

**FIGHT
MND.**
IT TAKES PEOPLE

ANNUAL REPORT

**20
23**

ALL IN FOR MND.



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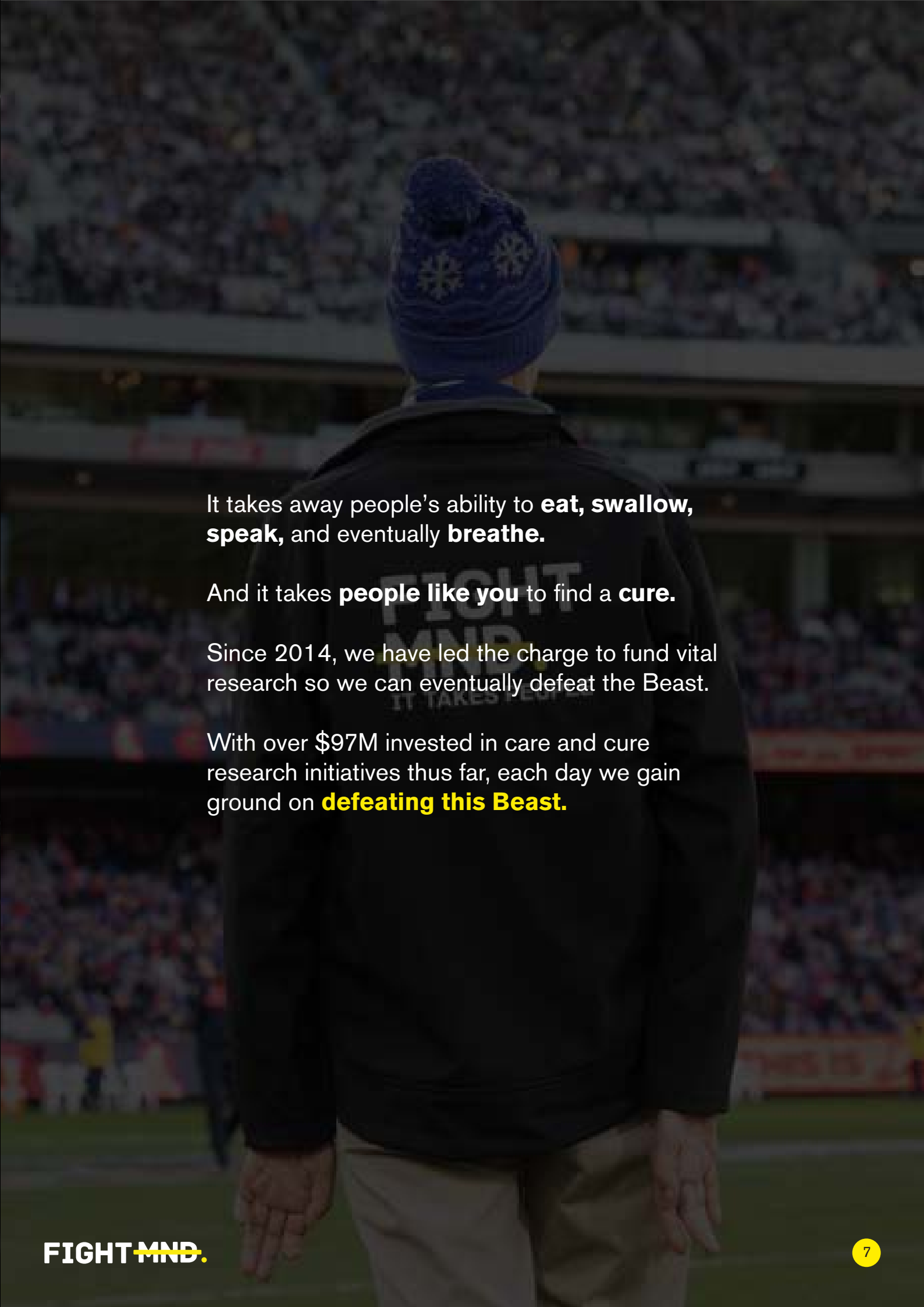
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INTRODUCTION





**MOTOR
NEURONE
DISEASE
(MND) IS A
BEAST OF
A DISEASE.
IT'S
RELENTLESS.
BUT SO ARE
WE.**



It takes away people's ability to **eat, swallow, speak,** and eventually **breathe.**

And it takes **people like you** to find a **cure.**

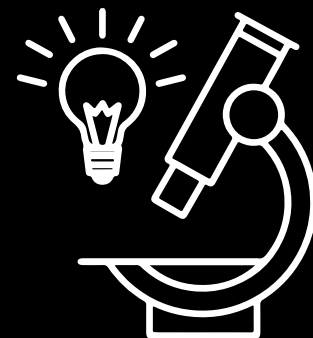
Since 2014, we have led the charge to fund vital research so we can eventually defeat the Beast.

With over \$97M invested in care and cure research initiatives thus far, each day we gain ground on **defeating this Beast.**

OUR MISSION

We are driven by a singular and urgent vision; a world free of **Motor Neurone Disease**.

Through the collective efforts of our supporters, we **raise awareness** and **fund vital research** to improve the quality of life and find a cure for those living with MND.



We do this with...

INTEGRITY

URGENCY

EFFICIENCY

BOLDNESS

COMMUNITY

THE STATS

**AVERAGE LIFE EXPECTANCY
AFTER MND DIAGNOSIS IS...**

**27
MONTHS**



**EACH DAY, 2 PEOPLE
DIE OF MND, ^{AND 2}
ARE DIAGNOSED. ^{MORE}**

**CURRENTLY, MORE THAN
2,100 AUSTRALIANS
LIVE WITH MND.**

**20
00**

JOINT LETTER FROM CEO AND CHAIRMAN

IT TAKES PEOPLE.

In reflecting on the year 2023, we are again incredibly humbled by everyone who joined the fight against MND and everything that we have been able to achieve together. After **10 years of FightMND**, we remain even more committed to felling the Beast that is Motor Neurone Disease.

The outstanding support we continue to receive from our major partners, sponsors, people living with MND and supporters has allowed us to invest over \$90 million over the past 10 years, break records and fund vital research and care projects.

In our search for an effective treatment or cure, we have been deliberate about investing to accelerate progress by developing our Cure Investment Strategy, which has four pillars:

- Investing in research;
- Investing in building the infrastructure to support research;
- Growing the MND research workforce; and
- Connecting MND researchers nationally and internationally

This year, we have been able to commit a further \$16.5 million into MND Research, including support of 23 projects and six career development awards on top of the \$86.6M we have invested since inception.

We continue to invest to improve the lives of people with MND in Australia – this year launching our inaugural Care Research grants and revamped Care Support grants. Hearing that we have helped to relieve some of the burden of living with MND makes it all worthwhile.

To our volunteers, team, and every person who wore a Beanie, pulled up their Socks, or rallied their friends to fundraise – thank you. You are the heart of our organisation.

We thank our dedicated and talented researchers who continue their rigorous and unrelenting search for a cure. It's a tough battle and we celebrate your progress and breakthroughs, big and small.

To our major partners Coles, Bunnings and Coles Express, our media partners Channel 7 and the Herald Sun, the AFL and its clubs, and our suppliers – we simply could not do this without you, and for that, we are eternally grateful.

Of course, a special thanks to the Victorian government for their \$250,000 donation to the Big Freeze campaign and a further \$250,000 in support of Daniher's Drive.

Finally, our Board – thank you for your continued voluntary support, expertise and commitment to the cause. We would particularly like to thank Lewis Martin for his contribution as he departed in June 2023 and a warm welcome to Peter Charles who joined the Board in November 2023.

A cure will be found through our collective efforts. It really does take people and we are invigorated by the support from across the Australian community.



Dr Fiona McIntosh

Dr Fiona McIntosh
FightMND CEO



Mike Schneider

Mike Schneider
Chairman



SECTION

2

2023 AT A GLANCE



2023 AT A GLANCE

Thanks to the generous support of our FightMND family, in 2023 we were definitely **ALL IN** for **MND**.



ACTIVATIONS:

Activations occurred in Melbourne, Brisbane and Perth.



WHAT WE SET OUT TO DO IN **2023**

OUR GOALS/STRATEGY

In 2023, we were definitely **all in for MND**.

We had another highly successful Big Freeze 9 with some iconic sliders, the most Beanies sold in the history of the campaign and over \$15 million raised. Daniher's Drive was back in full swing with over \$2 million raised and a fantastic road trip to Swan Hill, Shepparton and Creswick. We had terrific support from our major donors and community fundraisers who supported us in ways big and small.

We continued to make progress in accelerating towards a treatment or cure for MND, investing over \$16.5 million in MND Research in 2023 alone. Our purpose is to champion hope and to lead the fight against MND, which we are now doing on an international scale - FightMND is now one of the top three funders of MND Research globally.

We also continued to improve the lives of people living with MND in Australia by awarding 22 Care Support Grants valued at \$3.67 million to organisations around Australia who support people with MND.

And we launched Australia's first ever MND Care Research Grant scheme with five worthy recipients receiving over \$1 million in grants.

Every year we take a step closer to beating the Beast that is MND and 2023 was no different.

It takes people.



SECTION **3**
IMPACT



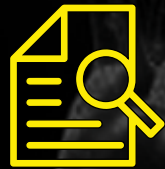
2023 INVESTMENT IN CURE

IN 2023, FIGHT MND
COMMITTED A FURTHER

\$16.5M

INTO MND RESEARCH
INITIATIVES

23 NEW MND RESEARCH PROJECTS



7

IMPROVING &
ACCELERATING
TRANSLATION
(IMPACT)
PROJECTS

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DISCOVERY
PROJECTS

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MND DRUG
DEVELOPMENT
PROJECTS

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CLINICAL
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2023 INVESTMENT IN CURE

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MID-CAREER
RESEARCH
FELLOWSHIPS



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EARLY CAREER
RESEARCH
FELLOWSHIPS

1

ANGIE CUNNINGHAM
PhD SCHOLARSHIP
& GRANT-IN-AID

20 23

ADDITIONAL FUNDS INVESTED

2

DANIEL MCLOONE
MAJOR RESEARCH
INITIATIVES
(CO-FUNDED
WITH MND
AUSTRALIA)

3

OTHER RESEARCH
INITIATIVES
(VICTORIAN BRAIN BANK,
MASSEY PARK GRANT,
COVID-19 IMPACT
SUPPORT FUNDING)

A MESSAGE FROM DR BEC SHEEAN

FightMND Director of Cure Research and Programs

IT TAKES PEOPLE.

Thanks to all our incredible donors, partners and supporters. Over \$16.5 million was committed towards 23 MND Research projects from researchers across Australia and around the world.

Some of the innovative projects we supported this year include the development of a new drug targeting a recently discovered MND pathway, the development of an early diagnostic test to help diagnose MND faster and several unique studies to grow our understanding of how a person's genetics contributes to the risk and incidence of MND.

We also supported six outstanding researchers across Australia who will receive funding to support them and their research for the next four years. This will allow them to continue their innovative, world-leading work in the lab and clinic.

This year, **we were excited to collaborate with MND Research Australia** for the first time to co-fund two \$1 million national collaborative projects, connecting our researchers to work together better and fast-track progress towards beating the disease.

I would like to extend an enormous thank you, on behalf of everyone at FightMND, to our MND research experts from across the globe who donate a significant amount of their time to assess our applications and help ensure that the funds raised throughout the year go to the most promising projects to help beat the beast that is MND.



Bec Sheean
Director of Cure Research
and Programs

Lastly, in December I was grateful to attend the international ALS/MND Symposium in Basel, Switzerland. It was incredible to see the volume of fantastic work in MND from across the world and the progress the field is making. **Every step forward brings us closer to our vision of a world without MND.**

We know that research is expensive, it takes time and we still have a way to go, but **we are so grateful to have our supporters and our incredible research army in the fight together.**



OUR JOURNEY TO FIND A CURE

2019

Support researchers through fellowships to build capacity and sustainability, inclusion of grants addressing the challenges of research translation.

2017

Moved to a more targeted investment strategy in the drug development pipeline and clinical trials, filling a critical gap in the Australian MND research landscape.

2023

FightMND launched Australia's only Care research grants. It was also a milestone year with a record \$20.6 million invested across Cure and Care initiatives.

2022

We embarked on a review of our strategy which resulted in the development of our Care Strategy 2023 – 2025, changing the way FightMND support people affected by MND.

2015

We began investing in research.

▶ LOOKING AHEAD

Between 2023-2025 FightMND will introduce a new infrastructure scheme to support Australia's MND research sector. We're also investing in Care initiatives to empower those living with MND and their families, connect the care ecosystem domestically and internationally, and develop tools to support and enhance the MND workforce.

RESEARCH SPOTLIGHT:

VALE JUSTIN YERBURY

Professor Justin Yerbury lost his battle with MND in 2023. The award-winning University of Wollongong (UOW) professor was only 49. Professor Yerbury became passionate about studying the rare degenerative condition following the death of his mother, grandmother, and aunt from the disease – in the space of six weeks – in 2002.

As Professor in Neurodegenerative Disease at UOW, he continued to focus on studying MND with his team at the Illawarra Health and Medical Research Institute. Dr Bec Sheean said,

"I was lucky enough to have known Justin and worked alongside him in my research days. I was blown away by the passion he had for research and his commitment to supporting early-career researchers. His contribution to the MND field is enormous and will continue into the future through his dedicated team at UOW. Justin was a kind and brilliant man and an MND warrior and his strength inspired so many to join the fight."

Even once he started showing signs of MND in 2016, Professor Yerbury continued his work on MND. Professor Yerbury's work showed that that protein deposits found in motor neurons resulted from dysfunction in a process known as protein homeostasis. This breakthrough, which could lead to new therapies, was awarded the University of New South Wales Eureka Prize for Scientific Research, and the award for Excellence in Medical Biological Sciences in the 2022 NSW Premier's Prizes for Science and Engineering.

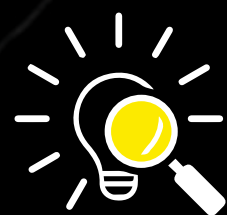
As well as receiving support from FightMND for his research across multiple projects, Professor Yerbury also assisted FightMND as a grant reviewer and panel member even as his disease progressed.



More than 2,100 people live with MND in Australia and Professor Yerbury remained determined to improve their lives.

"I want a better life for people with MND and I want to make MND a treatable disease."

Professor Yerbury is survived by his wife Rachel and two daughters, Talia and Maddison. His team of dedicated researchers have promised to carry on his work.



2023 CURE RESEARCH GRANTS

In 2023 we awarded the following grants to some of the best and brightest MND researchers in Australia, the USA, and Canada, so we can get one step closer to defeating the Beast.

To read about these projects in more detail, click [here](#).

CLINICAL TRIALS

Clinical trials test promising new drugs, or drugs already approved for other diseases or conditions in people with MND.

Professor Steve Vucic
The University of Sydney, NSW

Phase 2/3 Clinical Trial

A randomized, phase II/III trial on the biological and clinical effects of acetyl-L-carnitine in MND.

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.



DRUG DEVELOPMENT PROJECTS

Drug Development projects are focused on advancing promising new drugs or therapies through the final stages of testing, in preparation for clinical trials for MND patients.

Professor Peter Crack
The University of Melbourne, VIC

Discovery of STING inhibitors for the treatment of Motor Neuron Disease.

Professor Peter 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. Prof Crack is a first-time recipient of FightMND funding.



Associate Professor Joseph Nicolazzo
Monash University, VIC

Selective blockade of microglial Kv1.3 with HsTX1[R14A] for the treatment of Motor Neurone Disease.

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.



DRUG DEVELOPMENT PROJECTS

Associate Professor Peter Crouch

The University of Melbourne, VIC

A blood-brain barrier permeable DHODH inhibitor for treating MND.

A/Prof 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.



Doctor Dunhui (Oliver) Li

Murdoch University, WA

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

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.



DRUG DEVELOPMENT PROJECTS

Dr Fazel Shabanpoor

The Florey/The University of Melbourne, VIC

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

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 gene design reduces a form of a protein called SOD1, that is harmful to motor neurons.



Dr Damien Toulorge

ENCEFA, France

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

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.



Professor Lars Ittner

Macquarie University, NSW

Translating a novel gene therapy for MND towards clinical testing.

This project will test the safety and effectiveness of a new gene therapy targeting TDP43, 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. Prof Ittner is a first-time recipient of FightMND funding.



DRUG DEVELOPMENT PROJECTS

Dr Thanuja Dharmadasa

The Florey/The University of Melbourne, VIC

Understanding the earliest signs of MND development.

Dr Dhamadasa 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 with the inherited form of MND before symptoms emerge, to understand the earliest signs of disease and to enable treatment for MND to begin much earlier than is currently possible



DISCOVERY PROJECTS

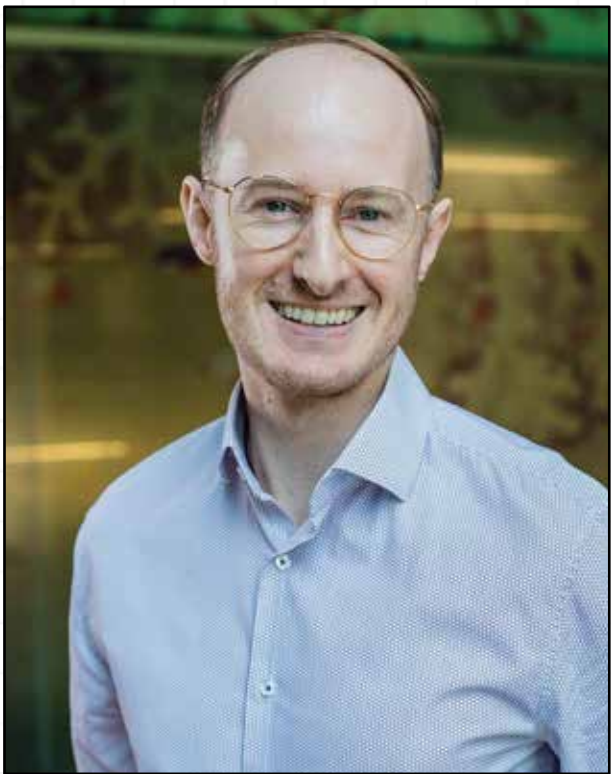
Discovery projects aim to resolve one or more current unknowns in the MND research sector, focused on discovering why MND occurs and what contributes to its progression. Outcomes should significantly advance our understanding of MND, and substantially increase the likelihood of accelerating the development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

Doctor Adam Walker

The University of Queensland, QLD

Investigating neuronal support cells and their dysfunction in MND.

Dr Adam 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.



Professor Roger Chung

Macquarie University, NSW

Understanding how TDP-43 regulates genes in MND.

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.



DRUG DEVELOPMENT PROJECTS

A/Prof Mary-Louise Rogers
Flinders University, SA

How does human endogenous retrovirus cause MND.

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



IMPACT PROJECTS

Dr Lyndal Henden
Macquarie University, NSW

Delving deep into the MND genome to reveal somatic mosaicism.

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.



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

A/Prof Gabriel Trajano
Queensland University of Technology, QLD

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

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



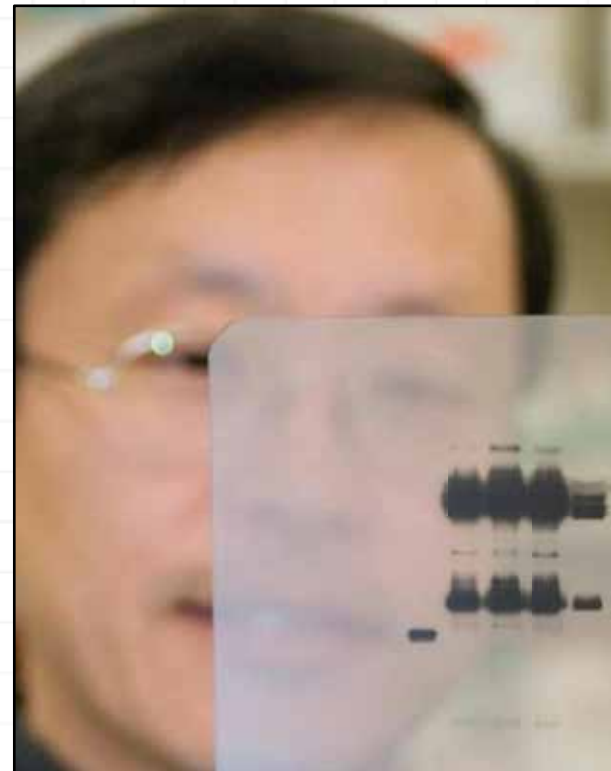
IMPACT PROJECTS

A/Prof Woojin Kim

The University of Sydney, NSW

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

A/Prof 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.



Prof Roger Chung

Macquarie University, NSW

Developing novel gene expression control mechanisms for MND gene therapies.

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.



IMPACT PROJECTS

Dr Emma Scotter

The University of Auckland, NZ

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

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.



Dr Jean Giacomotto

Griffith University, QLD

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

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 at Griffith University is a first-time recipient of FightMND funding.



IMPACT PROJECTS

A/Prof Joseph Nicolazzo
Monash University, VIC

Developing blood-brain barrier penetrating inhibitors of fatty acid binding protein 4 to reduce microglia-mediated neuroinflammation in MND.

A/Prof 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.



RESEARCH FELLOWSHIPS

A/Prof Kelly Williams
Bill Guest Mid-Career Research Fellow
(Macquarie University, NSW)

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

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



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 midcareer 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.**

A/Prof Catherine Blizzard
University of Tasmania, TAS

Can we tailor excitation therapy for MND?

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



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.

Dr Frances Theunissen
The University of Notre Dame, WA

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

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



Dr Stephanie Rayner
Macquarie University, NSW

Improving the likelihood of translation of novel Degradar technology for the treatment of MND.

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.



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.

Lead: Dr Albert Lee
Macquarie University, NSW
PhD Candidate: Ms Flora Cheng

Identification and characterisation of RNA-protein interaction in pathological aggregates of TDP43 in MND

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.



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.

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

Unravelling the early cortical signature of MND in vivo.

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.



MCLOONE RESEARCH INITIATIVES

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.

IMPACT PROJECTS

Lead: Prof Bradley Turner
The Florey/The University of Melbourne, VIC

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

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.



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

Exploring disease heterogeneity across MND clinical phenotypes using a multi-modal, multicentre neuroimaging approach.

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. fastprogressor 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.



OUR 2023 – 2025 CARE STRATEGY

Global research into MND Care is significantly underinvested in, and consequently, underdeveloped. However, with increased funding and a targeted focus, Care research has the potential to grow strongly and translate into outcomes that can improve the lives of people affected by MND in a relatively short timeframe.

In 2022, FightMND changed the way we support people affected by MND. Through research, surveys, and interviews with local and international MND associations, members of the Lived Experience community, researchers, health professionals, and peer organisations, we developed our Care Strategy 2023 – 2025.

The vision of our new Care Strategy is to improve the lives of people affected by MND by investing in three strategic pillars:

- Evidence: Care-focused research to inform better Care
- Standards: The development of National MND Care Guidelines to enable Australia to deliver best practice MND Care and guide Care research priorities.
- Support: Targeted support for people impacted by MND

Between 2023 – 2025, we will be investing in a range of initiatives to power MND Care that improves the lives of people with MND and their families, connect the Care ecosystem both in Australia and internationally, and develop enablers to improve and empower the Care research and support workforce.

SUMMARY & PROGRESS

FightMND is committed to ensuring that Australians diagnosed with MND can live as independently as possible, for as long as possible.

In 2023, in collaboration with Perpetual's IMPACT Philanthropy program, FightMND invested \$3.67 million in Care Support Grants. This investment provided \$50,000 to \$250,000 in financial support to organisations or allied health clinics that directly help people living with or affected by MND.

A second Care Support Grant round opened in October 2023, with a greater focus on two key priority areas:

- Supporting people who are diagnosed with MND over the age of 65; and
- Programs or initiatives that were collaborative or would support people affected by MND at a national level.



2023 CARE RESEARCH GRANTS

Our inaugural MND Care Research Grant in Australia opened in April 2023 – the first MND research grant in Australia solely focusing on improving MND Care.

This Grant provides funding opportunities for research focused on increasing survival and/or improving the quality of life for people diagnosed with, or affected by MND, through the improvement of MND Care in Australia.

Two funding opportunities were available:

- **Guideline-focused Care Research Grants:** To support research that provides evidence to inform and accelerate the development of a set of National MND Care Guidelines
- **Innovations in MND Care Research Grants:** To support projects that look at innovative ways to improve care.

14 applications were received, and were assessed by both national and international experts in MND care and care research, with top performing applications assessed again by an external panel comprising of MND clinicians, researchers and people living with MND.

Grant recipient announcements will be made in 2024.

PROFILE: PETER CHAMBERS

After being diagnosed in 2019 with MND, Peter Chambers has been involved in raising awareness around MND and has found that sharing his journey is both rewarding and therapeutic. Peter has spoken at many FightMND team events, and his positive outlook and his motto around being happy has been an inspiration to our team.

Peter was a panel member in FightMND's 2022 Care Support Grants advisory panel, and his lived experience and expertise were invaluable.

“It’s been humbling to see the dedication and hard work organisations like FightMND undertake on behalf of the MND community - if I can provide a little bit back, if I can add something to the process, then it’s really valuable.”

Since then, Peter has also been involved in a project spearheaded by MND Australia, and funded by FightMND, to reduce the barriers that people living with MND face, and gaps in representation, when trying to participate in research projects, advocacy, and education and awareness raising activities.

“It’s been a good experience, and extends my mind because it gives me something to do, and I feel privileged to see the work that goes on behind the scenes.”

Based in Melbourne, Peter has been the beneficiary of the amazing care that is available in Victoria through both Calvary Health Care Bethlehem and MND Victoria. As well as accessing care and support, Peter has also been able to access equipment available through MND Victoria's equipment hire program, a program that has received funding support from FightMND over the years.



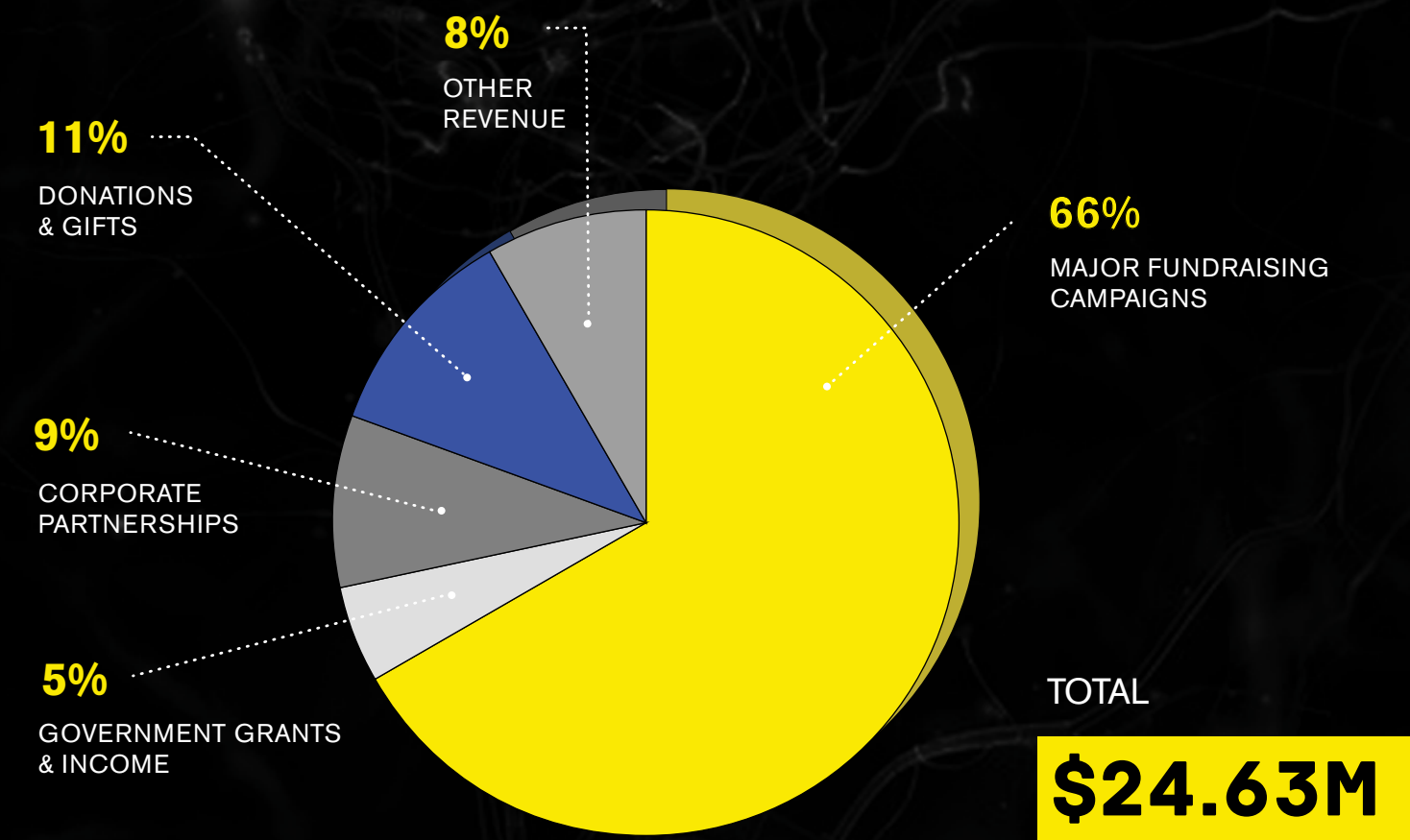
SECTION

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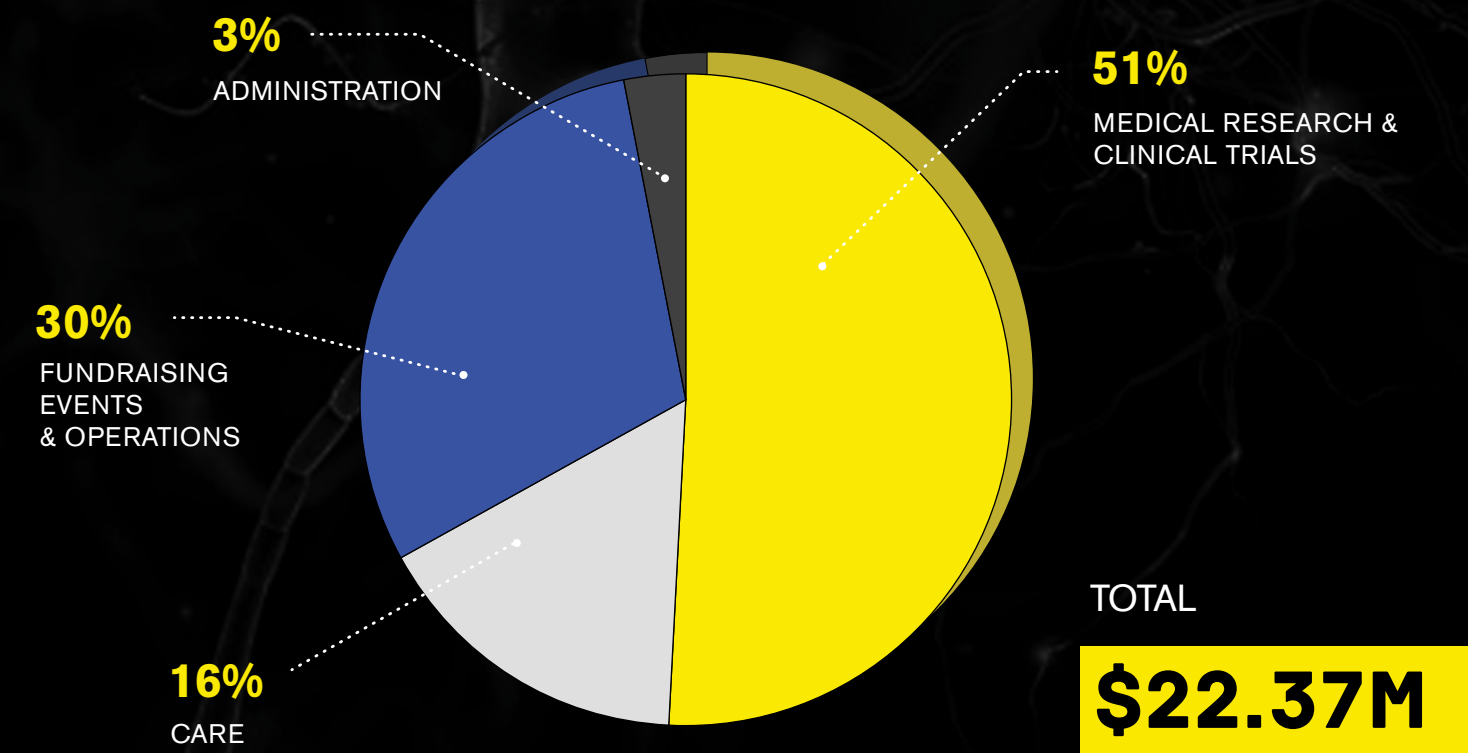
FINANCIALS



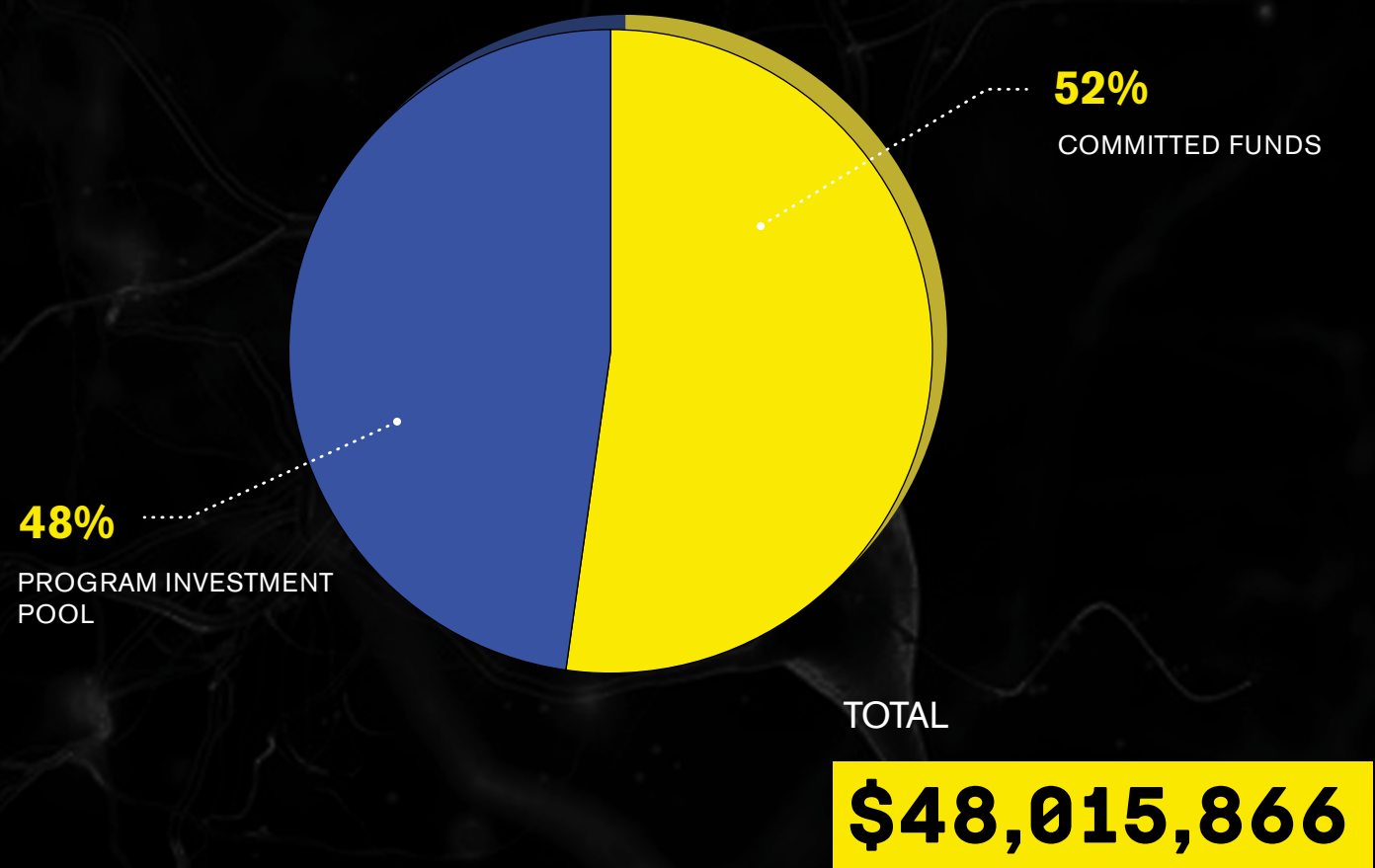
WHERE OUR MONEY COMES FROM



WHERE OUR MONEY GOES



FINANCIAL RESOURCES



► NOTE: The financial information provided is a summary only. It does not include all of the information normally included in a statutory financial report. If you require further information, please email info@fightmnd.org.au.

SECTION **5**

FUNDRAISING & CAMPAIGNS



SUMMARY OF FUNDRAISING, CAMPAIGNS & COMMUNITY

In 2023, we saw our incredible community of supporters once again go **ALL IN against the Beast that is MND**. Many buckets were tipped, many were dunked, a merry few slid and hundreds of thousands of people donned their Beanie's or pulled up their Big Freeze socks all in the name of FightMND, and we could not be more grateful.

Big Freeze 9 raised **\$15.8M** by campaign end. The King's Birthday clash of Collingwood and the Melbourne Demons head-to-head proved a nail-biting game and our generous celebrity sliders such as international super-star Eric Bana, global surf legend Mick Fanning, pioneering jockey Michelle Payne and many more braved the icy cold water on game day dressed as hero's or villains, cheered on by the record-breaking crowd of 97k attendees at the iconic MCG.

In line with our mission to 'Freeze the Nation', we once again travelled west with the West Coast Eagles fundraising for their marquee WA Freeze game, and for the first year we headed north to the sunny state where the Brisbane Lions showed their solidarity by hosting their own QLD Freeze game, complete with celebrities to dunk in icy waters.

Laughter and buckets of ice filled the community as our community DIY Big Freeze hit a record year, with over 500 fundraisers taking part in events across the country – we had sports teams, workplaces and schools activating their own mini freezes with dunk tanks aplenty, lots of sliders in fancy dress and hundreds of classic Ice Bucket Challenges.

Post Big Freeze, we set our sights on the inaugural Daniher's Drive which took place mid-October, an event with a focus on celebrating regional communities whilst raising vital funds for MND cure research and care initiatives. Over 250 individuals in 43 cars took part on the regional tour raising over \$2M via community fundraising events and raffles.

Over 1000 supporters took on a fitness challenge via the 27 Challenge or a running event – that's a lot of kilometres covered!

We are so grateful to have such a special community of supporters from every corner of the nation who are committed to the fight against MND.



BIG FREEZE 9
ALL IN FOR MND.

\$15.8M
DOLLARS RAISED

97k
PEOPLE AT THE MCG

450
RECORD-BREAKING VOLUNTEERS

9
ICONIC CELEBRITY
SLIDERS



FOR BIG FREEZE 9, WE WERE ONCE AGAIN **ALL IN** – STANDING SIDE BY SIDE IN THE FIGHT AGAINST MND.

Our campaign began with the unveiling of a powerful mural honouring Neale Daniher created by talented artist, Vincent Fantuzzo – showcased in the heart of Melbourne for the entirety of our Big Freeze campaign.

From Perth to Queensland, **Big Freeze 9** reached its climax at the King's Birthday clash between AFL teams Melbourne and Collingwood. The MCG was once again packed with a sea of blue Beanies, sending a powerful message to all those in the stadium and watching at home. The day commenced with a powerful march from Federation Square to the MCG, led by the man himself, Neale Daniher, alongside his wife Jan and the entire Daniher family.

With Conrad Sewell taking the stage, the atmosphere was electric and the crowd captivated. With a star-studded line up, our brave sliders who took the icy plunge included Mick Fanning, Shaun Burgoyne, Tayla Harris, Aaron Finch, Tony Shaw, Abbey Gelmi, Jason Dunstall, Michelle Payne and Eric Bana, each providing a captivating spectacle for fans both in the stadium and watching at home.

Thanks to such an amazing effort, Big Freeze 9 raised a staggering **\$15.8 million** – proudly announced on Global MND Awareness Day in June on the grounds of the MCG.

We want to thank all those who contributed to making Big Freeze 9 the success that it was - our generous partners, donors, volunteers and the broader FightMND community.

Whilst the fight is far from over, this achievement is the culmination of effort from so many, with proceeds allocated towards crucial care support and vital research, **all in the pursuit of a cure for the relentless beast that is MND.**





MICK FANNING

Aussie surfing champion



TAYLA HARRIS

AFLW Melbourne footy player



ERICA BANA

Actor & comedian



TONY SHAW

Collingwood footy legend



MICHELLE PAYNE

Pioneering jockey & horse trainer



AARON FINCH

Aussie cricket great



SHAUN BURGOYNE

Port Adelaide & Hawthorn footy great



ABBEY GELMI

Journalist & media personality



JASON DUNSTALL

Hawthorn footy great

SLIDER PROFILE

ABBEY GELMI

WHY DID YOU WANT TO BE INVOLVED WITH BIG FREEZE 9?

When the Daniher family asked me to take part, I couldn't say yes quickly enough. Truly one of the great honours of my career to be asked to play my part.

WHAT WAS YOUR FAVOURITE MEMORY FROM BIG FREEZE 9?

The smile on Neale's face and squeezing Bec's hand on the platform just before taking the plunge into the ice is a moment that will stay with me forever. They put in so much work to make the Big Freeze the enormous success it is, and sharing a small part of the joy as they see the MCG full of Beanies and beaming faces is so special. I'm in awe of the Daniher family and all they've achieved in the face of this insidious disease.

WHAT DOES THE BIG FREEZE MEAN TO YOU?

The Big Freeze to me typifies the magic that can happen when we come together as a community for the greater good. It doesn't matter what team colours you wear - on Big Freeze day, we are all Blue and it truly transcends football. FightMND and the Big Freeze means hope in the face of the Beast, and gets stronger year on year.

WHAT WOULD YOU LIKE TO SAY TO OUR FIGHTMND COMMUNITY?

Once part of the FightMND family, there's nothing you won't do to help. I look forward to doing my bit for years to come.



VOLUNTEER PROFILE

SHANNON OSRIN

WHAT DOES THE BIG FREEZE MEAN TO YOU?

I give my time to Big Freeze because it's such an important cause that needs an urgent cure. I was initially inspired by Neale Daniher's amazing courage and determination to have as many people learn about MND and how it impacts everyday Australians. This is such a cruel disease, and I am grateful to play a part in this.

HOW DID YOU GET INVOLVED IN THE BIG FREEZE IN 2023?

I saw a post on Twitter in 2022 about calling for volunteers and I was excited to get involved. I have followed the progress of the Big Freeze campaign and was so encouraged to see how Australia comes together to support this campaign every year.



WHAT MADE YOU VOLUNTEER WITH US?

This was my second year in a row and I keep meeting so many interesting people, some that had family members with lived experience, and I thought, "this is more than just footy". This year, I was lucky enough to be part of the Collingwood guard of honour. Looking up at the 90K plus crowd, it (kind of) felt like I was a player for a bit!

THANK YOU TO OUR VOLUNTEERS

With a record-breaking 450 volunteers across three states, including our youngest at just eight years old, we were overwhelmed with the outpouring of support during Big Freeze 9.

You sold our beanies, collected important donations and 30 of you joined us at our online Beanie Headquarters helping us send out online Beanie orders throughout the campaign.

- 284 VOLUNTEERS IN VICTORIA
- 104 VOLUNTEERS IN WESTERN AUSTRALIA
- 62 VOLUNTEERS IN QUEENSLAND



BIG FREEZE FOREVER

The Big Freeze Forever (BFF) is a club that honours all of our past and current sliders who brave the icy plunge each year.

Since the Big Freeze's inception, we have welcomed 112 Australian celebrities and sports stars who have been generous enough to donate their time for our cause. The BFF Club is our way of staying connected with each individual and their families, by sending each year's beanie with their 'slider number' featured on it, so they may continue to support and advocate for the cause across socials, media and marketing platforms year on year.

We are incredibly grateful for the support we receive each year and look forward to expanding the Big Freeze Forever program with our Big Freeze 10 sliders.



BIG FREEZE 9 SOCKS

In 2023, our **Big Freeze Socks** campaign officially became part of Big Freeze. We sold 27,500 pairs of Socks and raised a whopping \$407,865 – launching on 9th of March and selling out by 25th of May 2023.

Big Freeze 9 Socks were extremely popular with sporting clubs and local businesses around Australia with:

- 188 SPORTING CLUBS
- 104 BUSINESSES, AND
- 40 SCHOOLS

...all enthusiastically pulling on our Socks!

The Community Round on 18-19 June 2023 brought the Big Freeze to local sporting clubs and communities around Australia. It was great to see so many players and local community members showing their support for FightMND by wearing the Big Freeze 9 Socks. We are extremely grateful for all the support shown from sporting clubs, schools and communities around Australia.



\$407,865

TOTAL RAISED

27,500

PAIRS OF SOCKS SOLD

340

SPORTING CLUBS, SCHOOLS & BUSINESSES AROUND AUSTRALIA



\$1M

DOLLARS RAISED

197

TEAMS

200+

FUNDRAISERS

Our supporters went ALL IN and got behind **DIY Big Freeze** again, bringing the fun of the Big Freeze to their local communities. Taking part was as simple as an ice bucket challenge in their backyard, school or hosting a Big Freeze event with a slide or dunk tank at their sports club or workplace.

The majority of our community fundraisers efforts stem from sports clubs, schools and workplaces with fundraisers driven by supporters with either a personal connection to MND or a passion to support FightMND. Notably, the Slattery DIY Big Freeze, now in its second year, raised an impressive \$40,003, a testament to the dedication of two daughters organising the event in honour of their mother battling MND.

It was inspiring to see the FightMND community get involved with DIY Big Freeze in their own unique ways.

Malvern Primary School in Victoria introduced a run club at lunchtime with a goal of running 100km. Alongside achieving this incredible goal the school hosted an ice bucket challenge raising \$37,638 in support of FightMND.

We hope that 2024 will bring more community events from outside of Victoria and that our new fundraising platform will provide our incredible community fundraisers more support.



DIY BIG FREEZE EVENT PROFILE

Returning for its second year, supporters in Geelong brought **DIY Big Freeze to Drysdale Reserve**. With a 30% jump in attendees, 4,000 people created a sea of blue with our Big Freeze Beanies.

The Mayor of Geelong, Trent Sullivan, was amongst 16 local personalities to brave the slide and the freezing water waiting below at Drysdale Recreation Reserve. An enthusiastic crowd clapped and cheered, enjoying the inventive costumes as diverse as Dame Edna, Cameron Ling and Elmo!

Big Freeze Geelong ambassador and nephew of FightMND leader Neale Daniher, James Bruest said they were overwhelmed to eclipse last year's fundraising total - raising over \$50,000.

"We were just stoked with the day - the sun was out, the crowds were big and the sport on the day was really close as well. The sea of blue beanies was really impressive; we were just blown away by the community support once again."



"Seeing Neale's fight over the last ten years has been pretty inspiring. Everyone admires him, his grit and his leadership. It inspires us to get that win and that cure for him."

Thank you to all the supporters and participants for making this a huge success and a big thanks to the Drysdale Football Netball Club for again hosting the Geelong Big Freeze event, raising vital funds for MND Research.





\$2M

DOLLARS RAISED

250

PARTICIPANTS

Daniher's Drive is FightMND's famous four-day annual road trip across regional Victoria and neighbouring states, raising funds and awareness for MND research and care along the way.

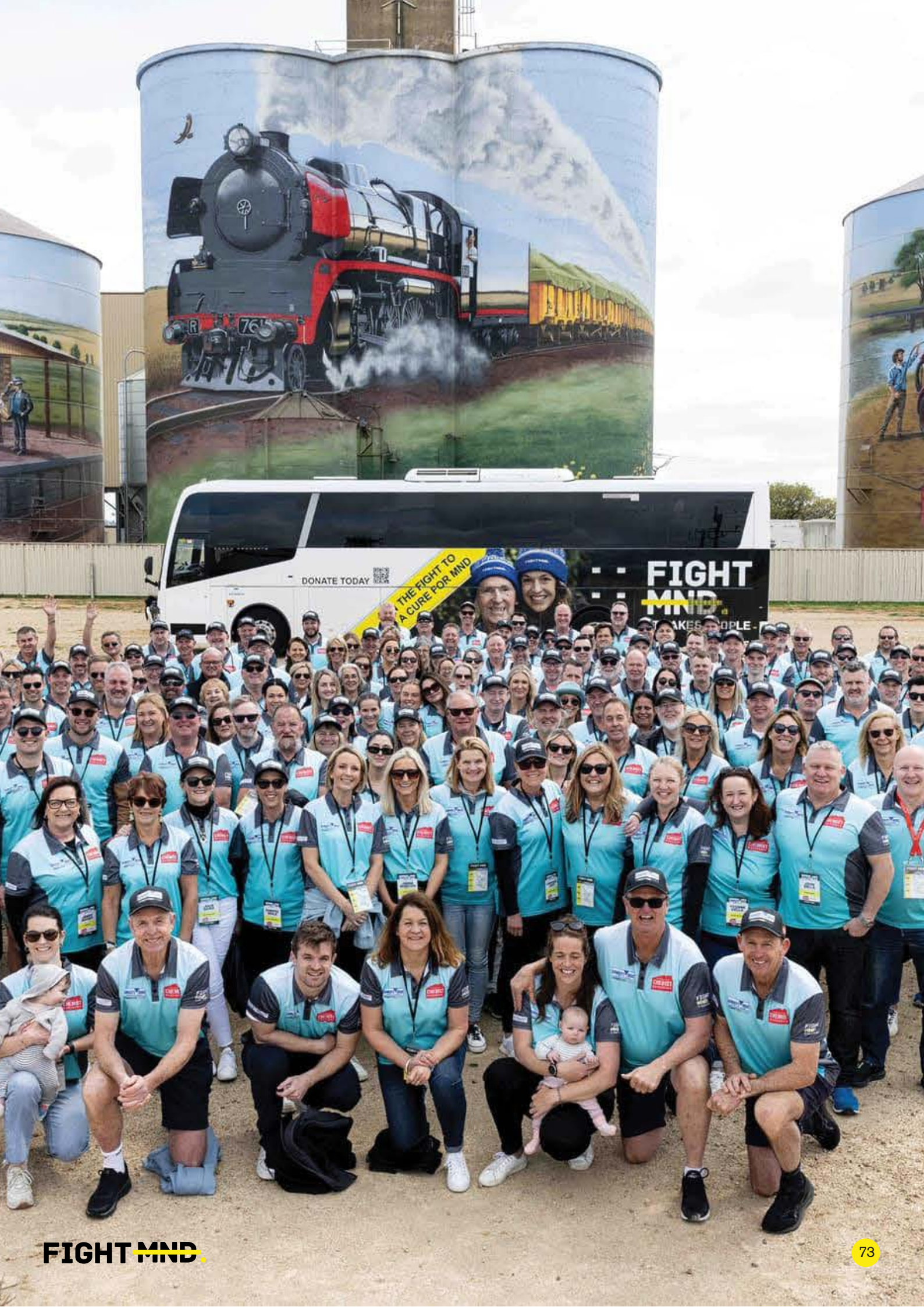
The 2023 event saw 250 participants travel from Melbourne to Swan Hill, Shepparton and Creswick.

This year, we were delighted to raise over \$2 million for FightMND. Key contributions included:

- Over **\$1M** from our Daniher's Drive fundraisers
- Raising over **\$195,000** from the Daniher's Drive Jayco raffle
- Chemist Warehouse running a hugely successful in-store donation drive raising over **\$400K**
- A generous **\$250,000** donation from the Victorian State Government

A huge thanks to our silver sponsor PSC Insurance, and night event sponsors Bayside Coaches and CMV Truck and Bus, for again supporting the Daniher's Drive.





MEET DANIHER'S DRIVE PARTICIPANT, GARETH ROBERTS.



Gareth Roberts lost his father Ian to MND in October 2013 but he inspired his son until the end.

Participating in **Daniher's Drive** in memory of his father, Gareth's memories include the many cars Ian owned, especially his 1981 Skoda 120L.

"It was a faded orange, beaten-up old car but he loved it. He would take us on family outings every week – basically take us everywhere."

In January 2023, Gareth bought the same model for \$250 and dedicated his weekends to getting it to look exactly like his Dad's, right down to the 'turbo' sticker on the back.

Joined by his brother-in-law Alex, he drove that car as part of the four-day road trip through Victoria's Swan Hill, Shepparton and Creswick.

"THIS IS PART OF ME COMING TO TERMS WITH LOSING DAD 10 YEARS AGO."

On this 10-year anniversary, Gareth wanted to give back to FightMND and bring a bit more awareness to the cause by taking part.

"I want to make sure that my kids and their generation don't have to go through this. We shouldn't be losing people in the prime of their lives."



\$129k

TOTAL RAISED

197

NATIONAL FUNDRAISERS

27 CHALLENGE PROFILE

27 Challenge is a virtual peer-to-peer fundraising event that the whole community can get involved in. Over the month of September, participants are challenged to complete 27 minutes of exercise a day and they can choose whatever recreational activity they like.

27 Challenge was created during the pandemic as a virtual peer-to-peer fundraising event targeting friends and family of those affected by MND, and the greater community, to take on a challenge over 27 days.

In 2023, the 27 Challenge saw a hybrid approach incorporating state-based community-led activations.

A standout in South Australia was the Thomas Foods International (TFI) Walk which raised over \$35,000 by encouraging their workplace to fundraise and walk 27km from Adelaide CBD to the Coast.

There were many other incredible efforts from all around Australia, a few of the top fundraisers from NSW, VIC and TAS were Marco Lori, Manvir Bal, Stev Lackovic and Archie Payne.



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FIGHT MND.

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SECTION

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COMMUNITY FUNDRAISING



MORE COMMUNITY FUNDRAISING

We had many incredible fundraising events take place this year, including golf events, crazy hair days, and a very special couple who in place of gifts, asked guests to donate to FightMND on their wedding day.

Supporters laced up their runners and hit the pavements across Australia at the major running events, with over 1,000 supporters running to support FightMND in 2023.

TOM BARR SMITH

In July, Tom Barr Smith took on the Simpson Desert in his Porsche and raised over \$143,000.

Tom and his family have been dedicated supporters of FightMND for many years after Tom's wife Jenny passed away from MND. Jenny was among the 5-10 percent of people with MND who have the familial gene.



RUN FOR ROSSY (R4R)

Run 4 Rossy returned for its third year - an annual event run by Karen Ross and loved ones in honour of Chris Ross who was diagnosed at the young age of 31 and passed away in August 2023.

The event was an incredible success with over 450 participants and raised over \$120,000. The event will return in 2024 to raise more funds for FightMND and honour Chris's spirit and determination to "keep on livin".

A massive thank you to our amazing community who dedicated their time and energy to raise vital funds for MND research.

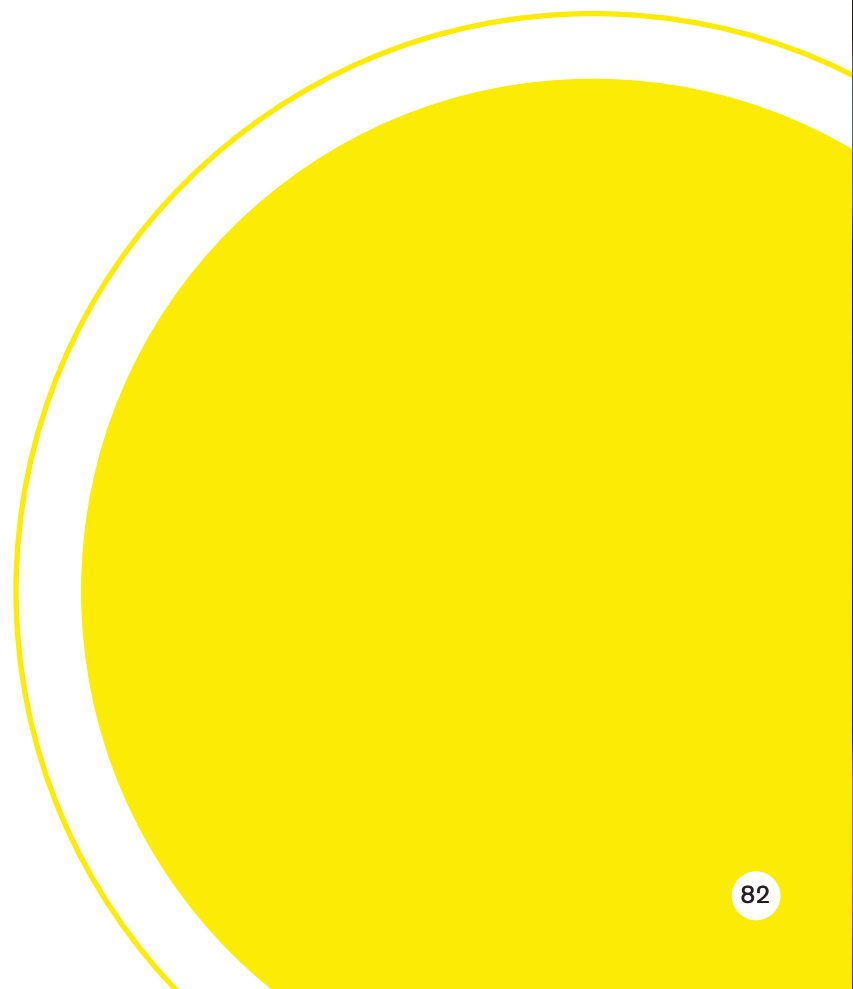
As Tom Barr Smith says,

“This wonderful world will be an even better place, should our collective dollars and scientists bring about a positive result in the treatment and ultimately a cure for MND.”

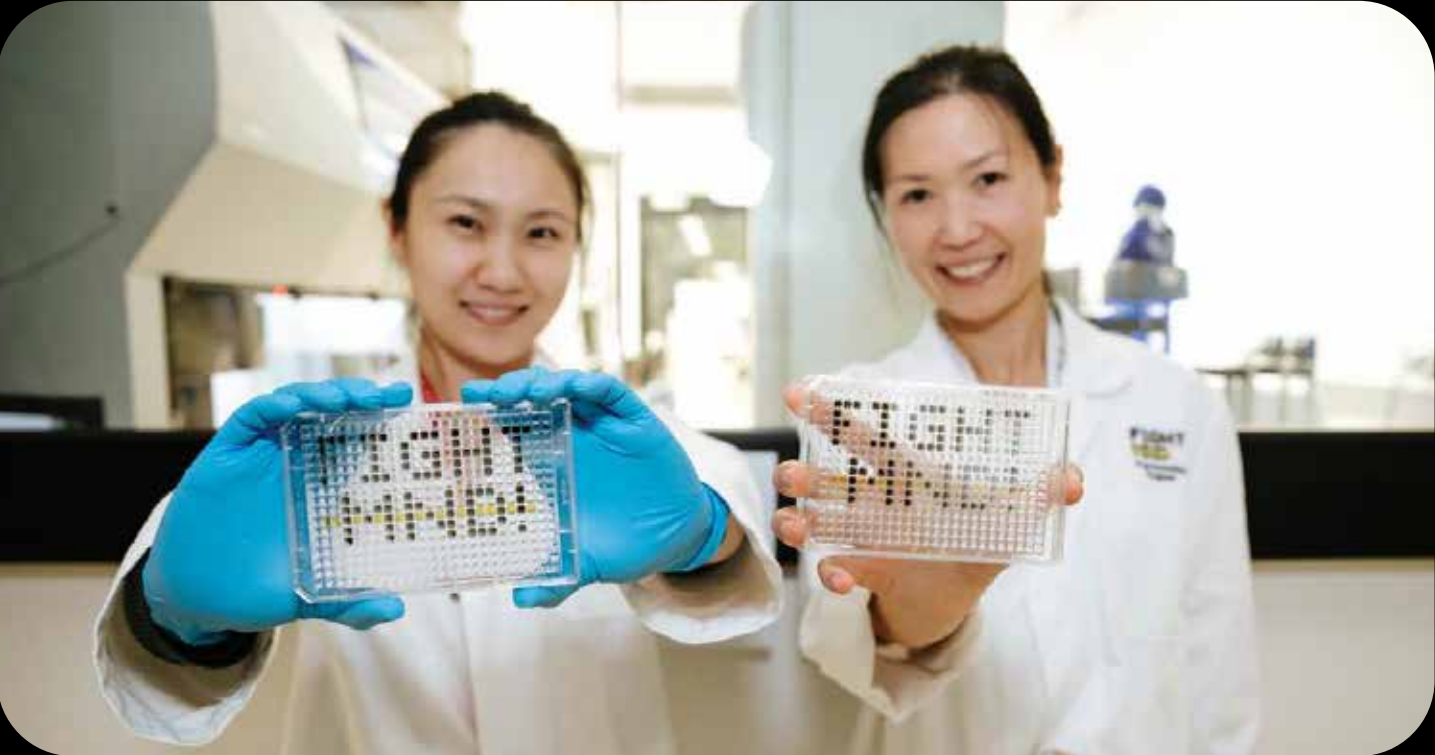


SECTION **7**

RECOGNITION



RECOGNITION



FIGHTMND CLUB

Established in 2021, the **FightMND Club** is our major donor program. These supporters are vital members of our FightMND family and represent the next cohort of leaders lining up to continue the fight against the Beast. In 2023, we held four stewardship events for the FightMND Club.

These events were a fantastic opportunity to connect and engage with some of our most loyal and generous supporters, and thank them for their continued support. Our former Chair Bill Guest hosted the annual FightMND event in his home where our Chair, CEO and a person living with MND shared their experience of living with MND. We gave our guests an overview of our Care Support and Research Grants and invited them to support.

Three lunches with FightMND Chair, Mike Schneider, were held, providing FightMND Club members an exclusive experience and engage them in an intimate setting. This was an opportunity to provide FightMND Club members an exclusive experience and engage them in an intimate setting.

Thank you to our FightMND Club donors who generously contribute funds to support vital research and care. Your support makes a difference and is integral to our success. For more information about the program, head to fightmnd.org.au/fightmnd-club/

PARTNERS

MAJOR PARTNERS



OFFICIAL PARTNERS



MEDIA PARTNERS



SUPPORTING PARTNERS



PARTNERS

ACTIVATION PARTNERS



EVENT PARTNERS



FROM ALL OF US AT TEAM FIGHTMND,
we give thanks to our amazing, inspiring, supportive partners. Your generosity and commitment to being ‘all in’ means we are one step closer to finding a cure and beating the Beast that is MND.

COLES

Coles joined the fight in 2018 and has raised an incredible \$30 million for FightMND to date. As a major partner of the Big Freeze, the entire Coles network stands with FightMND and continues to create meaningful interactions with their customers to raise awareness and funds for MND research.

Coles impressively delivered a multifaceted Big Freeze campaign and raised \$8.5 million for FightMND.

Big Freeze 9 was brought to life in store with the return of the iconic blue Beanies, Pork donations, donations at registers and the introduction of the Peters Limited Edition Big Freeze Icy Pole. Coles’ support throughout the campaign was unmissable, with significant investment in marketing and media support.

Coles Group General Manager of Corporate and Indigenous Affairs Sally Fielke said the Big Freeze campaign is Coles’ single biggest community fundraiser every year.

“Coles is proud to have raised more than \$30 million in six years to help FightMND find a cure for Motor Neurone Disease. It’s a cause that is close to the hearts of many of our customers, suppliers and team members and an important way for us to support the health of Australians.”

Thank you, Coles Group.





BUNNINGS

Bunnings has been a major partner of FightMND since 2019. Every year, the iconic Australian hardware business sells Big Freeze Beanies in all stores, reaching customers nationwide and finds new, fun ways to support the Big Freeze to raise awareness of the campaign.

In addition to a bespoke TVC and AFL integrations, Bunnings supported Big Freeze with the inaugural Polar Plunge event which was live streamed on the Today Show.

Bunnings had record sales with an amazing 60,129 beanies sold, resulting in over \$1.5 million raised for FightMND.

Bunnings Chief Customer Officer, Ryan Baker, notes Bunnings is proud to be supporting FightMND for the fifth year running.



“Each year, we see an amazing amount of enthusiasm across our team, customers, and community in going all-in on the fight against MND. In 2023, we took our commitment to the next level, securing national coverage of our Polar Plunge for Neale and everyone who has been diagnosed with this devastating disease.”

Thank you, Bunnings.

AFL

The AFL has stood with FightMND as an Official partner from day one, helping create and shape the Big Freeze we know and love. Through their generosity and support, we have built a world-class event, turning the MCG blue on King’s Birthday each year at the Melbourne vs. Collingwood match.



ACTIVATION PARTNER CLUBS

The partnerships FightMND holds with AFL clubs helps to provide an amazing platform to build awareness, drive donations and merchandise sales to help fight the Beast that is MND.

FightMND's partner clubs - Melbourne FC, Collingwood FC, West Coast Eagles and Brisbane Lions - showed incredible professionalism, drive and generosity to support the cause.

They all deserve credit for their efforts in helping promote and making each event special - events that supporters won't forget and keeps them coming back year after year.

VIVA

After **VIVA** purchased Coles Express in May 2023, it continued the long-standing Big Freeze partnership established with the Coles Group.

In 2023, Selected Coles Express stores sold adult Beanies and supported with a 4c fuel discount, to raise an incredible \$967,300 for FightMND.



SECTION

8

THANK YOU

LOOKING FORWARD

2024 AND BEYOND

As we take a moment to reflect on past success, and all the wonderful people who have helped us fight the Beast, we are also excited about what's ahead. The mantra 'It Takes People' is again at the forefront.

HERE'S A SNAPSHOT OF OUR EFFORTS FOR 2024:

- Big Freeze 10 - bigger and better than ever on its 10th birthday
- A new exciting route for Daniher's Drive
- The launch of a new research infrastructure grant scheme
- Hosting an international scientific roundtable in August
- Investing to develop a National Care Guideline for people living with MND and
- Launching our second round of Research grants and Care support grants

Dr Fiona McIntosh, CEO of FightMND, emphasises the collective effort needed to defeat the Beast that is MND:

"This year, it's an all in fight. We couldn't do it without the unwavering support of our community and partners, whose generosity and dedication enable us to make a real difference for people impacted by MND. For that, we are extremely grateful and their efforts help drive our own commitment to keep fighting the Beast."

THE FIGHT IS **NOT OVER**



When you donate to **FightMND**, you provide hope to people living with MND as well as their families – hope that one day, there will be an effective treatment or cure for this devastating disease.

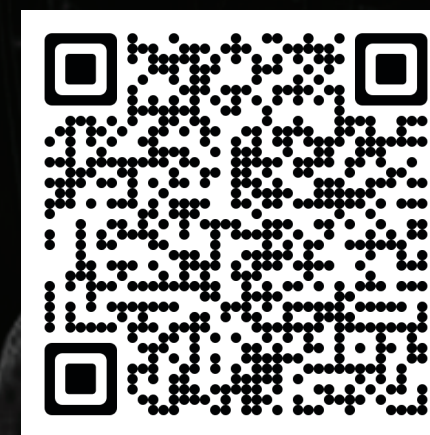
Donate now to improve care for people living with MND, fund research into more effective treatments, and eventually, find a cure.

Together, we can defeat the Beast.

support.fightmnd.org.au/donate

DONATE **BELOW**

To continue supporting our fight against the Beast,
please donate here:



Fight MND
PO Box 3073 Burnley North,
Victoria 3121

Phone: 1800 344 486
ABN 627 403 50704