitude for the generosity of the supporters of FightMND. Their ongoing commitment plays a pivotal role in enabling MND researchers to pursue groundbreaking projects and accelerate the development of new treatments and technologies that will have a significant and lasting impact on the lives of people with MND."



DISCOVERY PROJECTS

Discovery projects aim to understand why MND occurs and what drives its progression. These projects advance our understanding of MND, increasing the chances of developing effective treatments or a cure.

Seven projects received funding during FightMND's 2024 grant round.

PROJECT: The Cellular Consequences of Oligogenic/Polygenic Inheritance in MND

PROJECT LEAD: A/Prof Anthony Cook

INSTITUTION: University of Tasmania, Tas

AMOUNT FUNDED: $996,179

PROJECT SUMMARY:

A/Prof Cook's team are testing the idea that a combination of genetic risk factors, rather than a single gene, may make people more prone to developing MND. Understanding the interaction of genetic risk factors may uncover new targets for therapeutic development.

"Research that benefits our communities is best done with input from all those in that community – we each have our part to play in improving the lives of those with MND. Every contribution helps a new hypothesis to be tested, or a new drug to be trialled."

PROJECT: Deciphering the role of muscle-derived extracellular vesicles in MND pathology

PROJECT LEAD: A/Prof Shyuan Ngo

INSTITUTION: The University of Queensland, Qld

AMOUNT FUNDED: $999,998

PROJECT SUMMARY:

Muscle loss is a prominent effect of MND. This project will explore the relationship between muscles and MND, testing if molecules made in muscle are responsible for the onset and development of MND. Confirming this would open new avenues for therapeutic development.

PROJECT: Alternative splicing in the pathogenesis of MND

PROJECT LEAD: Dr Rebecca San Gil

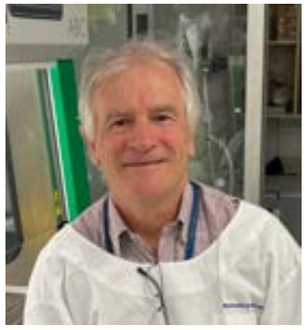
INSTITUTION: The University of Sydney, NSW

AMOUNT FUNDED: $1,000,000

PROJECT SUMMARY:

While a protein called TDP-43 misbehaves in almost all cases of MND, the consequences of this misbehaviour are largely unknown. This project will map out how and why TPD-43 misbehaves, and how this protein critical to motor neurone health, becomes harmful to motor neurones and causes MND. It will also identify new drug targets for MND.

Dr Rebecca San Gil was the inaugural FightMND Early-Career Research Fellow.



PROJECT: Mechanisms that promote the health of the motor unit in MND

PROJECT LEAD: A/Prof Peter Noakes

INSTITUTION: The University of Queensland, Qld

AMOUNT FUNDED: $1,000,000

PROJECT SUMMARY:

Connections between motor neurones and muscle are lost in MND, leading to prominent muscle loss. This project will determine why this connection is lost, and tests if a new drug can protect muscles and slow the progression of MND.

A/Prof Noakes is a first-time recipient of FightMND funding.

PROJECT: Establishing how and why protein aggregates escape molecular chaperones in the context of MND

PROJECT LEAD: Prof Heath Ecroyd

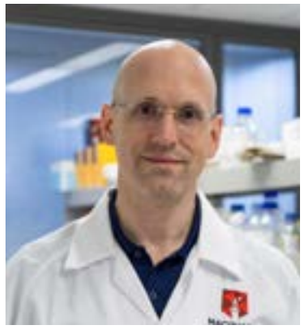
INSTITUTION: The University of Wollongong, NSW

AMOUNT FUNDED: $955,561

PROJECT SUMMARY:

Clumping of proteins in motor neurones is a hallmark characteristic in MND. The body contains natural defence mechanisms that normally clear these clumps, but this system breaks down in MND. This project will uncover why this clearance system fails and identify ways to re-activate it.

Prof Ecroyd is a first-time recipient of FightMND funding.



PROJECT: Inhibition failure in MND

PROJECT LEAD: Prof Lars Ittner

INSTITUTION: Macquarie University, NSW

AMOUNT FUNDED: $821,863

PROJECT SUMMARY:

Motor neurones are part of a network in the brain controlling movement. A critical part of this network are interneurones, a type of neurone supporting the activity of motor neurones and communication between motor neurones and muscles. MND affects both motor neurones and interneurones. This discovery project examines how and why interneurone function breaks down in MND and if targeting interneurones is a viable therapeutic strategy.

“We hope to gain new insight into the earliest cellular events that eventuate in MND.”

PROJECT: How does TDP-43 stay soluble and functional – Identifying molecular targets for early TDP-43 condensation

PROJECT LEAD: A/Prof Marco Morsch

INSTITUTION: Macquarie University, NSW

AMOUNT FUNDED: $1,000,000

PROJECT SUMMARY:

Clumping of a protein called TDP-43 in motor neurones is a hallmark characteristic of MND. This discovery project will investigate some of the earliest changes in TDP-43 protein that make it susceptible to clumping and identify ways to prevent this from occurring.

“This investment is crucial for translating our findings from research into potential therapies, significantly advancing our progress toward clinical applications.”

THE DR IAN DAVIS OAM AWARD

Dr Ian Davis OAM believed conquering MND required supporting patient-focused research marked by excellence, innovation and scientific rigour. To honour his legacy, the Dr Ian Davis OAM Award celebrates outstanding research and innovation. It is awarded to the top-ranked grant of the year.

This year marks the inaugural presentation of this prestigious award.

ABOUT DR IAN DAVIS

Dr Ian Davis was passionate about research. He graduated as Dux of Bachelor of Medicine and Surgery at Flinders University in 2006, achieving first class honours. After undertaking physician training at St Vincent's Hospital in Melbourne, he specialised in Haematology at the Peter MacCallum Cancer Centre. However, in 2011 Ian was diagnosed with motor neurone disease. He was just 33 years old.

Following his diagnosis, Ian channelled his energy into driving MND awareness, drug discovery and clinical trials for Australians living with MND. His frustration with the lack of awareness and research progress in MND drove him to establish FightMND alongside Neale Daniher AO and Pat Cunningham in 2014.

Ian's background in cancer research was pivotal in shaping FightMND's research strategy. Pivotal to this was strategic and targeted investment in patient-focused research. Through his tireless work and campaigning, Ian has helped establish Australia as one of the world's leading MND research hubs.

Ian died from MND in November 2018. His legacy lives on through the MND community, working to drive awareness and find a cure for this insidious disease.

"Ian was a brilliant mind and an incredible mentor and friend. His vision for MND research has seen a complete change in the research landscape, a shift in research focus in the sector and an excitement and enthusiasm in the entire MND community.

His contribution to the MND field continues to live on and grow through his legacy at FightMND."

Dr Bec Sheean
Director, Cure Research and Programs
FightMND

PROJECT: Targeting Motor Neurone Hyperexcitability with Drug-Controlled Gene Therapy

PROJECT LEAD: Dr Margreet Ridder

INSTITUTION: The University of Queensland, Qld

AMOUNT FUNDED: $285,625

PROJECT SUMMARY:

In MND, motor neurones are overactive, which is detrimental to their health and leads to their death. This IMPACT project (see pg 16) will test if a gene therapy that slows down motor neurone activity improves their health and prevents MND. Gene therapies look to correct defects in key genes which are contributing to MND onset or progression.

Dr Ridder is a first-time recipient of FightMND funding.

IMPACT PROJECTS

IMProving and ACcelerating Translation (IMPACT) projects support key areas of research focused on overcoming the hurdles and challenges in MND research contributing to failed drug development or clinical trials.

Outcomes from these projects include:

- improvements in drug design and delivery
- treatments targeting 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.

DISEASE HETEROGENEITY

Disease heterogeneity research looks at the reasons why MND starts at different ages, in different areas of the body, and progresses at different rates in different people.

PROJECT: Using the spatiotemporal dynamics signature of molecular pathology to decipher disease heterogeneity in MND

PROJECT LEAD: A/Prof Shyuan Ngo

INSTITUTION: The University of Queensland, Qld

AMOUNT FUNDED: $299,991

PROJECT SUMMARY:

This project helps us understand why MND presents differently in people. It will map how, where and when genes are expressed in the brain during the onset and progression of MND. Findings will be available as a webtool for researchers to foster new ideas and questions.

DISEASE BIOMARKERS

There is currently no definitive way to diagnose or track the progression of MND. Biomarker research aims to find a measurable characteristic that can define the onset of MND or track its progress, meaning treatment can be started as soon as possible.

PROJECT: Predicting functional decline in MND using metabolic-body – ''MetaBody" mapping

PROJECT LEAD: Dr Thomas Shaw

INSTITUTION: The University of Queensland, Qld

AMOUNT FUNDED: $299,991

PROJECT SUMMARY:

This project will perform MRI scans of the body and brain to identify signatures of MND that can be detected throughout the disease course. The outcomes of this study will lead to faster and more accurate diagnosis of MND, enabling treatments to start sooner.

Dr Shaw is a first-time recipient of FightMND funding.

"We have developed the 'MetaBody map' based on a collaboration in our team between psychologists, engineers, and neuroscientists interested in combining novel ideas for clinical research."

PROJECT: Neuroimaging of TDP-43

PROJECT LEAD: Dr Ole Tietz

INSTITUTION: Macquarie University, NSW

AMOUNT FUNDED: $299,495

PROJECT SUMMARY:

Clumping of TDP-43 protein inside motor neurones is a hallmark feature of MND. However, no method exists to detect TDP-43 in patients to allow for a definitive diagnosis. This project will develop an imaging technique that scans and detects TDP-43 clumps in the brain. This will quicken the diagnosis of MND and enable earlier start of treatments.

Dr Tietz is a first-time recipient of FightMND funding.

PROJECT: Development of blood-based biomarkers of pathological brain changes that drive clinical MND

PROJECT LEAD: Dr Rachel Tan

INSTITUTION: The University of Sydney, NSW

AMOUNT FUNDED: $299,997

PROJECT SUMMARY:

MND causes many damaging changes in the brain that are unable to be detected while individuals living with MND are alive. This project will determine if changes that occur in the brain can be detected by a blood test. A successful project will pave the way for better diagnostic tools for MND, quicken the diagnosis of MND and enable earlier start of treatments.

Dr Tan is a current FightMND Bill Guest Mid-Career Fellow.

GENE THERAPIES

Gene therapies look to correct defects in key genes which are contributing to MND onset or progression.

PROJECT: Tackling early axonal degeneration in MND: a novel gene therapy for lasting silencing of SARM1 in TDP-43 proteinopathies

PROJECT LEAD: Dr Alan Yu

INSTITUTION: The Florey / The University of Melbourne, Vic

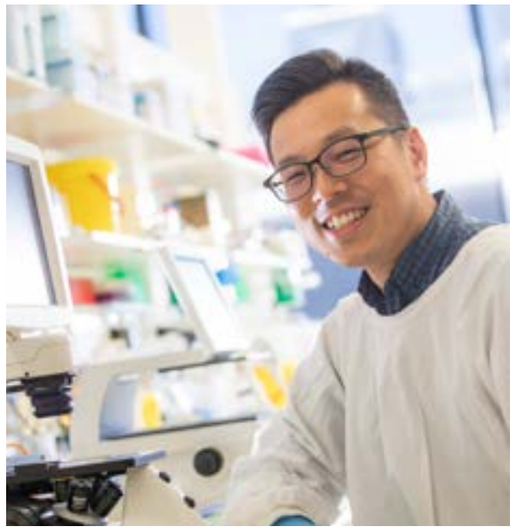
AMOUNT FUNDED: $299,996

PROJECT SUMMARY:

This project is developing a new strategy to repair and protect dying motor neurones. It is testing a potential gene therapy targeting a key gene that controls ‘cell death’ signals in a motor neurone. If successful, this approach may slow or stop disease progression.

Dr Yu is a first-time recipient of FightMND funding.

“With the assistance of this grant we can establish a new research program with an industry partner to develop a novel and targeted gene therapy to stop disease progression at the earliest possible stage.”



PROJECT: Novel Gene Therapy Approaches for Targeting Aging in MND

PROJECT LEAD: Dr Sina Shadfar

INSTITUTION: Macquarie University, NSW

AMOUNT FUNDED: $299,977

PROJECT SUMMARY:

Aging is a major risk factor for developing MND. This project is testing if a gene therapy that activates the anti-aging processes in motor neurones will slow or prevent MND.

Dr Shadfar is a first-time recipient of FightMND funding.

“By addressing the underlying mechanisms of aging, the goal is to discover new therapeutic avenues that could potentially slow down or alter the progression of MND, ultimately improving patient outcomes..”

PROJECT: Developing novel disease-specific gene therapy vectors for MND

PROJECT LEAD: Prof Yazi Ke

INSTITUTION: Macquarie University, NSW

AMOUNT FUNDED: $300,000

PROJECT SUMMARY:

A major limitation of current gene therapy approaches is their inability to specifically reach motor neurones. This project will trial a new delivery mechanism designed to specifically target MND-affected motor neurones, improving the effectiveness of gene therapy treatments.

Dr Ke is a first-time recipient of FightMND funding.

“This research could potentially lead to a more personalised approach to gene therapy treatments.”

DISEASE MODELS

Before a drug can be trialled in humans, we need more accurate cell and animal models of MND to better test which therapies are having the most benefit without harmful side effects. Studying model systems can also help us understand how MND develops.

PROJECT: Identifying Drivers of Neuroneal Dysfunction by Studying Myelinated Axons in iPSC-derived Organoids

PROJECT LEAD: Dr Samantha Barton

INSTITUTION: The Florey / The University of Melbourne, Vic

AMOUNT FUNDED: $299,872

PROJECT SUMMARY:

This study aims to re-create MND in “mini-brains” that are grown from the skin cells of individuals affected by MND. This 3D model of MND in a dish will become an important tool for researchers to study how and why motor neurones become unwell and die.

> **“Understanding the biology of MND is key to identifying effective drug targets so we are extremely appreciative to FightMND for funding our fundamental research.”**

PROJECT: Developing new MND disease models to study TDP-43 pathology

PROJECT LEAD: Dr Annika van Hummel

INSTITUTION: Macquarie University, NSW

AMOUNT FUNDED: $300,000

PROJECT SUMMARY:

Sporadic MND, where the cause of disease is unknown, accounts for ~90% of all MND cases. Modelling this form of MND remains a key gap that is preventing our ability to develop and test new treatment approaches. This project aims to recreate sporadic MND in a laboratory setting. A successful project will enhance our ability to test treatments in a model reflecting the majority of MND cases.

Dr van Hummel is a first-time recipient of FightMND funding.

> **“I hope this project brings us a little closer to finding a cure by giving us new models to better understand disease processes, and new molecules to target in our efforts to treat the underlying causes.”**

DRUG DELIVERY

A major challenge of MND therapeutics is that delivering drugs to the brain and motor neurons where it will have the most benefit is particularly difficult. Drug delivery projects look for ways to overcome these challenges.

PROJECT: Developing an extracellular vesicle-based nanoplatform for precision targeting of intraneuroneal TDP-43

PROJECT LEAD: Dr Shu Yang

INSTITUTION: Macquarie University, NSW

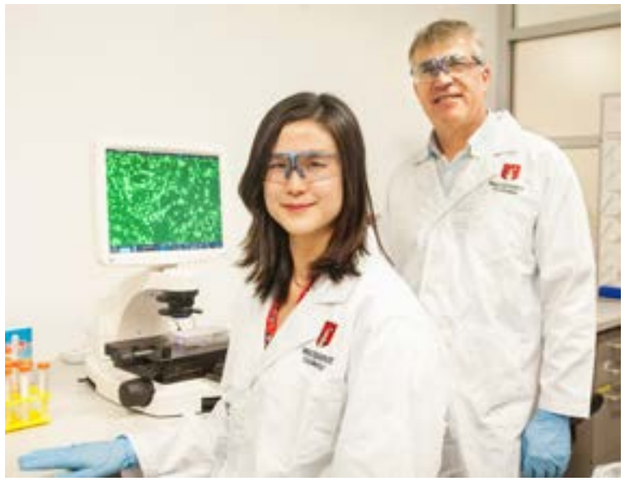
AMOUNT FUNDED: $300,000

PROJECT SUMMARY:

A downfall of current MND treatments is the inability to specifically target motor neurones. This project aims to use the body's natural message delivery systems to ensure therapies act specifically on motor neurones affected by MND. If successful, this will enhance the effectiveness of therapies and reduce unwanted side effects.

Dr Yang is a first-time recipient of FightMND funding.

"This funding will enable us to optimise our strategy for neuroneal delivery for MND."



THE MASSEY CHARITABLE TRUST GRANT

The Massey Charitable Trust has had a long-standing partnership with FightMND since 2020. This is the 3rd tranche of funding from the Trust and is their highest contribution so far. We would like to thank the Trust for their continued funding of this vital research into MND.

PROJECT: Can we stop the spread of disease in MND?

PROJECT LEAD: Prof Tracey Dickson and A/Prof Catherine Blizzard

INSTITUTION: University of Tasmania, Tas

AMOUNT FUNDED: $70,000

PROJECT SUMMARY:

Although the spread of MND through the brain and body is not fully understood, it is known to affect two distinct brain regions and muscles. Researchers at the University of Tasmania have developed a unique model that isolates these affected areas. This study will use the model to investigate how MND spreads and identify ways to stop it.

BILL GUEST MID-CAREER FELLOWSHIP

Mid-career research fellowships encourage outstanding researchers to choose or to continue to focus on MND as their primary area of research. The four-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 fellow's research program is focused on causes of MND and elucidating disease mechanisms, with the goal of developing more effective treatments, and a curen for MND.

This fellowship is named in honour of Bill Guest AM, the inaugural chairman of FightMND. In 2024, FightMND is awarding one mid-career research fellowship.

PROJECT: Taming microglial inflammation as a therapeutic avenue to treat MND

PROJECT LEAD: Dr John Lee

INSTITUTION: The University of Queensland, Qld

AMOUNT FUNDED: $720,000

PROJECT SUMMARY:

The mid-career research fellowship advances Dr Lee's career in a four-year research program. His research aims to understand how the brain's immune system contributes to the onset and progression of MND. Through this research, Dr Lee aims to identify new targets for drug development.

Dr Lee is a first-time FightMND grant recipient.

EARLY-CAREER RESEARCH FELLOWSHIP

Early-career research fellowships encourage talented researchers to focus on MND as their primary research area. The four-year fellowship provides recipients with the opportunity to establish their own independent research programs, build collaborations and further themselves as an MND researcher. The fellow's research program is focused on causes of MND and elucidating disease mechanisms, with the goal of developing more effective treatments, and a cure for MND.

In 2024, FightMND is awarding one early-career research fellowship.

PROJECT: Targeting neuroinflammation in MND with inter-alpha inhibitor proteins

PROJECT LEAD: Dr Liam Koehn

INSTITUTION: Monash University, Vic

AMOUNT FUNDED: $540,000

PROJECT SUMMARY:

This fellowship will support the development of Dr Koehn's research career in a four-year program. His research focuses on reducing inflammation in the brain. Dr Koehn will trial different modifications of a new drug targeting inflammation. Dr Kohen will trial different versions of a new drug to find the best way to deliver it to the brain and see if it can reduce MND symptoms.

Dr Kohen is a first-time FightMND grant recipient.

ALS SCHOLARS IN THERAPEUTICS SCHOLARSHIPS

The ALS Scholars in Therapeutics scholarships is a two-year program designed to engage clinician-scientists and post-doctoral fellows to gain training and experience in therapy development for amyotrophic lateral sclerosis (ALS, also known as MND). This is conducted at their home institution with an option for industry experience in year two. This scholarship works to identify, support and mentor the next generation of researchers.

FightMND contributes a portion of this scholarship in partnership with the Sean M. Healey and AMG Centre for ALS at Massachusetts General Hospital, ALS Finding a Cure.

The total amount funded towards this scholarship in 2024 is $450,194.

PROJECT: Developing a self-regulating TDP-43 degrader therapeutic for MND

PROJECT LEAD: Dr Jennilee Davidson

INSTITUTION: Macquarie University, NSW

PROJECT SUMMARY:

TDP-43 is a protein that becomes harmful to motor neurons in most people affected by MND. TDP-43 is therefore an attractive target for treating MND. Dr Davidson will validate and test a candidate gene therapy designed to only target harmful forms of TDP-43 in motor neurons. This will remove harmful TDP-43 from motor neurons while allowing normal TDP-43 that maintains motor neuron health to continue functioning.

PROJECT: Investigating Convergent Molecular and Cellular Signatures of Microtubule Instability in MND

PROJECT LEAD: Dr Kaya Matson

INSTITUTION: University of Pennsylvania, USA

PROJECT SUMMARY:

Dr Matson will examine how different known genetic mutations in MND affect the structure of cells, specifically motor neurons. It is hoped this will lead to new treatments that can restore the health of motor neurons affected by MND.

PROJECT: Defining genetic modifiers and genomic targets of DNA damage caused by the C9orf72 hexanucleotide repeat expansion in MND

PROJECT LEAD: Dr Jay Ross

INSTITUTION: Stanford University, USA

PROJECT SUMMARY:

In this project, Dr Ross will identify areas of the genome that are damaged in MND, potentially contributing to disease. Dr Ross will work to identify the cause of this damage, with the aim to slow MND progression by correcting the damage.

INFRASTRUCTURE PROJECTS

National research infrastructure grants focus on establishing, strengthening and sustaining national-scale infrastructure for MND research in Australia.

These grants aim to increase investment into innovative and essential MND research infrastructure and foster partnerships for co-developing research facilities.

PROJECT: Establishment of a clinical-grade synthetic small RNA therapeutic manufacturing facility locally for early-phase human clinical trials

PROJECT LEAD: A/Prof Rakesh Veedu

INSTITUTION: Murdoch University and Perron Institute, WA

AMOUNT FUNDED: $600,000

PROJECT SUMMARY:

Gene therapies are a rapidly emerging area of therapeutic development. However, facilities to manufacture clinical-grade gene therapies do not exist in Australia. In partnership with the West Australian Government, Murdoch University and SynGenis, FightMND is co-funding the establishment of a research facility with clinical-grade gene therapy manufacture capabilities at the Royal Perth Hospital. The facility will allow rapid translation of research findings to patient outcomes for MND and many other disorders.

PROJECT: Sporadic ALS Australia Systems Genomics Consortium (SALSA-SGC)

PROJECT LEAD: A/Prof Allan McRae

INSTITUTION: The University of Queensland, Qld

AMOUNT FUNDED: $796,000

PROJECT SUMMARY:

SALSA-SGC is a consortium of clinical sites around Australia collecting biological samples and clinical data from MND patient volunteers. These samples can be used by researchers to further discovery into the causes of, and potential treatments for, MND. This funding allows for continued collection and storage of patient samples, increasing the availability and diversity of MND-patient specific research material.

CARE
INVESTMENT

While the search for an effective treatment or cure is underway, FightMND is supporting the MND community through its investment in care research and initiatives.

FightMND is not a care service provider. This is the role of MND Australia, the state MND associations, MND&Me and other organisations serving the MND community.

FightMND's care investments focus on three key priorities, developed in consultation with the MND community:

EVIDENCE	STANDARDS	SUPPORT
Funding care-focused research to inform the best practices for supporting people with MND, their carers and families.	Investing in the creation of national standards and guidelines for MND care.	Providing targeted support through organisations that deliver MND care and services.

These efforts aim to enhance the quality of life for Australians living with MND and their caregivers.

$15.11M TOTAL INVESTED IN CARE PROJECTS AND INITIATIVES

3 STRATEGIC PRIORITIES FOR CARE INVESTMENT

EVIDENCE

investing in care-focused research

- **$0.69M** invested in innovations to improve quality of life and extend survival
- **$0.49M** invested in research to inform best-practice MND care

STANDARDS

development of national standards for MND care

- **$2.00M** invested into developing National MND clinical care guidelines

SUPPORT

investing in targeted support

- **$8.46M** invested in equipment and at home needs
- **$3.47M** invested in initiatives to improve care and the quality of life for people with MND and their families

STANDARDS

Standards projects focus on the development of national standards for MND care.

PROJECT: Development and implementation of the Australian MND Guidelines

PROJECT LEAD: Professor Zachary Munn

INSTITUTION: Health Evidence, Synthesis, Recommendations and Impact (HESRI), University of Adelaide

AMOUNT FUNDED: $2,000,000

PROJECT SUMMARY:

The team at HESRI, alongside experts and individuals with lived experience of MND, will develop evidence-based guidelines for Australian MND care. This initiative aims to enhance the MND care ecosystem, improving outcomes and quality of life for those living with MND.

SUPPORT

Support initiatives focus on providing targeted support and improving quality of life for people impacted by MND.

PROJECT:

A Friend's Place – specialist grief and bereavement care service for families impacted by MND (National Collaboration)

ORGANISATION:

National Centre for Childhood Grief

AMOUNT FUNDED:

$186,550

PROJECT SUMMARY:

A Friend's Place is a collaboration between the National Centre for Childhood Grief and MND associations throughout Australia. The initiative provides packages of specialist care to families with children aged from 3–17 who have a close family member living with MND. This initiative follows a successful FightMND supported pilot program in New South Wales and Victoria.

"This program will support families impacted by MND to understand and cope with the challenging realities, emotions and thoughts around their grief and loss."

PROJECT:

Inclusive resources for people impacted by MND from Culturally and Linguistically Diverse (CALD) communities

ORGANISATION:

Motor Neurone Disease Association of Australia Inc.

AMOUNT FUNDED:

$238,114

PROJECT SUMMARY:

This initiative aims to create inclusive resources for people with MND from CALD communities in Australia. These resources, including fact sheets and videos, addresses an identified gap in existing information and resources available to these groups. Co-designed alongside people with lived experience the materials will be available via MND Australia's national information resources platform, MND Connect in 2025.

"This project aligns with MND Australia's commitment to achieving an MND-aware Australia."

PROJECT:

Cough Assist and MND

ORGANISATION:

Motor Neurone Disease Association of Victoria (MND Victoria)

AMOUNT FUNDED:

$80,000

PROJECT SUMMARY:

This program is set to develop comprehensive training and information resources for specialist allied health professionals on the prescription, titration, and maintenance of cough assist machines. Additionally, up to three cough assist machines will be purchased and made available to people living with MND through MND Victoria's equipment service library.

PROJECT:

Advanced practice in gastrostomy management at Calvary Health Care Bethlehem (CHCB)

ORGANISATION:

Calvary Health Care Bethlehem Limited

AMOUNT FUNDED:

$99,723

PROJECT SUMMARY:

This initiative aims to establish a dietitian-led gastrostomy clinic at Calvary Health Care Bethlehem and Barwon Health, specifically for the MND community. The initiative aims to upskill dietitians to ensure safe and effective gastrostomy management, a crucial part of their specialised services. It also aims to support external dietitians, health professionals, and support workers in the community, including those in regional areas.

PROJECT:

Equity in Aged Care

ORGANISATION:

Motor Neurone Disease Association of Tasmania (MND Tasmania)

AMOUNT FUNDED:

$100,000

PROJECT SUMMARY:

The number of people living with MND in Tasmania has increased by approximately 20 percent in the last two years. Support for those diagnosed over the age of 65 and not on the NDIS is significantly less compared to NDIS participants. This investment will provide 20 care packages to Tasmanians over 65 years of age living with MND who are not NDIS participants. These packages will help them access essential daily services such as self-care, mobility, and domestic support.

"The grant allows MND Tasmania to continue to support Tasmanians, whilst focusing on other areas of under-investment."

PROJECT:

Providing equipment services to people living with MND

ORGANISATION:

Motor Neurone Disease Association of SA Inc. (MNDSA)

AMOUNT FUNDED:

$125,000

PROJECT SUMMARY:

This initiative supports people with MND over 65 by providing essential supports and equipment, helping them live with dignity at home. MNDSA will prioritise upgrading critical equipment for those ineligible for NDIS funding due to being diagnosed after 65. Additionally, investment in augmentative and alternative communications will expand specialist services for those who can no longer speak.

PROJECT:

Equipment provision for people with MND

ORGANISATION:

Motor Neurone Disease Association of Western Australia (MNDWA)

AMOUNT FUNDED:

$125,000

PROJECT SUMMARY:

Assistive equipment is a core need for people living with MND, as the symptoms of the disease impact mobility. These symptoms can be significantly degenerative and progressive. By providing this equipment loan service it allows for maintaining independence and quality of life, safety, comfort and continued participation in work and social activities.

PROJECT:

Implications of Voluntary Assisted Dying (VAD) on bereavement outcomes of family carers of people with MND

ORGANISATION:

Perron Institute of Neurological and Translational Science

AMOUNT FUNDED:

$225,817

PROJECT SUMMARY:

This project aims to develop an educational program for healthcare professionals supporting MND patients and their families through the VAD process. It will compare the experiences and bereavement outcomes of MND family carers in WA and Victoria, distinguishing between those bereaved by a VAD death and a natural death. The study will provide crucial insights into end-of-life decision-making, informing better service provision and bereavement support in Australia.

"This grant allows Perron Institute researchers to survey people affected by a VAD death or a natural death, and develop and deliver an education program to healthcare professionals across Australia."

PROJECT:

Bridging health equity gaps for Australians with MND: Co-designing solutions with the MND community

ORGANISATION:

UNSW

AMOUNT FUNDED:

$248,619

PROJECT SUMMARY:

The UNSW research team will collaborate with the MND community to identify barriers to accessing specialist MND healthcare in Australia and co-design solutions to bridge equity gaps. This project aims to connect more people living with MND, especially those outside metropolitan areas and over 65, with specialist care. The outcomes will inform the development of new or revised care models and improve pathways for generalist healthcare professionals to access support and education.

"The long-term goal is that the co-designed solutions from this work are implemented to improve the lives of people with MND."

Please contact our Programs team on 1800 344 486 or researchgrants@fightmnd.org.au for more information.

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