

**FIGHT
MND.**
IT TAKES PEOPLE

ANNUAL REPORT

2022
PLAY ON.



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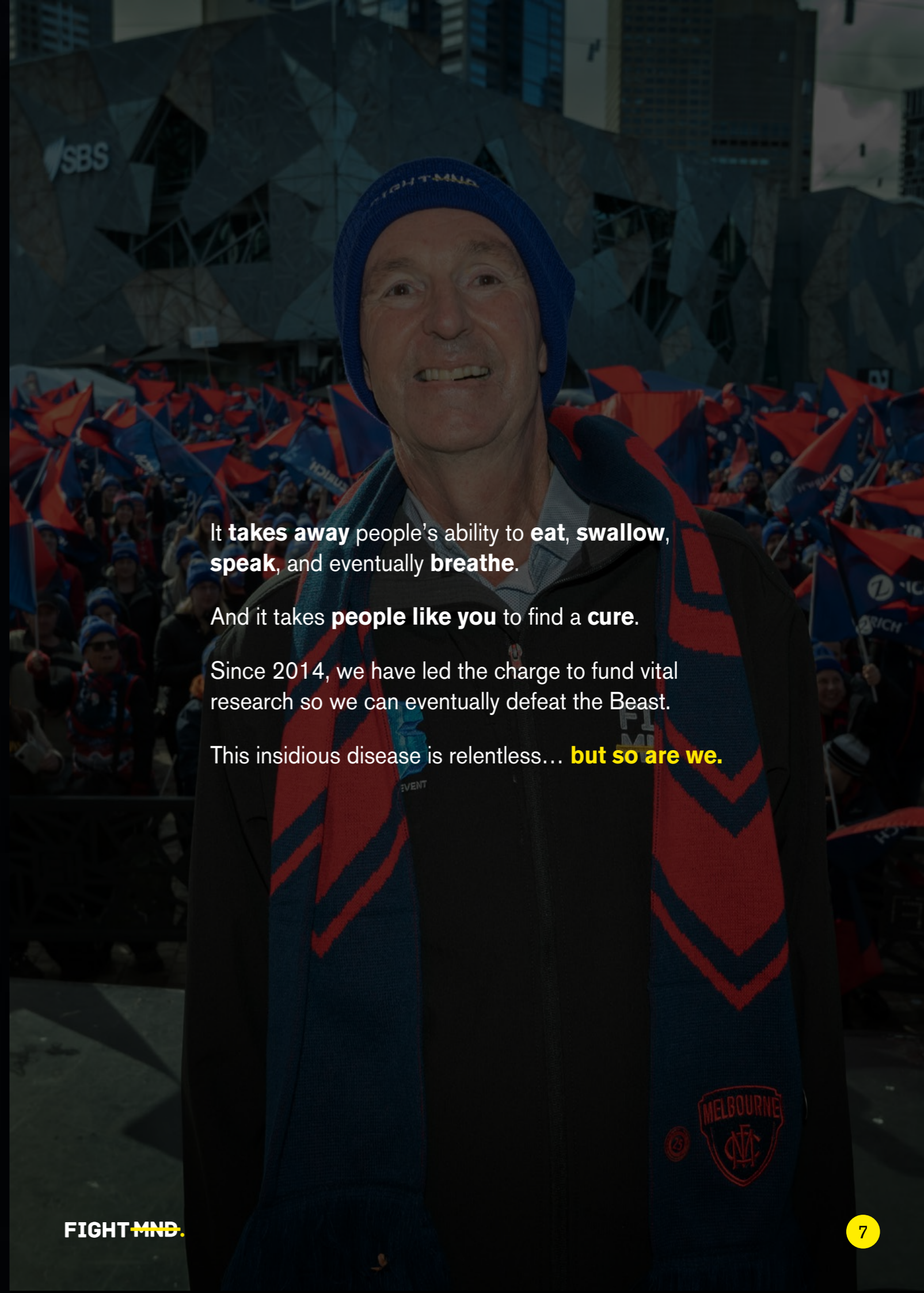
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1

INTRODUCTION



**MOTOR
NEURONE
DISEASE
(MND) IS A
BEAST OF
A DISEASE.
IT TAKES
PEOPLE.**



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.

This insidious disease is relentless... **but so are we.**

Average life expectancy after MND diagnosis is

27 MONTHS

Each day,

2 PEOPLE

die of MND, and **2 more** are diagnosed

Currently, more than

2,000

Australians live with MND

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

JOINT LETTER FROM CEO AND CHAIRMAN

The year 2022 stood as a testament to what we are capable of when we stand together in the face of adversity.

Pandemic-related lockdowns were challenging for FightMND because we were missing the heart and driving force of everything we do – community and connection.

After two years of uncertainty, we resolved to make one thing more certain than ever – our mission to live in a world free of Motor Neurone Disease. In 2022 we emerged from lockdown and once again held some of our iconic events in their full form.

Our message was simple. We called on the FightMND family to step up - **Beanie On, Play On**, and our wonderful community did just that.

We proudly broke another fundraising record and were able to commit \$13.4 million to MND research projects in our search for a cure, including two clinical trials, two drug development projects, and 10 IMPACT projects.

While research for a cure is urgent and critical, we also recognise that people with MND and their families need better care support. In 2022, our Care Strategy was developed with the vision to improve the lives of Australians affected by MND. This strategy will see investment into research, and the development of National Guidelines to help clinicians and carers provide better care for MND patients.

We would like to extend our heartfelt gratitude to every person in the FightMND family who brings us closer to our vision each day.

To our FightMND Club major donors – thank you for stepping up as our next generation of leaders.

To our Board – thank you for your voluntary support and commitment.

We extend our thanks to our outstanding network of dedicated researchers, whose passion and relentless efforts bring us closer every day to the ground-breaking discovery that will beat the Beast.

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

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.

A cure is found in our collective efforts. For now, we will keep playing on.



Dr Fiona McIntosh

Dr Fiona McIntosh,
FightMND CEO



Mike Schneider

Mike Schneider,
Chairman



SECTION **2**

YEAR AT A GLANCE



2022 AT A GLANCE

Thanks to the generous support of our FightMND family, in **2022** we were able **'Play On'** and continue funding vital research for MND.

\$24.4M

raised

Returned to the MCG for
BIG FREEZE 8

Developed a new
CARE
strategy

\$13.4M

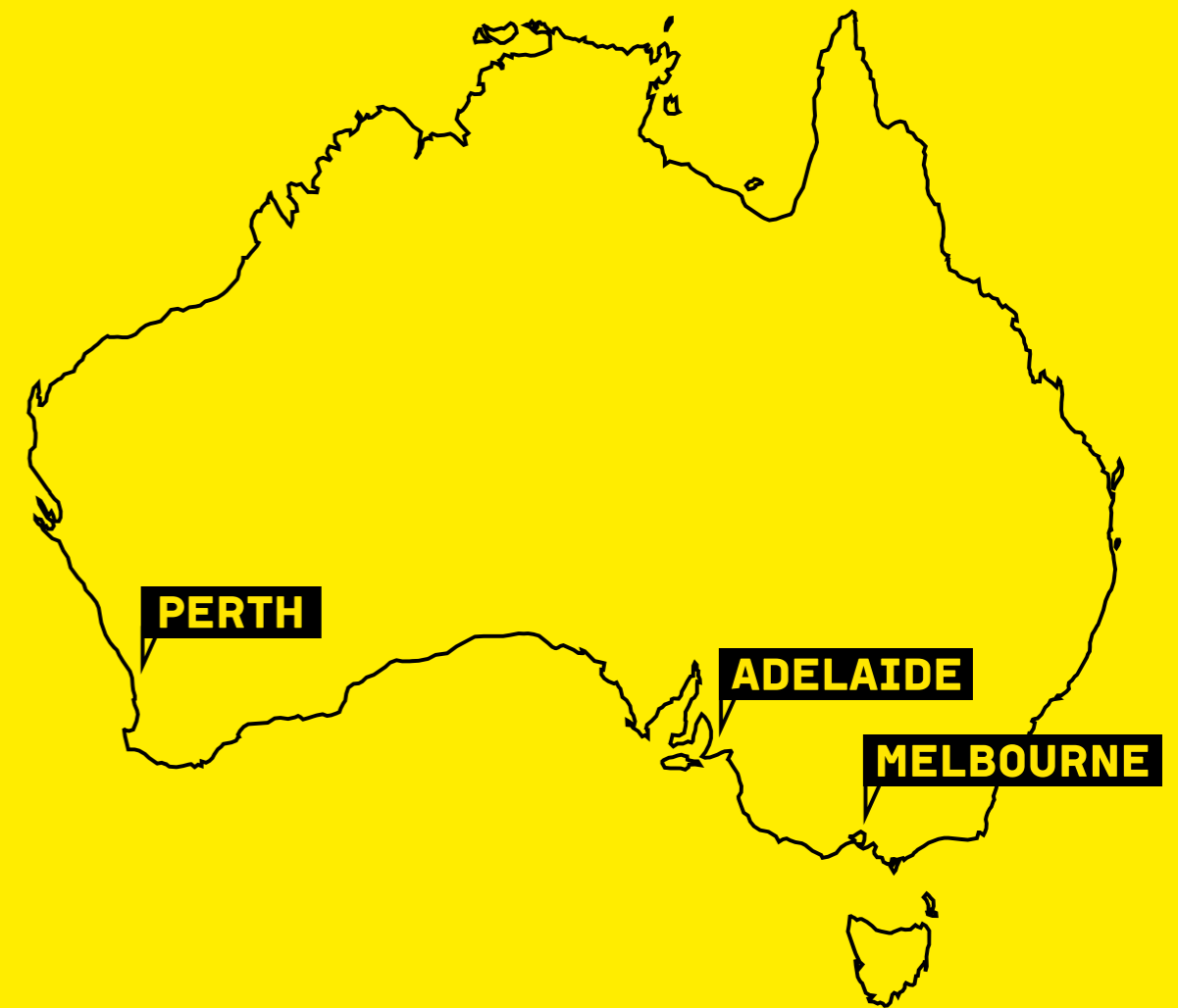
Invested into MND research

25

new MND research projects supported

ACTIVATIONS

Melbourne, Perth, and Adelaide



300

Daniher's Drive participants

624

27 Challenge participants



WHAT WE SET OUT TO DO IN **2022**

OUR GOALS

ENGAGEMENT

Rally our FightMND community to raise national awareness, share our impact, grow our supporter base, and deepen our partnerships

GROWTH

'Freeze the nation', diversify our fundraising, and develop longer term partnerships with government

IMPACT (CURE)

Beat the Beast by funding world-class research, collaborate internationally, build the MND workforce capacity, facilitate knowledge-sharing, and invest in research infrastructure

IMPACT (CARE)

Improve the lives of people living with MND by investing in a program of care-focused research, the development of national standards and guidelines, and targeted support for people impacted by MND

WHERE WE INVEST

CURE

Our goal is to invest eighty per cent of available funds to find an effective treatment or cure

CARE

Our goal is to invest twenty per cent of available funds to improve the lives of people with MND in Australia

OUR FIGHTMND SUPPORTERS

- AFL community
- Families and friends of people impacted by MND
- Sporting clubs
- Schools
- Workplaces
- MND research community

SECTION **3**

IMPACT



CHARLIE OATES

lost his dad to MND

\$13.41M

committed to MND research initiatives

25 NEW MND RESEARCH PROJECTS

2

clinical trials

2

drug development projects

10

Improving and Accelerating Translation (IMPACT) projects

6

research fellowships

3

projects discovering MND causes

2

collaborative initiatives for MND research

\$69.32M

committed to MND research

14

clinical trials

24

new drugs in the pipeline

8

sites collecting clinical and genetic data from 150 MND patients

436

attendees at the FightMND Australasian MND symposium

7

sites conducting clinical trials

555

patients to participate in FightMND funded trials

2

new drugs progressed from the lab to clinical trial

A MESSAGE FROM DR BEC SHEEAN

FightMND Director of Cure Research and Programs

Thanks to the support of our incredible donors and supporters in 2022, FightMND were able to commit another \$13.4 million into research.

This year's projects will look at MND from different angles - to support early diagnosis, track how a person's disease is progressing, and develop better tools for studying MND in the lab. Most importantly, these projects are focused on impact with goals to improve the lives of people living with MND.

In 2022 we introduced a new project scheme – Discovery grants. These aim to unlock the causes of MND and to better understand the mechanisms of disease. We hope by understanding the causes of the disease, this will enable therapies to be targeted at early disease events - **and stop MND in its tracks.**

We are also funding six fellowships to support established and emerging leaders in MND research in Australia and across the world. By helping us fund high-quality research and connecting the world's most innovative MND minds, **together we are playing a lead role in the global fight to find a cure** for this devastating disease.

From everyone at FightMND, a heartfelt thank you. Research is expensive, and it takes time. **But we have momentum, progress is being made - and more than ever, we're up for the fight.**



Bec Sheean
Director of Cure Research
and Programs



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

2022

2022: Embarked on a review of our current strategy to better understand the MND research landscape, identify gaps, and ensure every donation is making the most impact on people with MND

2022

Provide support for discovery research specifically targeted at better understanding disease mechanisms and identifying the causes and risk factors of MND

2015

We began investing in research

▶ LOOKING AHEAD

In close consultation with the MND research community, peer organisations, government, and people with lived experience, we will develop a new **Cure Research Strategy** that addresses current local and global needs in research, creates opportunities for collaboration and partnerships, and reduces duplication of research efforts to ensure funding is allocated well and accelerates progress.

We look forward to sharing the new strategy with you in 2023.



RESEARCH SPOTLIGHT

DR. ADAM WALKER

Bill Guest Mid-Career Research Fellow,
The University of Queensland

PROJECT

Clearing TDP-43 pathology for MND therapy



“I’m excited to see our basic science research now moving closer towards finding ways that we can apply new knowledge to helping people with MND.”

Dr Adam Walker was awarded the Bill Guest Mid-Career Research Fellow in 2022, named in honour of inaugural FightMND board chairman Bill Guest AM. Dr Walker will lead a team to study several facets of TDP-43 pathology in MND to uncover new treatment strategies.

“This project will allow us to find ways to apply our knowledge of how

problems with the TDP-43 protein cause nerves to die, to identifying the most promising strategy to stop that in people living with MND. By understanding the disease mechanisms and testing which genes and proteins can protect nerves, we will be able to design new therapies for MND in the future.”

Thank you Dr Walker for your incredible dedication to MND research. It is thanks to brilliant research teams like yours, that we can continue our fight against the Beast.

2022 CURE RESEARCH GRANTS

In **2022** 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.

Associate Professor Bradley Turner

The University of Melbourne, VIC

Phase 2 Clinical Trial

Safety and efficacy of Ambroxol in individuals with MND (repurposed medication) This trial is a long-term safety and efficacy study of an already-approved drug re-purposed for MND. Preclinical studies that progressed this drug to clinical testing in people with MND were supported by a FightMND Drug Development grant.

“Ambroxol targets multiple key disease pathways implicated in MND, including disruption of connections between motor neurons and muscle which occurs very early in MND.”



Professor Matthew Kiernan

The University of Sydney, NSW

Phase 3 Clinical Trial

Randomised double-blind placebo-controlled trial of Lithium Carbonate in MND.

This trial will test the effectiveness of a drug in a specific group of MND patients that have changes in a gene called unc13A. The trial is an international study with the Australian arm including 57 MND patients at seven sites across the country.

“The MAGNET clinical trial will launch precision medicine in MND, by establishing whether we can use an individual’s genetic signature to determine if they are more likely to benefit from the investigative drug’s neuroprotective effects.”



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.

Dr Giovanni Nardo

Mario Negri Institute for Pharmacological Research (IRFMN), Milan, Italy

Therapies targeting muscle

Intramuscular allosteric agonism of purinergic P2X7 receptor as a pharmacological approach to enhance skeletal muscle regeneration in MND

This international project is building a collaboration between researchers at the Mario Negri Institute in Italy and The University of Queensland.

“The main strength of our proposal lies in the use of an easily accessible and low-cost candidate drug, for which biosafety has already been tested in humans.”



2022 CURE RESEARCH GRANTS

Dr Tony Reid

EpicentRx, California, USA

Treatments targeting multiple causes of MND

Validation of the clinical stage drug candidate RRx-001 as a novel disease modifying therapeutic for MND.

Because RRx-001's safety has already been demonstrated in people, successful project outcomes will allow quick transition of the drug to a Phase 2 clinical trial for MND. This international project is a collaboration between researchers at EpicentRx, Inc., in the USA, The University of Queensland and Royal Brisbane and Women's Hospital.

"Curiously, and unexpectedly, we found that one of the drugs we use to treat cancer, RRx-001, may have the potential to reduce the symptoms of MND and make a significant difference in the quality of life for patients with MND."



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 an acceleration in the development of more effective treatments or cure for MND.

Associate Professor Anthony Cook

University of Tasmania

Genetic and Environmental Interactions

Epidemiology in a dish: using human iPSC to discover common and genotype-specific molecular signatures of the multi-step hypothesis of MND.

The project will provide new insights into causes of MND and identify new targets that direct the design and development of therapeutics aiming to treat MND more effectively.

"This project is the first to systematically dissect how combinations of genetics and a variety of environmental exposures promote motor neuron degeneration."



Dr Danny Hatters

The University of Melbourne, VIC

Rescuing the blockage of critical functions in motor neurons caused by gene defects

Trouble at the ribosome in C9ORF-72-driven MND.

Successful outcomes will identify new therapeutic targets that prevent the formation of proteins that block the function of machinery critical to the viability of motor neurons.

"More insight is needed at the fundamental level to understand what drives the earliest steps of pathogenesis to enable new therapeutic strategies to be developed. Our research is directed at this goal."



2022 CURE RESEARCH GRANTS

Dr Jeffrey Liddell

The University of Melbourne, VIC

Changes in the function of cells in the brain and spinal cord that normally support motor neuron health

Multiomic interrogation of patient-derived neurotoxic glia.

The project will identify key chemicals released by glial cells that are harmful to motor neurons, and new potential targets for developing more effective treatments for MND.

“We are seeking to develop and investigate improved models of MND.”



COLLABORATIVE INITIATIVE PROJECTS

Collaborative Initiatives projects aim to establish new or expand on existing MND research programs, platforms and initiatives that enable researchers to collect, share and analyse data and drive collaboration with a range of stakeholders to deliver patient-focused initiatives. Outcomes should generate data, infrastructure, or resources to help facilitate research and contribute to the growing understanding of MND.

Dr Sicong Tu

The University of Sydney, NSW

MND Brain Imaging Initiative

AMII: Asia-pacific MND Imaging Initiative.

This initiative will create a national network that validates current imaging techniques as biomarkers for MND and tools for measuring the effectiveness of treatments for the disease.

“Accurate modelling of dynamic brain changes will add another dimension to enhance Australian clinical trial outcomes to deliver new treatment options for patients.”



Associate Professor Mary-Louise Rogers

Flinders University, SA

MND Biomarker Program

This international collaborative project will utilise the Ian Davis Flinders University Biomarker Facility which is funded by FightMND and named in honour of the late founder of FightMND, Dr Ian Davis OAM. The project will build a fingerprint of MND to fast-track diagnosis and identify causes of the disease.

“This is an exciting opportunity to work collaboratively with MND researchers in Europe and Australia to, for the first time, identify an ‘early signature or fingerprint’ of MND.”



2022 CURE RESEARCH GRANTS

IMPACT PROJECTS

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

Dr Rachel Tan

The University of Sydney, NSW

Disease heterogeneity

RNA binding proteins involved in the pathogenesis and disease heterogeneity of sporadic MND.

Identifying patterns of protein expression in the brain of people that lived with MND may help identify novel targets for treating specific subtypes of MND.

“Studying brain tissue from patients with different clinical symptoms and disease trajectories will significantly advance knowledge on the molecular proteins involved in the pathogenesis of MND.”



Professor Trent Woodruff

The University of Queensland, QLD

Disease heterogeneity/Disease biomarkers

Profiling monocytes in MND to assess disease progression and heterogeneity.

This project aims to develop a blood test that can detect inflammatory molecules in individuals with MND, identify the type of MND they have, and predict the optimal treatment for them.

“What excites us about this project is the potential to identify an inflammatory biomarker ‘signature’ from blood samples obtained from patients with MND.”



Dr Fazel Shabanpoor

The University of Melbourne, VIC

Gene therapies

Therapeutic targeting of TDP-43 through selective reduction of ataxin-2 expression with peptide-conjugated antisense oligonucleotides.

Supporting this project enables Dr Shabanpoor to continue his research into developing novel gene therapy strategies for treating MND.

“The exciting aspect of this project is the merger of two proven technologies - antisense and brain-penetrating peptides - to develop a novel and safe brain-penetrating peptide therapy.”



2022 CURE RESEARCH GRANTS

Dr Luke McAlary

The University of Wollongong, NSW

Gene Therapies

Targeted degradation of misfolded TDP-43 as a therapy for MND.

This project aims to target a pathology, misbehaving TDP-43 protein, present in almost all cases of MND.

“If these antibodies work to remove only toxic TDP-43 from cells, we have a potentially viable therapeutic method that may work in the future for those who suffer from MND.”



Dr Loren Flynn

Murdoch University, WA

Gene Therapy/Drug Delivery

Enhanced neuronal delivery, gene targeting and neuroprotection: development of a multimodal drug against MND.

This project is the first step towards developing a ‘low risk’ way to deliver genetic drugs into the brain, which will substantially benefit the quality of life of people living with MND.

“I’m excited that this project has the potential to treat MND from multiple angles, giving us greater opportunity to solve and treat this insidious disease.”



Associate Professor Bradley Turner

The University of Melbourne, VIC

Disease Models

Developing a validated C9orf72 mouse model of ALS/FTD using genome editing MND.

This project will address a key gap in the MND research field by developing a new model of MND that mimics the most common genetic cause of MND.

“This model will provide an invaluable resource to the global research community for testing disease hypotheses, pathology and therapeutic agents in the most common genetic form of disease broadly applicable to the MND population.”



Professor Aaron Russell

Deakin University, VIC

Disease Models

Evaluation of a novel inducible muscle-specific TDP-43 mouse model of MND.

This project is developing a ‘world-first’ model of MND, in which the onset of the disease occurs in muscle.

“The successful development and validation of our mouse model will provide a valuable tool to investigate the potential molecules inside muscle that impact MND.”



2022 CURE RESEARCH GRANTS

Professor Clare Parish

The University of Melbourne, VIC

Disease Models

Advanced modelling of upper motor neuron MND pathology using human pluripotent stem cells.

This project will use stem cells from people living with MND to establish an advanced disease model that recreates the specific types of motor neurons affected in MND.

“With a long-standing history in working with human stem cells, this is the first time our team has used patient lines to study disease mechanisms in MND.”



Associate Professor Anthony White

QIMR Berghofer Medical Research Institute, QLD

Disease Models/Drug Delivery

Development of a human MND Neurovascular Unit model to improve therapeutic translation in drug testing.

This project aims to develop an advanced model of the human blood-brain barrier. The new model will improve clinical translation by accurately screening if drugs with therapeutic potential for MND are able to access and act on intended targets in the brain.

“We hope to show that our novel cell model can show which drugs are most likely to enter the brain and spinal cord of people with MND and reach their target cells.”



Dr Adam Walker

Bill Guest Mid-Career Research Fellow,
The University of Queensland

Disease Models

New viral-mediated TDP-43 mouse models of MND

This project will develop a faster and more cost-effective way to generate mouse models of MND, and provide a new resource that speeds up the testing process for new drugs with the potential to treat MND.

“We aim to create better mouse models of MND that will be faster and easier to use.”



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 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 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 Adam Walker

Bill Guest Mid-Career Research Fellow,
The University of Queensland

Clearing TDP-43 pathology for MND therapy

Dr Walker will lead a team to study several facets of TDP-43 pathology in MND to uncover new treatment strategies.

“I’m excited to see our basic science research now moving closer towards finding ways that we can apply new knowledge to helping people with MND.”



2022 CURE RESEARCH GRANTS

Dr Rachel Tan

The University of Sydney

Reversing TDP-43 pathology and neuronal loss in sporadic MND.

This study is examining the expression of MND-related proteins in brains from a large group of MND patients who were clinically followed over the course of disease. Dr Tan is a first-time recipient of research funding from FightMND. This four-year Mid-Career Fellowship will help strengthen Dr Tan's independent research programs and research team.

"This project in a large cohort of patients with different disease presentations and trajectories will enable us to uncover significant insights into the pathobiological underpinnings that give rise to sporadic MND."



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 four-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 Taide Wang

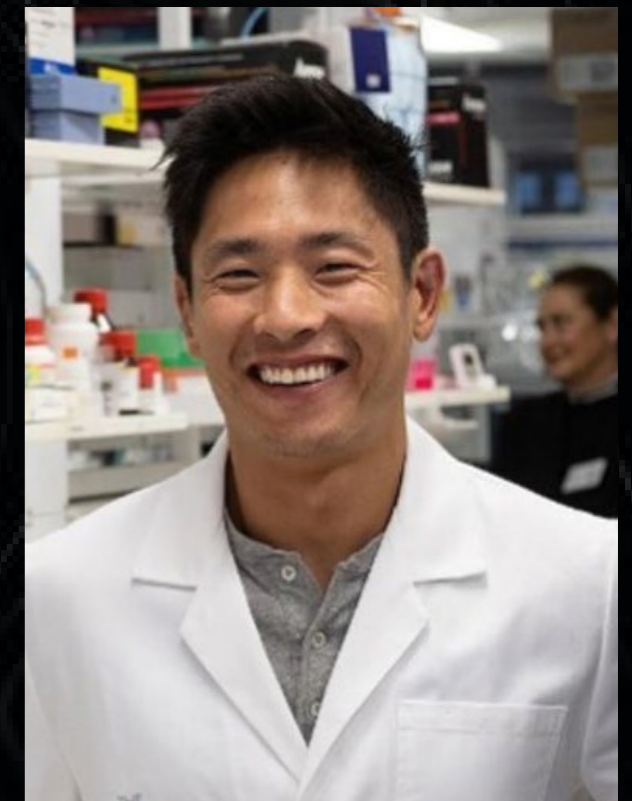
The University of Melbourne, VIC

Disease Models

Therapeutic targeting of ferroptotic cell death in MND.

Dr Wang was the inaugural recipient of the Angie Cunningham PhD Scholarship and Grant in Aid in 2019. This study is exploring a novel mechanism and cause of MND and may uncover new agents with promise for treating MND.

"The most exciting part of the study lies in the fact that the compounds are safe and orally bio-available. Thus, they may be an effective yet non-invasive therapeutic strategy for treating MND."



2022 CURE RESEARCH GRANTS

INTERNATIONAL FELLOWSHIPS

FightMND has partnered with the Sean M. Healey & AMG Center for ALS and ALS finding a Cure[®] to support young researchers researching new treatments for people living with in the ALS Scholars in Therapeutics program. The international two-year program is designed to engage physician-scientists and post-doctoral fellows to gain training and experience in therapy development for MND with a unique opportunity to gain industry experience in year two. By engaging motivated and creative individuals with a passion for bringing treatments to people living with MND, we are expanding the community of experts and expediting therapy development.

Dr Jacob (Jake) Mann

Northwestern University, USA

Microtubule-targeting agents and uORF ASOs to target NEK1 loss of function in MND



Dr Dylan Galloway

Washington University, USA

microRNAs as Novel Regulators of Differential Motor Neuron Susceptibility



Dr Roberta Piovesena

University of Montreal, Canada

Neuromuscular Junction: a promising starting point in the identification of ALS biomarkers



CARE

OUR 2023-2025 CARE STRATEGY

In 2022, we launched our new Care Support Grants Initiative in collaboration with Perpetual. This was targeted towards not-for-profit organisations focused on allied health and

care services that support the Australian MND community, and providing additional support in key areas of need.

IMPROVING CARE

Global research into MND care is significantly underinvested in, and consequently underdeveloped, especially when compared to cure research.

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, people with lived experience, 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

Support: Targeted support for people impacted by MND

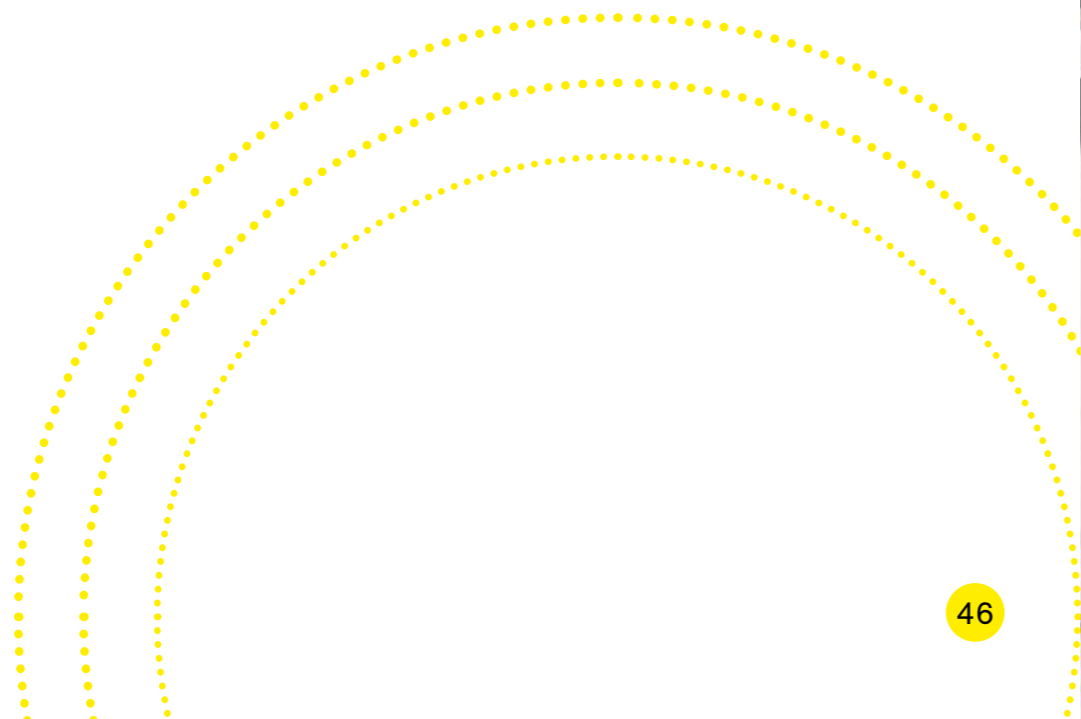
Between 2023 and 2025 we will be investing in a range of initiatives to power MND care that improves the lives of people with MND.



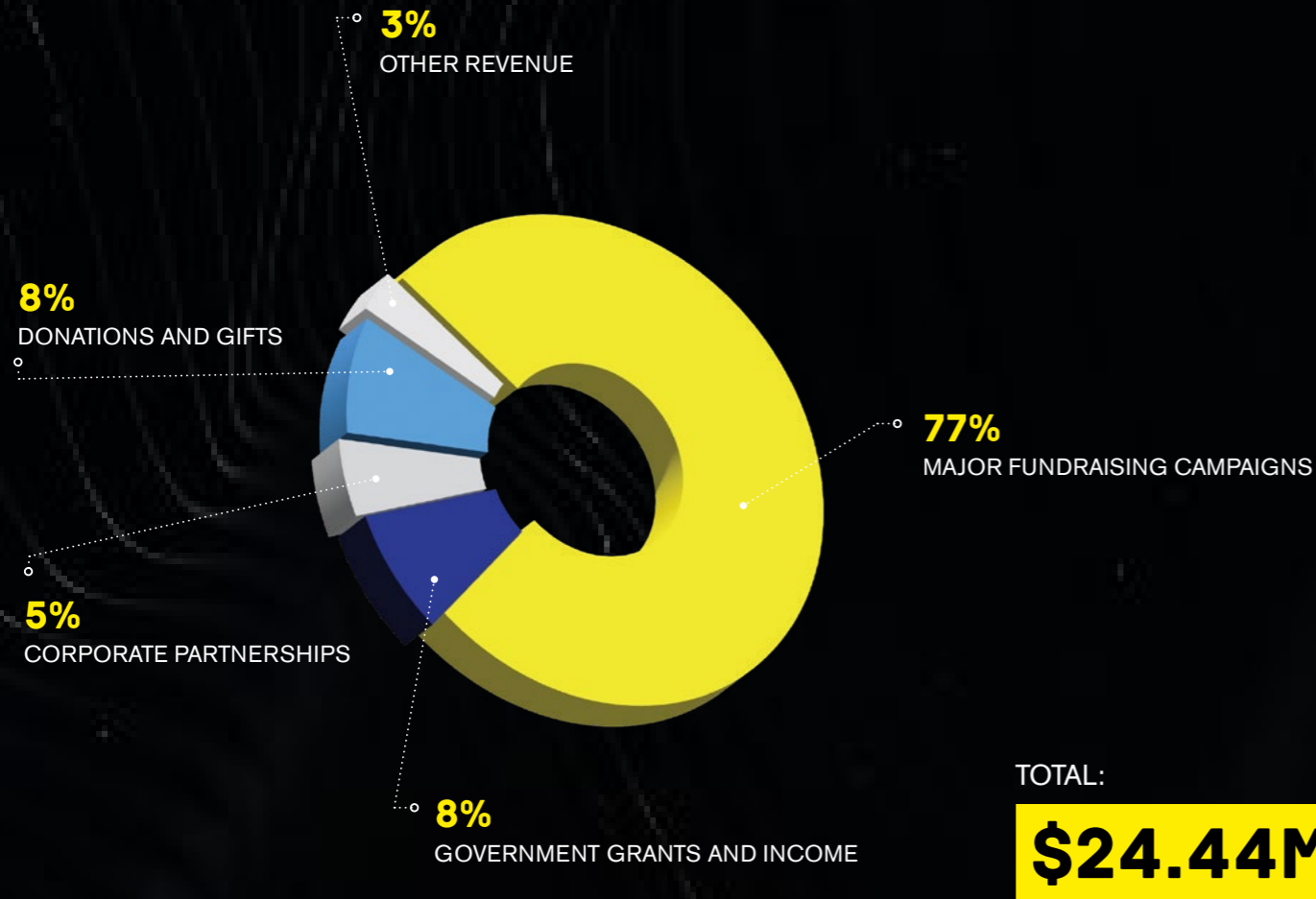
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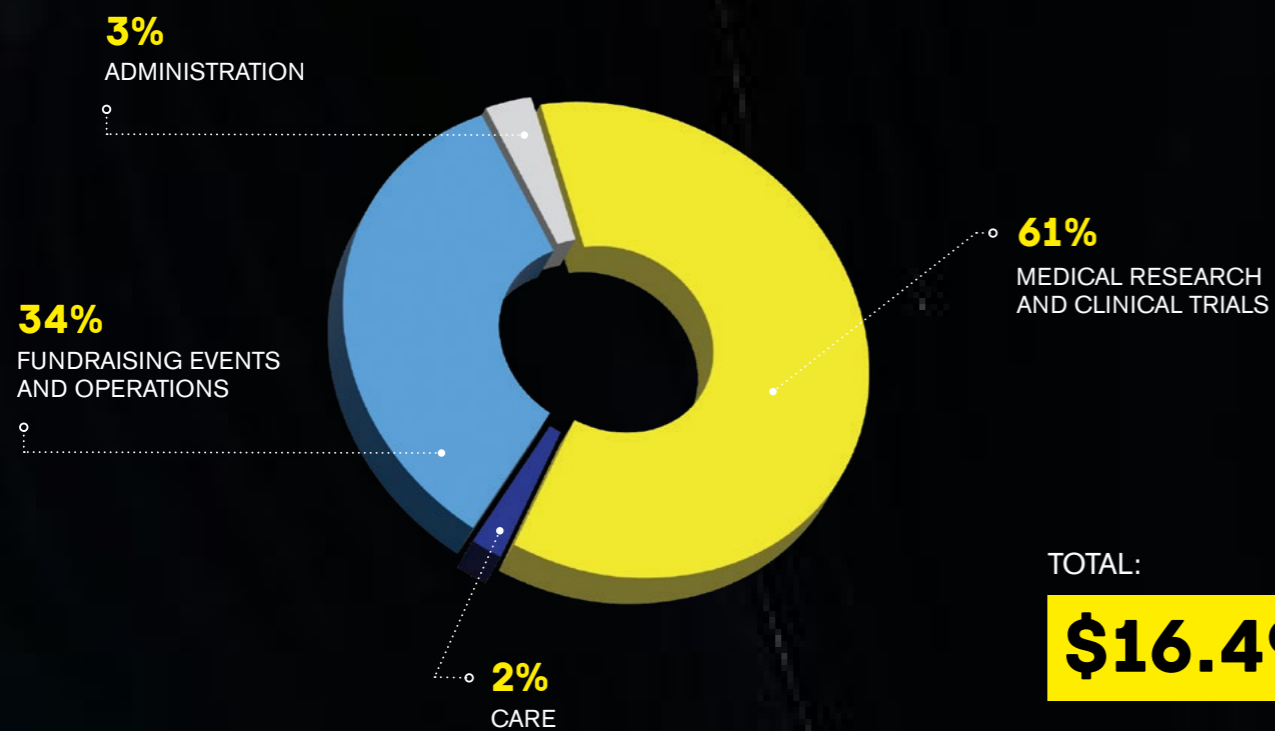
FINANCIALS



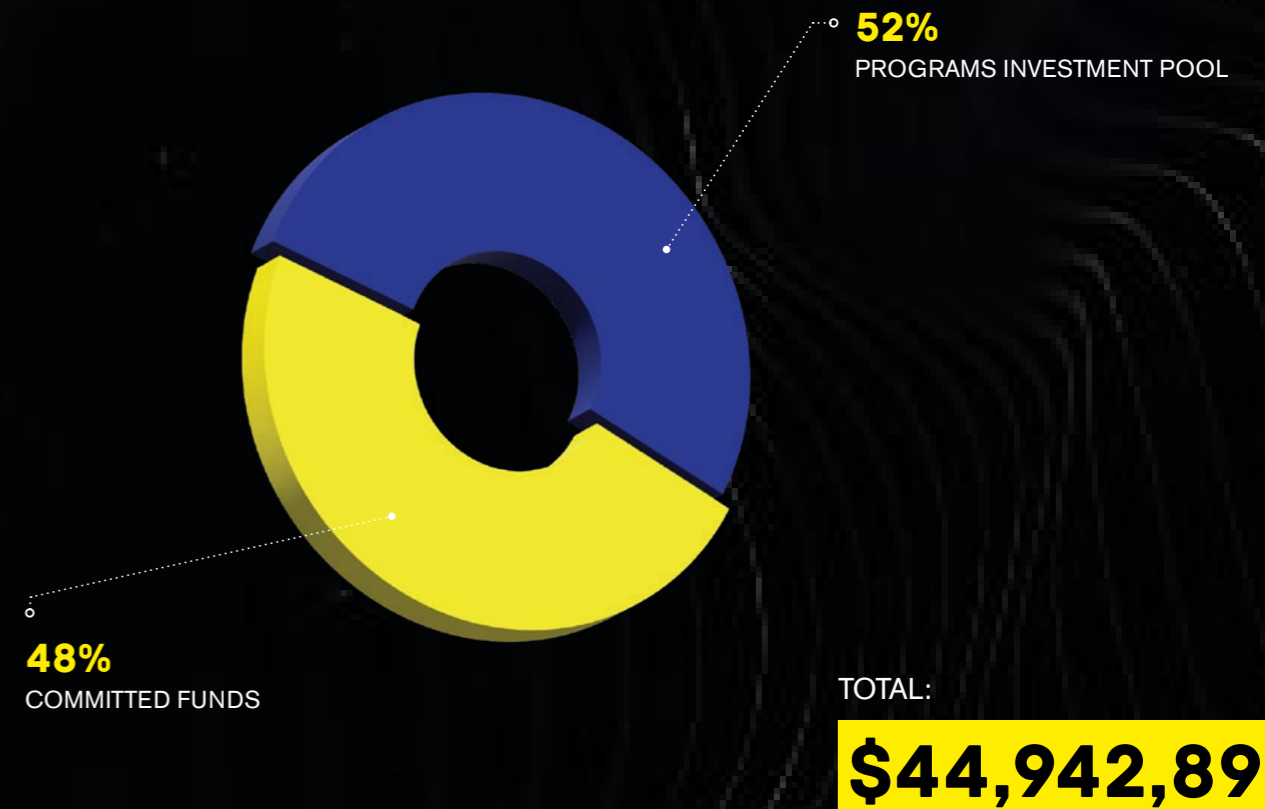
WHERE OUR MONEY COMES FROM



WHERE OUR MONEY GOES



INVESTMENT RESOURCES



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

SECTION **5**

CAMPAIGNS



BIG FREEZE 8

BEANIE ON, PLAY ON.

\$19.8

MILLION DOLLARS RAISED

76k

PEOPLE AT THE MCG

10

ICONIC CELEBRITY SLIDERS

506k

PEOPLE
TUNED INTO
CHANNEL 7
BROADCAST

235

VOLUNTEERS





As Australia emerged from the Covid pandemic, it was time to 'Beanie On, Play On' and lead with actions, not words.

Big Freeze 8 proved to be our most successful fundraising campaign to date, with a record-breaking \$19.8m raised to fund effective treatments and a cure for MND.

In 2021 we relocated to Sydney to comply with lockdown restrictions, so there was a special buzz in the crowd as the Big Freeze returned to the MCG in its full form for the iconic Queen's Birthday clash between Collingwood and Melbourne Football Club.

The day started with the mighty return of the Walk to the 'G, led by our Patron Neale Daniher. In the true spirit of 'Play On', thousands of people marched up Daniher's Way in support of Neale and beating the Beast.

The MCG quickly became a spectacle, covered in an astonishing sea of blue Beanies. A packed crowd of 76,059 spectators and another 506,000 viewers on Channel 7 witnessed 10 celebrities plunge into icy waters, rallying support and funds for MND research.

Amidst the excitement, Neale and Bec Daniher cheered each slider on, and the crowd went wild.

While it is a cruel and relentless disease, it's moments like these – where hundreds of thousands of people rally behind the cause - that give us hope for a future free of MND.

We challenged the FightMND family to help us raise an extra \$2m by half-time, and thanks to generous community and corporate donations, we achieved just that. Thank you to the Federal Government who also contributed \$4m.

Over the six-week campaign, our supporters and AFL clubs participated in activations in Perth, Adelaide, and people all over Australia wore their Beanies with pride.

We extend our heartfelt gratitude to our major partners Coles and Bunnings, along with the AFL, Channel 7, the Herald Sun, and all our other partners and suppliers for their unwavering support. The success of the Big Freeze could not be possible without you.

To every person who bought a Beanie, donated, volunteered, or helped spread the word – it is thanks to you that we can take significant strides in our fight against the Beast.



CLICK HERE FOR BIG FREEZE 8 HIGHLIGHTS

ASH BARTY

Aussie tennis legend



HAMISH BLAKE

Comedian



JAKARA ANTHONY

Winter Olympian



TERRY DANIHER

Essendon footy great



JUSTIN LANGE

Aussie cricket great



DAVID NEITZ

Melbourne footy great



EDDIE BETTS

Carlton and Adelaide footy great



RHONDA BURCHMORE

Entertainer



BEC MADDERN

TV personality



ANDY MAHER

Radio and TV personality



THANK YOU TO OUR VOLUNTEERS

Once again, we were amazed by the turnout of volunteers – the heart of our FightMND family. Our 'Vollies' generously supported the Big Freeze through tin-rattling, selling Beanies, or packing merchandise at Beanie HQ.

Thank you to every Vollie who helped us **Play On** in 2022.

▶ **235 VOLUNTEERS IN MELBOURNE**

▶ **90 VOLUNTEERS IN PERTH**



VOLUNTEER PROFILE

SPENCER MORGAN

Meet 13-year-old Spencer Morgan, whose family has volunteered for the Big Freeze for many years. Spencer also ran a Big Freeze campaign at his school, St Leonard's College.

"The Big Freeze is now a part of my family's annual calendar. We love the passion of the Danihers. They make us feel included and valuable.

My family has familial MND. I have watched several family members battle with MND and it is devastating. My Aunty Jo was one of the kindest and most amazing people ever, and yet she was struck down with MND. It was heartbreaking to watch. Nobody should ever have to suffer in that way. MND takes everything and is so cruel.

I intend to continue raising money for MND research and encourage other kids like me to get involved. It is fun, rewarding, and a better way to spend my time than on my computer (which I do love too). Together let's find a cure."



THE PET ROCK

"I was selling beanies on the concourse of the 'G when a member of the public approached me to give me this pet rock.

They explained they had no particular connection with MND, but were so captivated by Neale's fight and other's stories. They love being a part of the Big Freeze each year and donning their Beanie.

They painted the rock as a little token of their sentiment towards what Neale and FightMND were doing, and really wanted to make sure it got to the team.

I gave it to our CEO Fiona and ever since, she has used it as a great example of what the Big Freeze and FightMND means to Melburnians and the general public.

It's a touching story, and I was really honoured to be able to deliver it for her."

- Drew Howell

SLIDER PROFILE

TERRY DANIHER

Meet Terry Daniher, an Essendon football great and Neale's older brother. Terry was dressed as Crocodile Dundee and was our 98th slider.

"FightMND is on the yearly calendar because of the amazing support from the community, and all the hard work that goes on behind the scenes.

My favourite memory from Big Freeze 8 was the banter in the change rooms, meeting the other sliders, heading up the stairs, and seeing the grin on Neale's face – one of immense satisfaction as I was about to hit the icy water. The sea of blue Beanies was very noticeable.

Neale is chuffed at the support FightMND has received so far. We all understand it is a work in progress as research for a cure continues."

Hear more from our Big Freeze 8 sliders [HERE](#)



BIG FREEZE FOREVER...

This year was a particularly special year for Big Freeze, with our inaugural Big Freeze Forever initiative kicking off.

Our sliders are some of the loudest voices during the Big Freeze campaign. They use their public profiles to raise awareness about MND and remind Australians why we fight.

All 100 past sliders (and their families) received a Big Freeze Forever Beanie, embroidered with the unique slider number. This is a special way for us to say thank you each year, and for the sliders to wear their unique Beanies with pride. This tradition will continue for many years to come.

We thank all our Big Freeze sliders for their ongoing support, and their incredible ability to raise awareness for our fight.





\$3

MILLION DOLLARS RAISED

300

PARTICIPANTS

80

CARS

Daniher's Drive is our annual road trip through regional Victoria, where we visit the communities that have passionately supported FightMND since day one.

Many participants who join the Drive have been personally impacted by MND, and the Drive is an opportunity for us to come together and put the 'fun' back into fundraising.

Following cancelled events in 2020 and 2021 due to COVID-19, Daniher's Drive came back stronger than ever in 2022 – but it certainly wasn't without its challenges.

It was all systems go until devastating floods hit just days prior to the drive beginning. We quickly rerouted the event and were able to Play On, raising a record-breaking \$3m, including a \$1m donation from the Victorian State Government. An enormous thank you to Minister Pulford, Premier Daniel Andrews and to the Victorian State Government for this incredibly generous donation which takes us to more than **\$15 million raised** since the Drive first began in 2015.

Thank you to our major partner Chemist Warehouse for all your support, as well as PSC Insurance, Jayco, Bayside Coaches, and CMV Truck & Bus.

MEET DANIHER'S DRIVE PARTICIPANT, ANNIE PHYLAND.

Annie grew up in Wagga Wagga and has a long-standing friendship with the Daniher family.

When Neale was diagnosed with MND, FightMND became a cause Annie and her family felt compelled to support.

Over the years, Annie and her family came to know Neale and many others in their community who were courageously fighting MND, and unfortunately many have died from MND.

One of Annie's favourite ways to actively support MND research, as well as show support to Neale, is by participating in Daniher's Drive. This four-day road trip through regional Victoria holds a special place in her heart. She describes it as

“FOUR OF THE MOST WHOLESOME DAYS IN THE YEAR.”

Annie has participated in five Daniher's Drives. She cherishes the opportunity to meet remarkable individuals along the way and connect with people who have been on their own MND journeys, all within a unifying and loving environment.





**SockIt
2MND**
A FIGHTMND EVENT

\$349,700 RAISED

23,317 SOCKS SOLD

858 SALES IN VICTORIA

SockIt2MND was founded in 2017 by Neale's sister Dorothy and brother Chris. The campaign ran in the Riverina region with three football leagues, before expanding nationally in 2018.

One week after the Big Freeze, clubs across the country held a special match for the annual 'Community Round', where they pulled up their Socks and helped us in the fight against the Beast.

In its first year, SockIt2MND raised \$20,000. This year, thanks to the support of local football, basketball, soccer, and netball clubs, an impressive \$349,700 was raised, helping us fund vital MND research and care outcomes for people living with MND.

Thank you to the clubs, individual purchasers, and partners who helped us Play On in 2022. See you again next year!

113

SALES IN SOUTH AUSTRALIA

90

SALES IN WESTERN AUSTRALIA

95

SALES IN NEW SOUTH WALES



**CLICK HERE FOR MORE
ON SOCKIT2MND**



\$1.29

MILLION DOLLARS RAISED

859

NATIONAL FUNDRAISERS

DIY Big Freeze takes all the action from the Big Freeze at the MCG and places it into the local community. This year workplaces, schools, and sporting clubs helped us Play On and make a splash for MND research and care.

Through ice bucket challenges, cold water plungers, slides and 859 national fundraisers, **\$1.29m** was raised. What an incredible effort! No matter how big or small a DIY event is, **every bit counts in our fight to find a cure.**



The Bacchus Marsh and Greendale community rallied their mates and hosted a DIY Big Freeze for local resident Phil O'Keefe, who was diagnosed with MND in 2015.

Nearly 1,000 people attended, and the event was one of the top five DIY fundraisers in Australia. What an incredible community event!

Bacchus Marsh Football and Netball Club, Sunbury Football and Netball Club, and a bunch of local legends got together to raise \$59,000 – an extraordinary feat considering their initial target of \$15,000.

COVID lockdowns meant their 2021 event had to be cancelled, so in true Play On spirit, they got together and made an even bigger splash in 2022. The event featured local celebrity slider Doug 'Dougie' Hawkins, a 300+ gamer for Footscray.





\$296k

624

RAISED

NATIONAL FUNDRAISERS

When a person is diagnosed with MND they are given an average life expectancy of just 27 months. The 27 Challenge invites people to embrace this number and consider its significance for those impacted by the disease. During the month of September our amazing 27 Challenge participants ran, walked, cycled, or swam to raise vital funds for MND research.

ARCHIE'S 27 LAP RUN

At just 13 years old, Archie ran 27 laps of his school oval – just short of ten kilometres! He was joined by 27 people who ran one lap each, before taking turns plunging into their very own Big Freeze ice bath.

This brings Archie's fundraising efforts to almost **\$13,000** in three years.



27 HOUR SISTER LOVE SPIN

Bronywn Watt ran in honour of her sister Jenny who sadly died from MND earlier that year. This was Bron's third time running in the event.



SECTION **6**

COMMUNITY FUNDRAISING



PEDAL CURE 4 FIGHTMND

Ninety-four cyclists hit the road on a 900km, six-day cycle across the Riverina, raising more than \$500,000. Well done to everyone involved.



RUN FOR ROSSY (R4R)

R4R was created to support Chris Ross, who had been given the life-shattering news of an MND diagnosis at the age of 31. In R4R's inaugural year in 2021, Rossy ran a marathon. This year, MND took away Rossy's ability to speak and move.

So as all great mates would do, 450 people took on 21km, 10.7km, 5km, and 1km at the Collingwood Athletics Club to raise \$117,800 for vital MND research and care.

A wonderful event for a very special person.



ADAM BASTAS, NOOSA TRAIL RUN

Adam took on the 100km challenge in honour of his dad, who was recently diagnosed with MND.

"My goal for this ultramarathon is to raise \$2,000 to help FightMND. I've seen firsthand what this organisation does to improve the lives of people diagnosed with this horrible disease, and I promise you it's a worthy cause."

We cheered for you all the way to the finish line, Adam!



MIKE BOUDRIE

Mike ran 100km along Victoria's coast in September for his former colleague Warren 'Waz' Galgut, who was diagnosed with MND at 42 years of age. Mike raised \$21,000 to give hope to people with MND.

"My Mum nursed MND patients, when I told her about Waz she said, 'the worst bit is that only the best people seem to get MND'. And that is Waz right there. One of the best people I have met."



SIMON HANCOCK

Simon was diagnosed with MND in 2020 and has since raised \$13,600 for people living with MND.

"Our family's life was turned upside down that day in 2020 and has been forever changed. Whilst I live in hope a miracle cure can be found quickly, it is unlikely I will see one in my lifetime. So let's ensure others in the future don't have to deal with this shit. Any money you can give (no matter how large or small) will bring us that bit closer."

"Positive mental attitude right there! No arms but have legs and will ski. Creating amazing memories with my son skiing for the first time."

COLIN BELL

Colin took on Sydney's 14km City2Surf in memory of his dad, who died of MND four years ago. He initially set a target of \$2,000 and closed out the event raising a total of \$3,000 to support vital MND research.

"I wanted to do something to honour my father. He died of this debilitating disease, and for someone who at one time wouldn't know his strength, he was excited to do simple things like use a screwdriver!"

I wasn't sure about how much I wanted to raise but when I received interest from people who normally wouldn't do sponsorship, I got more excited. In the end I had the motivation to raise more and work up a good run time.

It was nice to be backed by FightMND. I felt like a valued part of the team. It was great to spread the word about the disease, and about where the research was going."



OTHER EVENTS FIGHTMND PARTICIPATED IN:

- Run Melbourne
- Blackmores Sydney Running Festival Sydney Morning Herald Half Marathon City 2 Surf, Sydney
- Cole Classic, Sydney
- Sunset Series 2022, Melbourne
- Run the Rock, Woodend VIC
- Point to Pinnacle, Tasmania
- Great Ocean Road Running Festival CityBay Fun Run, Adelaide
- Melbourne Marathon

SECTION

7

RECOGNITION



RECOGNITION

FIGHTMND CLUB

Established in 2021, the FightMND Club is our major donor program. Members contribute between \$10k and \$100k annually and are vital members of our FightMND family; the next cohort of leaders lining up to continue the fight against the Beast in our founders' legacies.

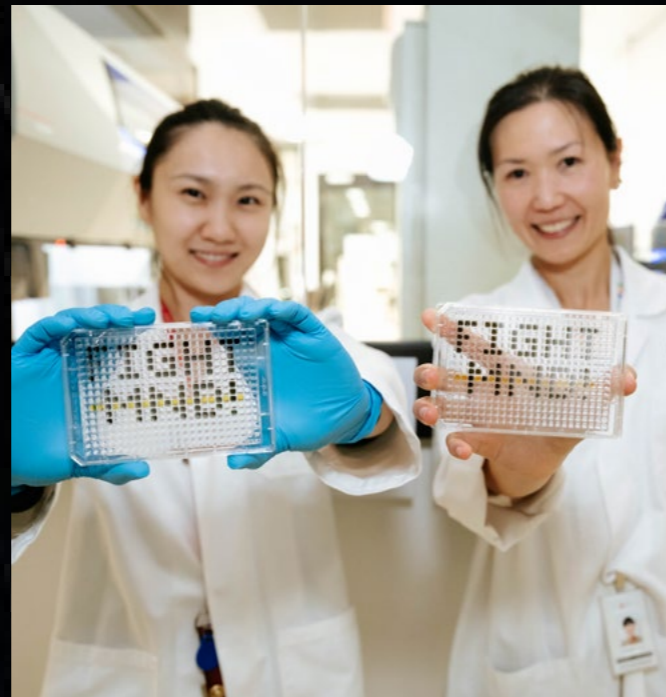
In 2022 we held two stewardship events for the FightMND Club at The Florey Institute of Neuroscience and Mental Health – the largest brain research centre in the Southern Hemisphere.

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.

Guests heard from Chairman Mike Schneider, Research Director Bec Sheean, and CEO Dr Fiona McIntosh. Jane Simpson shared her personal story as a carer for her husband, who sadly passed away from MND. Associate Brad Turner and his team of researchers provided exclusive lab tours, where members could see first-hand the inner workings of research labs, and the impact of their donations.

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. In 2022 you truly helped us 'Play On'.

For more information about the program, head to <https://fightmnd.org.au/fightmnd-club/>



PARTNERS



RECOGNITION



BUNNINGS

For the fourth year running, the dedicated Bunnings team supported the Big Freeze. Nearly 60,000 Beanies were sold, contributing more than \$1.5m to MND research.

To celebrate the Big Freeze, six Bunnings stores across Australia hosted a celebrity sausage sizzle fundraiser. Aussie icons like Olympic champion Kyle Chalmers, AFL legend Matthew Pavlich, and Melbourne's favourite newsreader Peter Hitchener helped serve up snags to the local community. All funds raised went directly towards the Big Freeze 8 campaign.

Thank you, Bunnings.



COLES

Coles Group has made a tremendous contribution to our fight against MND and has been a major partner of the Big Freeze for five years. Thanks to their ongoing support, we have been able to continue funding essential MND research.

During Big Freeze 8, Coles Group raised a record \$8.6m across its supermarkets and Coles Express stores, taking its total contribution to FightMND to \$20m since the partnership began.

Customers could head in-store or online to purchase a Beanie or a selected Australian Pork product to support the Big Freeze.

For the fifth consecutive year, Coles' Aussie pork farmers got behind the Big Freeze, generously donating funds and showing support by proudly wearing their beanies on farms across Australia.

“Our team members, customers and Aussie pork farmers are incredibly passionate about raising funds to help find a cure and better



treatments for MND and it's now our single biggest fundraising campaign at Coles.”

– Michael Courtney (Coles Express Executive General Manager)

Thank you, Coles Group.

RECOGNITION

CLEMENGER

Thank you to Clemengers BBDO for helping us create 'I'm Neale Daniher' to kickstart Big Freeze 8 and share the 'Beanie On, Play On' message far and wide.

'I'm Neale Daniher' was an emotive video featuring Max Gawn, Taylor Adams, Hamish McLachlan, Dilruk Jayasinha, Geva Mentor, Abby Holmes, and Kevin Sheedy. MND had recently taken away Neale's ability to speak, and so the celebrities delivered Neale's speech for him.

This struck a chord with the Australian public and spread awareness about the realities of this insidious disease. The creative was distributed on digital and out-of-home placements nationally.

Congratulations to Clemenger who was awarded a Cannes Lion 70 Silver Lion in the Social & Influencer category for this video.

A SPECIAL THANK YOU TO DR PATRICIA JOAN WILKINSON

Dr Patricia Joan Wilkinson AM was born in 1927 in Melbourne. An only child to her parents Henry and Louisa, Joan excelled in her education and pursued a career in medical research. She then studied nursing, gaining her Master of Health Administration and a PhD in Human Resource Management. Awarded an Order of Australia in 1991 for service to nursing, particularly in the field of education and administration, Joan valued philanthropy and donated to many charities in her lifetime, even leaving gifts in her will.

One such gift was to FightMND. We are so fortunate to have been bequeathed **\$500,000** from Joan's estate and would like to acknowledge the amazing legacy this will create, allowing us to fund cutting-edge MND research and vital care equipment for people living with MND.



SECTION **8**

THE BOARD AND CEO



THE BOARD AND CEO



DR FIONA MCINTOSH (CEO)



GARY NUGENT



MICHAEL SCHNEIDER (CHAIR)



LEWIS MARTIN



CAMILLA BRITTON



BILL GUEST



DR TREVOR CHONG



PATRICK CUNNINGHAM



NEALE DANIHER



DR JUDITH SLOCOMBE



MARK EVANS

SECTION **9**

THANK YOU





DONATE BELOW



THANK YOU

Thank you to our supporters for helping us take major strides in our battle against the Beast in 2022.

We've made a start, but there's still a long way to go. Our fight is far from over.

Together, we can defeat the Beast.

**FIGHT
MIND.**

IT TAKES PEOPLE

