



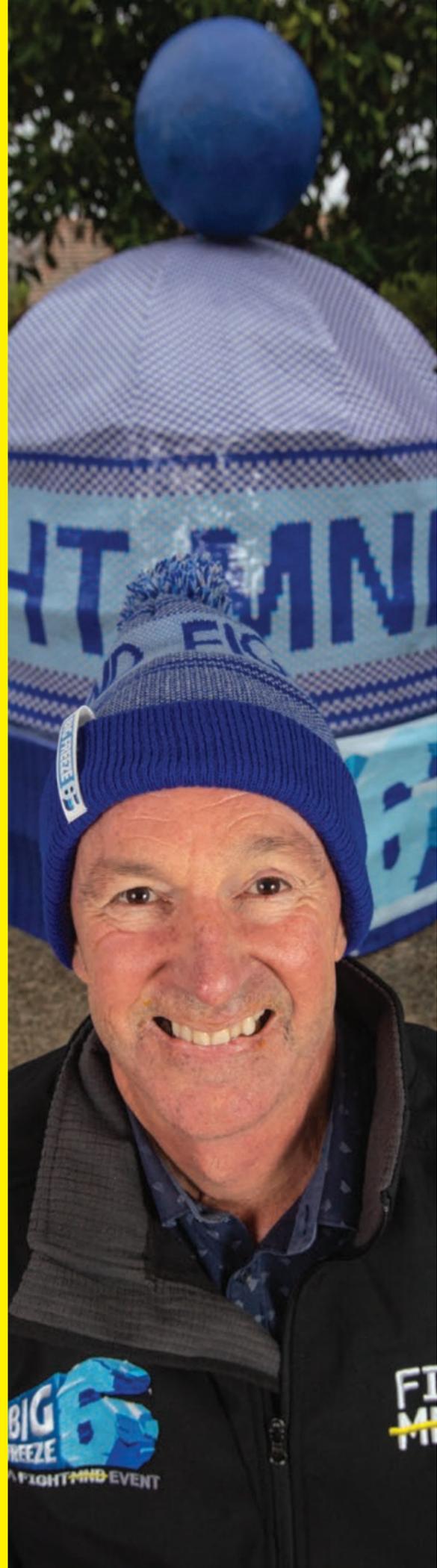
# FIGHT MND.

ANNUAL REPORT 2019/20



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# OUR PEOPLE

## FIGHTMND BOARD



Bill Guest  
*Chairman*



Pat Cunningham  
*Vice Chairman*



Neale Daniher  
*Patron*



Gary Nugent  
*Treasurer*



Dr. Trevor Chong



Dr. Judith Slocombe



Lewis Martin



Andrew Dillon



Mark Evans



Camilla Britton  
*(from May 2020)*

## FIGHTMND STAFF

<b>Jamie Howden</b>	CEO
<b>Bec Daniher</b>	Campaign Director
<b>Dr. Bec Sheean</b>	Research Director
<b>Katrina Parker</b>	Fundraising Director
<b>Adam Kinross</b>	Finance and Operations Director (until Nov 2019)
<b>Mark Lyons</b>	Finance and Operations Director (from Nov 2019)
<b>Andrew Holmes</b>	Communications Manager
<b>Anna Skelton</b>	Fundraising Manager
<b>Georgia Cornell</b>	Social Media and Campaigns Coordinator
<b>Lauren McKellar</b>	Campaigns Coordinator (until Dec 2019)
<b>Emily Paul</b>	Campaign Manager (from March 2020)
<b>Dr. Davor Stanic</b>	Research Coordinator
<b>Magdalena Ojeda</b>	Database Coordinator (until Nov 2019)
<b>Theo Sfiris</b>	Database Coordinator (from Jan 2020)
<b>Alene Lee</b>	Office Manager (from Jan 2020)

# CHAIRMAN'S REPORT

**WHEN I PENNED THIS CORRESPONDING REPORT FOR THE 2018/19 EDITION, I MADE A POINT OF SAYING I WAS LOOKING FORWARD WITH GREAT ANTICIPATION AND EXCITEMENT TO WHAT THE FUTURE HELD FOR FIGHTMND, BASED ON THE EVIDENCE OF HOW OUR ARMY HAS NEVER LET US DOWN...NEVER.**

Thanks to the sustained efforts of our Army, incredible progress has been made in the science laboratories over the past seven years. The battle has not yet been won, however with our supporters by our side, we continue to fight with optimism and hope.

As 2019 concluded, and 2020 began, the sentiment above held true. We were optimistic. We had staged another hugely successful Big Freeze at the G (the fifth edition in the series so far), another great fun-filled and energised Daniher's Drive event, SockIt2MND infiltrated the grassroots sporting communities like never before and once again we experienced a wonderful period of community engagement and fundraising in the fight against MND. It was a super period to reflect on.

There are far too many people individually to thank for their contributions to these successful events and fundraising efforts, so collectively, on behalf of the entire FightMND Board and team, I extend my thanks. You know who you are.

History will remind us that 2020 will not be as favourable to reflect on as we had hoped for many reasons.

In March 2020, the world changed when the coronavirus global pandemic struck and struck hard.

To all those who suffered in any way, through loss of family, business disruptions, mental health issues or any other health, social or economic impact felt, I extend my personal thoughts and best wishes to you and your families.

At FightMND, we worked hard as a team to adapt to the ever-changing landscape in front of us and continued to ask ourselves many questions. How would a charity like us ride through this period? How will we manage and conduct Big Freeze 6, and should we? Will we sell beanies? Will people buy beanies? Will they still donate to the fight?

Many of the contingency plans discussed were dependant on factors outside of our control. Our focus quickly turned to what we could control and what we felt was right to do given the circumstances, while respecting the hardships being experienced in the community.

Since inception, FightMND has repeatedly reinforced to our loyal army of supporters that the fight must go on. This was the strategy we adopted for our fundraising activities despite the interruptions. Sadly, time is not on the side of those living with MND so we did not believe we could halt or delay our final work.

The first half of 2020 was difficult, but we managed to get to the Big Freeze and raised an extraordinary \$11.9m through the toughest of circumstances.

The AFL, the 18 AFL Clubs, our media partners in Channel 7 and the Herald Sun, our retail partners Coles and Bunnings and all our valued partners, our fundraisers and volunteers all did their part, and we are indebted to you all.

The Federal Government and the Victorian State Government have been wonderful supporters of our Foundation over many years, and have contributed significantly to our cause, allowing us to invest vital funds into world-leading research. On behalf of the Board, I personally thank the Hon. Greg Hunt, Federal Minister for Health, the Hon. Josh Frydenberg, Treasurer of Australia and the Hon. Daniel Andrews, Premier of Victoria, for their commitment to FightMND and for providing the opportunity for our key research projects to continue.

We have a passionate and committed team at our Foundation who unconditionally immerse themselves into their work. I am extremely proud of them, and thank them for all that they do.



To my fellow FightMND Board Members, I thank you for your collegiate support around the Board table and for your contribution to maintaining our strong governance.

I thank and congratulate all the state MND Associations for the work they do in their respective jurisdictions to support those Australians living with MND. Australia is a world-leader in both research developments and care initiatives and the collective effort to support both is something we can all be very proud of.

The Australian community's financial support allows us to fund the best research projects available and continue to progress to our end goal of finding a cure for MND. I thank all our donors for staying with us and fighting the fight together.

Last, but by no means least, I again thank Neale Daniher for what he has created and nurtured at FightMND. He continues to inspire the team everyday despite his own battle with MND. His legacy continues to grow, and he significantly contributes to our Foundation by selflessly putting the interests of FightMND above all else. I trust I can speak on behalf of the entire FightMND Army by saying we are forever grateful for that.

Regards,

Bill Guest  
Chairman

# FIGHTMND FUNDED RESEARCH SUMMARY

## 2020FY FIGHTMND FUNDED RESEARCH

In 2019 FightMND committed another \$9M into MND Research projects across Australia. In addition to Clinical Trial and Drug Development Grants, FightMND supported Research Fellowships and a new grant scheme, IMProving and ACceleraTing Translation (IMPACT) grants. IMPACT grants are an important addition to the FightMND Research Grants portfolio as they address six (6) key hurdles that the MND research sector faces when designing, developing, delivering and testing new treatments for MND, while Research Fellowships support capacity building and career development for both early and mid-career researchers within the MND sector.

All research proposals were assessed by both national and international MND experts and an expert panel of MND clinicians and researchers to identify the most promising projects to support. The successful research projects include:

- » Phase III Clinical Trial - Triumeq (The Lighthouse trial 2)
- » Phase II clinical trial - Nanocrystalline gold (CNM-Au8)
- » Phase I clinical trial - Trimetazidine (Re-purposed medication)
- » Drug Development project - Rescuing motor neurons using a novel drug that blocks HDAC6
- » 7 IMPACT projects
  - » Disease susceptibility, precision medicine and MND
  - » New biomarkers for MND
  - » Establishing a new model of MND
  - » Enhancing drug delivery in MND
  - » Assessing changes in breathing and muscle strength in MND
  - » Pre-clinical steps towards a stem cell trial for MND
  - » Treating overactive immune defence systems in the brain
- » 3 Research Fellowships

Outside of our regular grant round, FightMND supported another two important research initiatives:

- » Sporadic ALS Australian – System Genomics Consortium (SALSA-SGC)
- » Victorian Brain Bank.

## CLINICAL TRIALS

In 2019, FightMND funded 3 new clinical trials; one Phase III trial, one Phase II and a Phase I.

### 1. PHASE III CLINICAL TRIAL OF TRIUMEQ (THE LIGHTHOUSE TRIAL 2) IN MND

#### Background

Researchers have shown previously that an ancient virus, hidden in the genome, may be responsible for ALS, becoming activated and leading to the death of motor neurons. This type of virus, called a HERV (human endogenous retrovirus), is in the same class of viruses as HIV. More recently, a specific HERV, known as HERV-K, has been shown to be the likely culprit in ALS. A common combination antiviral drug for HIV, Triumeq, is highly effective against HERV-K, and importantly, can cross into the nervous system. In the Lighthouse Study, a recent Australian clinical trial supported by FightMND, Triumeq was shown to be safe and well tolerated in MND patients.

#### The Project: Phase III Triumeq trial

The Lighthouse 2 study is a Phase III clinical trial to investigate the safety and efficacy of Triumeq, on blocking HERV-K and slowing disease progression in a large number of MND/ALS patients. The trial is a large multi-national trial conducted on 363 patients in 17 centres across Australia, Europe and UK.

**Principal Investigators:** Prof Julian Gold (The Albion Centre, Prince of Wales Hospital, Sydney) & Prof Leonard H. van den Berg (University Medical Centre, Utrecht)

**Number of Subjects:** Australian cohort likely 75 patients at 5-6 sites across Australia.

**Outcomes:** Outcomes from this trial will identify if Triumeq is an effective treatment for MND.

### 2. PHASE 2 CLINICAL TRIAL OF NANOCRYSTALLINE GOLD (CNM-AU8) IN MND

#### Background

Researchers have identified a new molecule, Nanocrystalline-Gold (CNM-Au8) that is able to target and reduce a number of the cell stress responses that occur in motor neurons in MND. They have shown that CNM-Au8 was able to protect motor neurons from oxidative stress, toxicity and hyperactivity and that it lengthened the lifespan of MND models in the laboratory. CNM-Au8 was safe and well tolerated in people in a Phase I clinical trial.

#### The Project: Nanocrystalline Gold (CNM-Au8) trial – RESCUE ALS

The RESCUE-ALS study is a Phase II clinical trial testing the safety of CNM-Au8 for treating MND and aims to demonstrate if CNM-Au8 slows progression of MND/ALS in patients.

**Principal Investigators: Prof Steve Vucic** (Westmead Hospital, Sydney) & **Prof Matthew Kiernan** (Brain and Mind Centre, Sydney)

**2 Sites: Prof Steve Vucic** (Westmead Hospital, Sydney)  
**Prof Matthew Kiernan** (Brain and Mind Centre, Sydney)

**Number of Subjects:** 42 subjects will be enrolled across the two sites.

**Outcomes:** A promising trial outcome would inform a larger Phase 3 trial in the next 2-3 years.

### 3. PHASE I TRIAL OF TRIMETAZIDINE IN MND

#### Background

About half of all patients with MND experience a change in their energy use that causes their body to consume more energy (termed hypermetabolic). Researchers have shown that hypermetabolism accelerates the spreading of MND throughout the body and is linked to an increased risk of death and faster rate of progression in people with MND. Researchers aim to reduce hypermetabolism in patients with MND and counter its detrimental consequences. Trimetazidine, a partial fatty acid oxidation inhibitor, has been shown to reduce hypermetabolism in patients with chronic heart failure and is licensed as treatment for angina. Trimetazidine has a favourable safety profile and, more importantly, reduces the expression of oxidative stress markers that are also increased in patients with MND.

#### The Project: Phase I Clinical Trial – Re-purposed medication Trimetazidine

This study is a Phase I clinical trial to test the ability of Trimetazidine, to normalise metabolism in MND and determine if this drug can be safely administered to MND patients. This study is to be conducted across three sites in the Netherlands, UK and one site in Australia at the Royal Brisbane and Women's Hospital.

**Principal Investigators: Dr Shyuan Ngo**, FightMND Mid-Career Research Fellow (University of QLD)

**Outcome:** Positive outcomes from this study would lead to a Phase II study where the effect of Trimetazidine on the slowing disease progression would be investigated.

# FUNDED RESEARCH SUMMARY (CONT.)

## DRUG DEVELOPMENT PROJECT

In 2019 FightMND funded one pre-clinical Drug Development project.

### RESCUING MOTOR NEURONS USING A NOVEL DRUG THAT BLOCKS HDAC6

#### Background

Motor neurons are nerve cells that create signals which allow them to communicate with each other and with other cells, including muscles to regulate muscle activity. The enzyme HDAC6 is involved in maintaining the structure of motor neurons, but in MND HDAC6 becomes damaging to motor neurons leading to their degeneration and failed communication with muscles. Researchers hypothesize that blocking these damaging effects of HDAC6 in MND will slow disease progression.

#### The Project: Pre-clinical testing of LAUR-301 in MND mice

This research team is testing if the drug ACY738, which blocks HDAC6, is able to protect motor neurons and their processes and can rescue communication between motor neurons and muscles. They will test ACY738 in three pre-clinical MND models. In addition, they will also screen another 150 compounds for their ability to block HDAC6 to identify the best drug candidate to advance forward towards clinical trial.

## IMPACT GRANTS

In 2019, FightMND supported seven IMPACT projects. IMPACT grants support projects focused on one or more of the following key issues contributing to the lack of translation of effective treatments through to clinical trial for MND/ALS:

1. Disease heterogeneity
2. Lack of relevant preclinical models
3. A lack of reliable disease biomarkers
4. The challenge of drug delivery into the brain
5. A lack of effective targeted gene therapies
6. The untapped potential of stem cell therapy

### 1. PROJECT: DISEASE SUSCEPTIBILITY, PRECISION MEDICINE AND MND

#### Project lead: Prof Julie Atkin, Macquarie University

**Priority area:** Disease variability in MND

This project investigates diversity in MND, aiming to categorise patients based on their distinct symptoms and presentation of unique biochemical markers. The purpose is to establish a platform that enables optimal and tailored treatments for MND patients, specific to the unique disease features of each individual.

### 2. PROJECT: NEW BIOMARKERS FOR MND

#### Project lead: Dr Fleur Garton, University of Queensland

**Priority area:** MND Biomarkers

This project aims to develop a rapid, sensitive and economical way to diagnose MND. By genetically assessing blood samples from individual MND patients, markers that accurately predict and track the progression of MND will be identified. This will advance the design of therapies that effectively treat MND.

### 3. PROJECT: ESTABLISHING A NEW MODEL OF MND

#### Project lead: Dr Mouna Haidar, Florey Institute of Neuroscience and Mental Health

**Priority area:** MND Disease Models

This project will create the first mouse model that replicates features of the most common form of MND, by causing regions of the brain that control movement to become overactive. This model will be used to test the effectiveness of potential treatments that may slow the progression or prevent MND.

### 4. PROJECT: ENHANCING DRUG DELIVERY IN MND

#### Project lead: A/Prof Joseph Nicolazzo, Monash University

**Priority area:** Drug Delivery

This project examines the function of the barrier that normally prevents the transfer of substances from the blood to the brain. The aim is to improve the ability of potential drugs to access the brain and treat MND more effectively

### 5. PROJECT: ASSESSING CHANGES IN BREATHING AND MUSCLE STRENGTH IN MND

**Priority area:** MND Biomarkers

#### Project lead: Dr Frederik Steyn, University of Queensland

This project will develop and validate a new way to diagnose MND by detecting abnormal breathing and weakening breathing muscles using on the spot blood tests.

### 6. PROJECT: PRE-CLINICAL STEPS TOWARDS A STEM CELL TRIAL FOR MND

#### Project lead: A/Prof Lachlan Thompson, Florey Institute of Neuroscience and Mental Health

**Priority area:** Regenerative medicine

This project will provide a thorough understanding of the effectiveness and benefits of stem cell therapy in a model of MND and advance the pathway to a well rationalised stem cell clinical trial for MND patients.

### 7. PROJECT: TREATING OVERACTIVE IMMUNE DEFENCE SYSTEMS IN THE BRAIN

#### Project lead: A/Prof Anthony White, QMIR Berghofer Medical Research Institute

**Priority area:** MND Disease Models

This project will develop a way to test the effectiveness of potential drugs designed to prevent the harmful effects of an overactive immune system in the brain, using immune defence cells obtained from MND patient blood samples.

# FUNDED RESEARCH SUMMARY (CONT.)

## FELLOWS

In 2019, FightMND were proud to award two Mid-Career Research (MCR) Fellowship and one Early-Career Research (ECR) Fellowship, to researchers who have shown outstanding contributions to research and a dedication to MND. Research Fellowships allow FightMND to support members of the MND Research Army in the early stages of their careers and establish themselves as future leaders in MND research.

### MID-CAREER RESEARCH (MCR) FELLOWS

#### 1. DR SHYUAN NGO (UNIVERSITY OF QUEENSLAND) - QUEENSLAND

This fellowship is in support of an established MND researcher to lead projects that investigate how deficiencies in the use of the body's energy stores contributes to the onset and progression of MND.

#### 2. DR FAZEL SHABANPOOR (THE FLOREY INSTITUTE OF NEUROSCIENCE AND MENTAL HEALTH) - VICTORIA

This fellowship will support an established MND researcher to lead projects that develop new potential treatments for MND that prevent the production of toxic substances in motor neurons and improve the ability of a motor neuron to clear the toxic substances it produces.

### EARLY-CAREER RESEARCH (MCR) FELLOW

#### 1. DR REBECCA SAN GIL (UNIVERSITY OF QUEENSLAND) - QUEENSLAND

Dr San Gil is working to develop a new way to prevent the formation of toxic substances in, or their removal from, motor neurons to prevent them from dying.

## OTHER RESEARCH INITIATIVES

### PROJECT: SPORADIC ALS AUSTRALIAN - SYSTEMS GENOMICS CONSORTIUM (SALSA-SGC)

#### Principal Investigators: Professor Naomi Wray (University of QLD)

In 2015, Professor Naomi Wray was awarded the Ice Bucket Challenge Grant from MND Australia to establish and support the Sporadic ALS Australian - Systems Genomics Consortium (SALSA-SGC) for three years. SALSA-SGC brought together seven major MND clinics across Australia to collect clinical data (symptoms, rate of disease progression) and biological samples from MND patients, creating a research bank that integrates clinical, lifestyle and biological information. The aims of this project are:

- » To establish consistent collection of longitudinal clinical information from people with MND, and create a resource for current and future research that guides the generation of new effective patient-specific preventive therapies.
- » To increase the understanding of genetic and non-genetic factors that contribute to MND, and guide the generation of new effective patient-specific preventive therapies.

This funding from FightMND allows the continued support of this Program for the next three years. Through support of SALSA-SGC, FightMND are able to support of researchers in the SALSA-SGC project and research nurses at eight MND clinics across Australia allowing MND patients at each of these sites the opportunity to be involved in important research to guide the treatment of MND.

### PROJECT: VICTORIAN BRAIN BANK

#### Principal Investigators:

##### Professor Catriona McLean

The Victorian Brain Bank (VBB) is a research resource facility that supports MND research by providing Australian and International researchers with easy access to well-characterised post-mortem brains, spinal cords, cerebrospinal fluid and related clinical data which has great potential to unlock our understanding of how MND occurs and which may lead to:

- » Improvements in diagnosis,
- » Development of early diagnostic tests,
- » Development of effective treatments; and ultimately
- » A cure.

The VBB also provides a vital diagnostic neuropathological service that:

- » Confirms neuropathology diagnosis, particularly in difficult cases, increasing clinician's awareness and understanding of atypical presentations of MND,
- » Confirms diagnosis for donor families, in whom MND may have hereditary or familial association and at risk of developing the disease,
- » Generates pathological description of MND and advance knowledge of some brain pathologies thus providing a powerful tool for education and research, and
- » Provides a gold standard to improve validity of all current and future MND research studies.

## DRUG DEVELOPMENT PIPELINE

THERAPEUTIC CANDIDATE	DISCOVERY RESEARCH	DRUG DEVELOPMENT		CLINICAL TRIALS				APPROVAL
	TARGET IDENTIFICATION	OPTIMISATION	SAFETY & MANUFACTURING	PHASE 1	PHASE 2	PHASE 3	PHASE 4	TGA APPROVAL
TW001-Oral Edaravone	▶	▶	▶	▶	▶	▶		
CuATSM	▶	▶	▶	▶	▶			
Tecfidera	▶	▶	▶	▶	▶			
Triumeq	▶	▶	▶	▶	▶			
IC14-mAb	▶	▶	▶	▶	▶			
PMX205	▶	▶	▶	▶	▶			
mEphA4-Fc	▶	▶	▶	▶	▶			
CuATSM + Ferroptosis inhibitors	▶	▶	▶					
GBA inhibitors	▶	▶	▶					
Neuropeptide Y	▶	▶	▶					
MIPS19048 (Rab 1)	▶	▶	▶					
PDI mimic	▶	▶	▶					
GRT-X	▶	▶	▶					
LAUR-301	▶	▶	▶					

▶ - Current FightMND funded projects

The Drug Development Pipeline showing therapeutic candidates supported through FightMND funding. Green arrows represent currently funded projects in 2018.

# CAMPAIGNS REPORT

## BIG FREEZE 6 JUNE 8, 2020

The 2020, and sixth, installment of the Big Freeze at the 'G was without doubt, one with a vastly different build-up to previous years. Thankfully, one with a very familiar outcome thanks to the continued support of the FightMND Army.

Through the sale of our iconic blue beanies, and our Army's amazing commitment to fundraising during the most difficult of years, Big Freeze 6 raised an extraordinary \$11.9 million, the largest total to date.

Big Freeze 6 was - as so many events in Australia were - severely impacted by the COVID-19 pandemic, and the annual extravaganza had to be reconfigured given the circumstances.

The 2020 AFL season went into a hiatus for a period of time and the blockbuster showpiece at the MCG between Melbourne and Collingwood, which is central to the Big Freeze event, just couldn't occur.

The need to deploy a well-considered contingency plan to successfully stage our annual fundraiser was realised and implemented early enough to yield another extraordinary outcome. We respectfully understood the challenges the community was facing. Many were threatened by unemployment, and other events and important family gatherings were cancelled. However, we adopted the position that the fight against MND was one thing that could not stop. It is still a killer, and it was now as important as ever to continue the fight.

In addition to the wonderful contribution from our FightMND Army, we again received outstanding support from our Major Partners - the Australian Government, our two major media partners Channel 7 and the Herald Sun, our major retail partners in both Coles and Bunnings, the AFL and BetEasy. We thank them for their strong and loyal commitment and for going above and beyond to make the incredible 2020 result a reality.

## 2020 'ICE CHALLENGERS'

- » Steele Sidebottom (Collingwood)
- » Taylor Walker (Adelaide)
- » Mitch Robinson (Brisbane)
- » Patrick Cripps (Carlton)
- » Orazio Fantasia (Essendon)
- » Michael Walters (Fremantle)
- » Joel Selwood (Geelong)
- » Brandon Ellis (Gold Coast)
- » Toby Greene (GWS Giants)
- » Christian Petracca (Melbourne)
- » Isaac Smith (Hawthorn)
- » Ben Brown (North Melbourne)
- » Tom Rockliff (Port Adelaide)
- » Jack Riewoldt (Richmond)
- » Brad Hill (St Kilda)
- » Isaac Heeney (Sydney Swans)
- » Brad Shephard (West Coast)
- » Bailey Smith (Western Bulldogs)

Both Coles and Bunnings sold beanies in store nationwide for the first time and the support the teams at each of the retailers provided us during the difficult year played a significant and vital role in achieving this record-breaking fundraising tally.

We extend our gratitude to Channel 7 Managing Director Lewis Martin and his team for creating a studio hosted broadcast on the Queen's Birthday to support the event in the absence of the ability to broadcast live from the MCG at the Big Freeze. Their passion to adapt and to find a way, including mobilizing the 18 AFL Clubs to be part of it provided a strong platform for the event to have a public presence therefore enabling people to support us again.

To each of the AFL Clubs, and everyone who contributed to putting the 'show' on, we extend our sincere thanks. All clubs embraced the challenge to come up with their own creative approach amid COVID-19 restrictions, and they all delivered for our important cause once again. There was a mix of ice bucket challenges, ice pools, large inflatable water slides and even the old family favourite, the "Slip 'n Slide". Despite being physically apart in 2020, the AFL community again showcased what it is to be united in spirit. For that we thank them.



## DANIHER'S DRIVE OCTOBER 10-13, 2019

Victorian Premier Daniel Andrews joined 309 participants at Werribee Zoo early on Thursday, October 10 to officially start the fifth staging of the annual Daniher's Drive fundraising event, raising an incredible \$3.1m.

While breakfast was being enjoyed, new acquaintances were being formed and old ones renewed, the Premier joined Neale Daniher on stage to announce a \$1m funding support of the event and FightMND. The announcement, met with rapturous applause, was the perfect positive way for the 4-day road-trip across regional Victoria to get started.

The 2019 route included community stops in Portarlington on day one, Maldon and Nagambie on day two and Alexandra on the final afternoon of day three.

We thank the Fairhaven Surf Lifesaving Club and Heathcote Football Club for hosting lunch on day one and two of the event.

The nightly dinner events were all held at magnificent venues. The RACV Club Goldfields in Creswick hosted dinner on night one. On night two we enjoyed a comedy and gala auction at the Wangaratta Racing Club with comedian Dilruk Jayasinha providing entertainment. The final evening saw us enjoy the hospitality of the Mornington Racecourse for our "Heroes & Villains" theme night.

To conclude the festivities and to draw the curtain on the event, brunch and presentations took place overlooking stunning views of Port Phillip Bay at the Ranelagh Club in Mount Eliza.

We extend a warm thanks to our incredible Daniher's Drive volunteer organisation committee, who meet regularly in the buildup to the event each year and contribute many, many hours of their own time to ensure the event is a success.

To all the participants, and to all the people who supported their individual fundraising efforts, we thank you from the bottom of our hearts. Almost 60% of the total funds raised come direct from fundraising efforts for the 12 months prior to it. Daniher's Drive is all about community – the community that supports us in our fight and in turn, we take the event to the community to support them.

Finally, and by no means least, thanks to our great Daniher's Drive partners for the vital support they provide.

### NAMING RIGHTS PARTNER



### EVENT PARTNERS



### NIGHT EVENT PARTNERS



# COMMUNITY FUNDRAISING REPORT

The strength of the support from the FightMND Army through community fundraising has grown every year. We are incredibly grateful for the ongoing contribution they make to our cause.

The number of community fundraising events held was down on previous years due to the pandemic. Despite it being an extremely challenging year for everyone in the community across Australia, particularly in Victoria, there were still several shining lights and significant fundraising contributions.

Sadly, we were advised that 80 planned community fundraising events did not go ahead. This was in addition to the cancellation of other major fundraising opportunities such as Run Melbourne, Blackmores Sydney Running Festival and City2Surf.

We are incredibly thankful to those fundraisers who found a way to still be involved in supporting the fight against MND throughout 2019/20.

COVID-19 put a hold on many annual community events, particularly those normally staged in the states hardest hit. Despite the inability to activate as normal, many supporters turned to the Big Freeze beanie, selling them within their community as they continued to support the fight.

With a record number of beanies sold during the Big Freeze 6 campaign, much of the success of beanie sales can be attributed to our army of fundraisers.

While Victoria, where many of our fundraisers reside, was hit the hardest due to lockdowns and restrictions, supporters in other states were still able to hold some events such as workplace fundraisers, golf days, fun runs, rides, walks and DIY Big Freeze events.

Do-it-yourself Big Freeze events were still very successful in the states that experienced minimal COVID restrictions.

In particular, congratulations and thanks to the organisers of the Lake Grace Pingrup and Boxwood Hills joint fundraiser in Western Australia. It is the third year the event has been held and it raised an extraordinary \$72,000 in 2019, taking the total funds raised since 2017 to \$174,000. This was the highest total raised from a DIY Big Freeze event.



A big thank you also to the community in Springvale who raised \$14,000 at their Big Freeze event.



In March, a group of 32 keen cyclists took to the highways throughout New South Wales and Victoria, covering 725km over 7-days to raise money for FightMND.

The event raised \$176,000.

While the whole 32 competitors rode the full route, over 100 additional riders joined in for various shorter sections of the ride.



This event honoured the Daniher family by beginning the journey in Ungarie, the 'home' of the Daniher family, and finished at the Essendon Football Club.

The event will be held biannually with the next ride scheduled for 2022.

We also extend our thanks to all the schools around Australia, both primary and secondary, that participated in fundraising throughout the year. Schools are great environments for simple to organise fundraising events such as ice bucket challenges, selling beanies, walks, fancy dress-up days and morning and afternoon tea events.



# FINANCIAL REPORT

IN 2020, FIGHTMND INCOME GREW AT 27% FOR THE YEAR, TO A TOTAL OF \$21.5 MILLION, REFLECTING THE INCREDIBLE SUPPORT RECEIVED FROM OUR PARTNERS, DONORS AND VOLUNTEERS. IN TURN \$12.7 MILLION WAS INVESTED INTO MEDICAL RESEARCH AND CLINICAL TRIALS TO PURSUE A TREATMENT AND A CURE FOR MOTOR NEURONE DISEASE ALONG WITH PROVIDING EQUIPMENT AND AIDS IN CARE FOR THOSE WHO SUFFER FROM MND.

FightMND continue to manage our cash reserves to address our substantial funding commitments for Cure and Care strategies and we are well on track to fund a new round of grants for 2021.

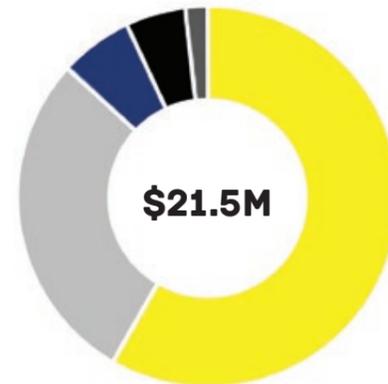
The 2021 Budget was approved by the Board and reflects ambitions of stability in our major fundraising campaigns during uncertain times. For the year ending 30 June 2021 we expect net fundraising income to be on par with 2020.

I thank my colleagues for their dedicated commitment and support in overseeing appropriate financial management and governance of the foundation. I also thank our partners, donors and volunteers who have helped us achieve a strong financial outcome for 2020.

Gary Nugent  
Foundation Treasurer

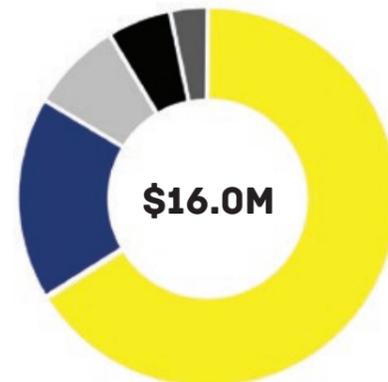
The summary financial information provided in this section was extracted from the audited general-purpose financial statements and does not include all the information and notes normally included in a statutory financial report. If you require a full set of the financial statements, please contact FightMND on phone 1800 344 486 or email [info@fightmnd.org.au](mailto:info@fightmnd.org.au)

## WHERE OUR MONEY COMES FROM



- 58% Major Fundraising Campaigns
- 29% Government Grants & Income
- 6% Corporate Partnerships
- 5% Donations & Gifts (excl campaign dons)
- 2% Other Revenue

## WHERE OUR MONEY GOES



- 66% Medical Research (Investment)
- 17% Fundraising Events (Expense)
- 8% Care Equipment (Investment)
- 6% Clinical Trials (Investment)
- 3% Administration (Expense)

## FINANCIAL TABLES

INCOME STATEMENT		2020	2019
<b>REVENUE</b>			
Donations, Gifts & Grants		11,046,229	11,116,749
Fundraising Events		8,941,966	5,072,367
Other Revenue		1,516,638	765,950
<b>Total Revenue</b>		<b>21,504,833</b>	<b>16,955,066</b>
<b>EXPENSES</b>			
Investment	Medical Research	10,561,067	8,208,106
	Clinical Trials	881,085	6,758,522
	Care Equipment	1,250,000	2,467,083
Expense	Fundraising Events	2,797,928	2,178,107
	Administrative	502,515	436,865
<b>Total Expenses</b>		<b>15,992,596</b>	<b>20,048,682</b>
<b>OPERATING SURPLUS/LOSS</b>		<b>5,512,237</b>	<b>-3,093,617</b>

BALANCE SHEET		2020	2019
<b>ASSETS</b>			
	Current Assets	37,158,345	28,190,035
	Non-Current Assets	12,818	5,214
<b>Total Assets</b>		<b>37,171,163</b>	<b>28,195,249</b>
<b>LIABILITIES</b>			
	Current Liabilities	13,025,626	12,368,116
	Non-current Liabilities	11,604,694	8,798,526
<b>Total Liabilities</b>		<b>24,630,320</b>	<b>21,166,642</b>
<b>NET ASSETS</b>		<b>12,540,844</b>	<b>7,028,606</b>
<b>MEMBER'S FUNDS</b>		<b>12,540,844</b>	<b>7,028,606</b>



# OUR PARTNERS

THANK YOU TO THE FEDERAL GOVERNMENT, THE VICTORIAN STATE GOVERNMENT AND ALL THE ORGANISATIONS THAT HAVE SUPPORTED FIGHTMND THROUGHOUT THE YEAR DURING BIG FREEZE 6 AND THE 2019 DANIHER'S DRIVE.

## GOVERNMENT



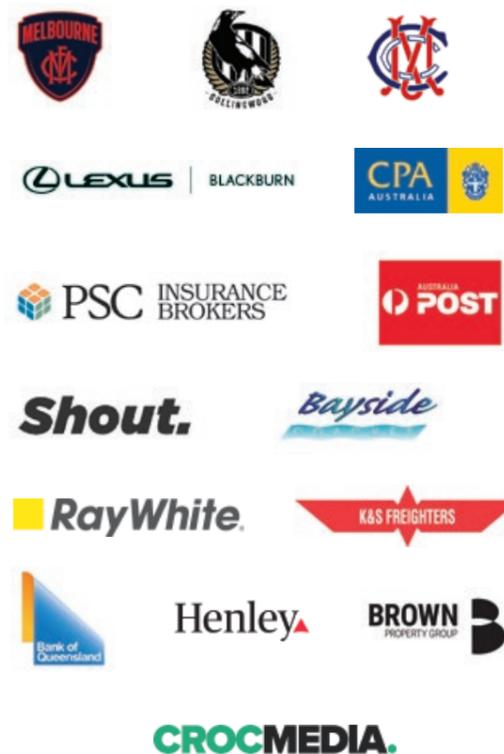
## MAJOR PARTNERS



## EVENT SUPPORTERS

AquaTechnic Pools  
Bells Ice  
Harry the Hirer  
Infusion 121  
King's Fibreglass

## SUPPORTING PARTNERS



Machship  
MSC Signs  
Net Ninjas  
Token Artists

# OUR DONORS

WE WISH TO ACKNOWLEDGE AND OFFER OUR SINCERE THANKS TO THE FOLLOWING DONORS WHO ALL CONTRIBUTED \$10,000 OR MORE TO FIGHTMND DURING THE YEAR.

Acknowledge Education Pty Ltd  
Alexia Patinyotis  
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Elizabeth And Tony Todaro  
Estate of Jennifer Dawn Kerr  
Estate of Susan Iris Deuchars  
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GPA Andrew Ursini Charitable Fund (GPAU)  
Hansen Little Foundation  
Hoppers Crossing Apex Club  
Hostplus  
Little Birdie / TopSport  
Lisa Ring (& Family)  
Mandy Deam Foundation

Margaret Dawn  
Mark Walkley  
Michael & Deb Hayward  
Michael Kerr  
Rallou Pty Ltd Massey Charitable Foundation  
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MIND.**

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