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# ANNUAL REPORT 2018/19



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# **OUR PEOPLE FIGHTMND BOARD**

# HND.

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Neale Daniher Patron



Dr. Judith Slocombe



Mark Evans



# CHAIRMAN'S REPORT.

AS I REFLECT ON THE FINANCIAL YEAR OF 2018/19, I DO SO WITH GREAT ANTICIPATION AND EXCITEMENT ABOUT WHAT LIES AHEAD FOR THE GLOBAL FIGHT AGAINST MOTOR NEURONE DISEASE IN THE IMMEDIATE FUTURE, AND BEYOND, GIVEN THE FOUNDATION'S FUNDRAISING SUCCESS, AND SUBSEQUENT MND RESEARCH FUNDING.

Despite the joy of that success, there was a pall of sadness that was experienced by everyone at FightMND, and our supporting 'Army', with the terribly sad passing of a dear friend, inaugural Chairman and the visionary behind FightMND, Dr. Ian Davis, in November 2018.

Ian was an inspiration to everyone who knew him, and he played an immeasurable role in establishing FightMND, and the progress made in clinical research into finding effective treatments and a cure for the insidious disease that is Motor Neurone Disease.

The courage and selflessness he displayed during his own personal fight against the disease he fought so hard to eradicate for future generations will be remembered by people around the world affected by 'The Beast' as a true mark of the man he was.

We are thankful to have had the privilege of having Ian positively impact our lives, and the lives of all affected by MND, and he will be fondly remembered. We extend our love and support to Ian's wife Mel, and son Archie, who will forever remain part of the FightMND family. Rest in Peace Ian.

2018/19 was an extremely positive period for FightMND with the fifth annual instalment of the iconic Big Freeze at the 'G and the fourth edition of Daniher's Drive, highlighting our major campaigns and yielding the best fundraising results for those two events since our inception in 2015. There are always extraordinary highlights to savour from every Big Freeze event at the MCG on the Queen's Birthday, and in 2019, an array of ex-AFL champions and Australian female sporting royalty led the charge for us. The celebrities that we approach to be involved in this amazing event always accept the invitation and immerse themselves in the spirit of the event with incredible enthusiasm and fun.

To the 14 sliders in 2019, you are thanked from the bottom on our hearts. Without your unconditional cooperation and support, we could not achieve what we have with this now iconic event on the Australian calendar.

The Big Freeze 5 extravaganza was a resounding success with a total of \$5.4 million raised during the campaign, which was greatly assisted by the generous contribution by the Federal Government once again.

Both the Morrison Federal Government and the Victorian State Government have been wonderful supporters to our Foundation over many years and have contributed significantly to our cause, allowing us to invest vital funds to world-leading research. On behalf of the Board, I personally thank the Hon. Greg Hunt, Federal Minister for Health, the Hon. Josh Fydenberg, Treasurer of Australia and the Hon. Daniel Andrews, Premier of Victoria, for their commitment to FightMND and the quest to find a cure for 'The Beast'.

To the wonderful and committed staff of our Foundation, led by our CEO Jamie Howden, I thank you all. Our small but passionate team in the office contribute countless hours of extraordinary work to deliver several successful campaigns and community fundraising events that enable FightMND to fund major MND research projects both domestically and internationally. I am extremely proud of our team and thank them for all they do.



To my fellow FightMND Board Members, many thanks to you all for your individual and collective contributions to our strong governance. It is vital that we remain a respected and agile Foundation and a leader in funding the best MND research worldwide that we can.

I thank all our donors, large and small, for your extraordinary contribution. The Australian community's financial support allows to fund the best research projects available and continue to progress to our end goal of finding a cure for the disease that an average of two Australians die from each day. Finally, I wish to extend my thanks to Neale Daniher who, through immense personal difficulty, has continued to play a vital role as the face and voice for the cause. Neale continues to put the fight against MND and our organisation first, supported by his loving family, and for that we are eternally grateful.

Regards,

1 Jun

Bill Guest *Chairman* 



# CEO'S REPORT.

AS CEO OF FIGHTMND, I HAVE LEARNT A GREAT DEAL ABOUT THE POWER OF PEOPLE AND WHAT I HAVE LEARNT ENTHUSES ME ABOUT THE FUTURE OF COMBATTING MOTOR NEURONE DISEASE.

Based on the work that our great organisation does, supported by our amazing FightMND Army, I believe that the power of our people is making significant inroads in the fight against 'The Beast'.

We know that FightMND was initially established and currently exists to fund world-leading, cutting edge medical MND research to discover effective treatments and ultimately a cure for Motor Neurone Disease.

We also know that the above has not been achieved – yet.

So while we can't celebrate reaching our ultimate goal at the present time, we can celebrate where we have come from as a Foundation and what progress has been made in the research sector in the past five years.

We believe that more effective treatments of MND will be available to MND patients within the next five years and that the global momentum of MND research is currently at its greatest.

The prospect of effective treatments and the global momentum is testament to the level of funds raised by our supporters, and where these funds have strategically and rigorously been directed – straight into the hands of worldleading researchers and MND laboratories throughout Australia and internationally. Our loyal FightMND Army can feel justifiably proud of having played a significant role in that. Since our inception in 2014, FightMND has invested \$28.8M into MND research and \$2.45M into purchasing vital care equipment to assist with care of MND sufferers around Australia.

In the 2018/19 year, FightMND proudly committed \$7.6 million to the best and brightest researchers in Australia and internationally so the brilliant work they do can continue. We understand the fight will be long, and the research will have its highs and lows but we know we are in the fight and landing some punches now. There is real momentum and that needs to be maintained so we continue to need the support of the FightMND Army.

At FightMND, we say 'It Takes People' and the past year illustrated that once again. We know that MND takes people. It takes people's ability to move, to speak, to eat, to swallow and ultimately to breath.

It also takes people to fight it. It takes people to rally to the cause, to fundraise, to volunteer, to care and therefore to play a role in the overall fight against MND. We are privileged to have 'our' people and we value them.

I would like to thank the Board of Directors of FightMND for their continued support and guidance and our hard-working team at FightMND. Strong governance is one of our key strategic pillars and our Foundation is fortunate to have an extremely invested and highly committed Board guiding us into the future.

I acknowledge and thank the staff of FightMND who commit tireless and valuable hours to deliver the many facets of our operations, from fundraising to communications to finance and research. I thank you for the work you all do to ensure FightMND remains a leader in MND fundraising and research with the ultimate goal of living in a world without MND.





With the expertise of the best and brightest researchers around the world supporting our fundraising efforts, we are progressing towards our goal but we are not there yet. We must continue to fight the fight. We know you will continue to support us, support those families living with MND and help those diagnosed in the future.

We are in this together.

Regards,

James Meul

Jamie Howden CEO



# REMEMBERING DR. IAN DAVIS

ON NOVEMBER 1, 2018, FIGHTMND CO-FOUNDER DR. IAN DAVIS LOST HIS COURAGEOUS BATTLE WITH MOTOR NEURONE DISEASE. FIGHTMND RESEARCH DIRECTOR, DR. BEC SHEEAN SHARES HER MEMORIES OF WORKING WITH IAN, HIS IMPACT ON GLOBAL MND RESEARCH AND THEIR FRIENDSHIP THAT ENSUED.

I first met Ian in 2014 when he came to visit our MND lab at the Florey Institute where I was working. He came to meet Brad Turner, who was our lab head, to see the work we were doing.

lan had a vested interest in our work - he had MND.

The things I really remember about Ian, aside from being very tall, was that he was really friendly and an incredibly optimistic person.

From the first conversation you had with lan, you just immediately liked him. I certainly did. Before meeting lan, I didn't know much about him. All I knew about him was he had MND and was trying to raise money and make a difference in the MND fundraising space.

History will show that lan indeed did make a difference, in more ways than he could have ever imagined.

People often ask me how would I describe Ian. That's easy. He was driven, confident with a strong vision and knew how to get things done. He could be very headstrong when he wanted something, which was a really positive thing.

He knew how to get people to join the cause with him. He led from the front.

Being headstrong and backing himself, lan ruffled a few feathers when he came into the MND sector. He just believed that what he was doing was right, and he wouldn't take no for an answer. He was so committed.



Thank goodness he didn't take no for an answer otherwise FightMND wouldn't be where it is today nor would the progression of global MND research.

To illustrate how much lan immersed himself into the Foundation and the cause when it was founded, he did almost everything from day one. I decided to do some fundraising for FightMND and when I first made contact to say I wanted to fundraise, it was actually lan that responded to my inquiry. That really surprised me because I assumed there was a lot of people working at the Foundation and someone in admin might respond to me.

In the early days, lan did everything from designing the logo to setting up the website, ordering the merchandise to then thinking about research and fundraising strategies.

Along with his wife Mel and son Archie, FightMND became his purpose in life. He was determined to make an impact. Over time, Ian's MND progressed to a point where he was unable to come into the office very much. We would chat over skype or over email, so it was a little challenging in the beginning. Then we were in constant communication all day everyday it seemed about what we were going to work towards but we were always making sure we were having a lot of fun at the same time.

The best days were the days he was able to come into the office. We spent hours talking about where we wanted to go in the future and what opportunities were out there. His vision enabled him to go above and beyond what I ever thought was possible.

When I am asked about the impact Ian made, it is a difficult question to answer. His impact was multi-faceted.

I honestly think Ian has single-handedly changed the way the rest of the world looks at Australia for MND research.

The type of research we fund, and the models we use to determine the best and most suitable research to fund can be, in the most part, attributable to lan.

These are elements of our Foundation that other organisations are now looking at and thinking it is a really good way of doing things. Ian helped to set a standard in MND research in Australia.

Having clinical trials available for MND sufferers was a high priority for lan because they give people hope.

lan's vision was that for those diagnosed, they have an opportunity to be involved in a trial as opposed to going to their neurologist and being told there is nothing that can be done for them. He worked 24/7. Even though he was the one with MND and losing the use of his hands, I couldn't keep up with the rate at which he was processing information, coming up with new ideas and new contacts. Ian has left several indelible legacies, but two stand out above all others. The establishment of the Foundation and his family, beautiful wife Mel and adorable son Archie.

We could just be a fundraising organisation, but we are so much more than that and are now having a real impact in the research sector. That is difficult to do when dealing with a disease like MND that is so hard to make progress on and have an impact, but we are.

The concept, and ultimate successful delivery, of the Australasian MND Symposium in Melbourne in 2018 will always be something we'll thank lan for. We reached out to a dozen MND experts internationally and we were hoping to get three or four of those people agree to come and speak, but because of the person lan was and his reputation, we had 10 international speakers want to come and be part the inaugural symposium.

The event was incredible successful and ended up being something the Foundation should be very proud of and can be attributed to the hard work of lan.

I know he died with the knowledge he made a big difference. We are in a better place now than before lan Davis. That is a great legacy.

Ian always taught me to make a decision and go for it. He lived his life like that, and I suppose having MND makes you not want to waste time.

I hear his little voice in my head often and that inspires me to continue to make a difference, like he wanted to do. He was a great leader, a great mentor and the those around the world impacted by MND will miss him.

Dr. Bec Sheean FightMND Research Director



# FIGHTMND FUNDED RESEARCH SUMMARY.

# 2018 FIGHTMND FUNDED RESEARCH

In 2018 FightMND has committed another \$7.6 million into MND research. Projects were assessed by a panel of independent MND experts, both national and international who reviewed the research grant applications before making recommendations on which research projects should be selected for funding. They include;

- » Phase III clinical trial of TW001 (Oral Edaravone)
- » Phase II clinical trial of Copper(II)ATSM
- » Phase I clinical trial of mEphA4-Fc
- » 2 Drug Development Projects + LAUR-301 + GRT-X
- » National Precision Medicine Program for MND
- » Biomarker Facility at Flinders University, South Australia

FightMND are proud of the strong governance and rigorous processes and procedures it undertakes to ensure the best projects are funded.

# **PHASE CLINICAL TRIALS**

In 2018, FightMND funded 3 new clinical trials; one Phase III trial, one Phase II and a Phase I.

#### 1. PHASE III CLINICAL TRIAL OF TW001 (AN ORAL FORMULATION OF EDARAVONE)

#### Background

The drug, edaravone is a free radical scavenger that targets oxidative stress, a process known to play an important role in the pathogenesis of MND. Analysis from clinical trials of edaravone have shown that it slows disease progression in a sub-group of patients who have been recently diagnosed and have lesser disability [for more info]. In 2015, the intravenous formulation of edaravone, known as Radicut®, was approved in Japan for the treatment of MND and in the USA it was approved under the name Radicava® in May 2017. Currently, it is not approved in Australia.

Radicut® and Radicava® are administered intravenously (like an intravenous drip) and the dosing regimen consists of 10 days of treatment, over a period of two weeks, followed by a 16-day drug holiday, a period in which the patient is not given edaravone. This method of administration is very taxing for patients and who need to visit clinics/hospitals on treatment days and for doctors/nurses who need to administer the drug.

#### The Project: Phase III TW001 trial

In 2015, Treeway, a biotechnology company in the Netherlands, demonstrated in clinical trials that adequate levels of edaravone can be obtained in the blood by oral administration of edaravone. At Treeway, orally administered edaravone is referred to as TW001. Treeway is developing Edaravone as a formulation so patients can take it via the mouth (oral) each day as a sustained delivery medicine.

The clinical trial of TW001 is a large international phase III trial, with FightMND funding the Australia component. The trial will commence towards the end of 2019.

#### Principal & Coordinating Investigators: TBD Global trial with Australian sites

**Number of Subjects:** Australian cohort likely 60 patients from 5-6 sites

# 2. PHASE 2 CLINICAL TRIAL OF CUATSM ORAL SUSPENSION

#### Background

The development of copper(II)ATSM (CuATSM) as a treatment option for MND started around 15 years ago when it and related compounds were tested in animal models of neurodegenerative disease. Over the years, the laboratory-based evidences supportive of CuATSM being an effective treatment accumulated to the extent where clinical testing in MND patients became a legitimate possibility.

In 2016, FightMND helped to support the phase I clinical trial where CuATSM was given to MND patients as a therapeutic for the first time. Results from the phase I trial indicated that CuATSM was safe and well tolerated in MND patients and a dose was identified that would be used in the next phase of testing.

#### The Project: Phase II CuATSM trial

This phase II study is being run by the company Collaborative Medicinal Development and will test an oral suspension of CuATSM in MND patients in both Australia. This study will be larger than the phase I study and has been designed as a placebo-controlled trial where both participants and doctors will be blinded to whether the participant is in the placebo or drug group. These factors, plus a number of other important aspects of the study design are vital when investigating the efficacy of a new drug. Outcomes from this phase II trial will confirm that CuATSM can be safely administered to MND patients and provide evidence of the efficacy of CuATSM in slowing disease progression.

#### Principal & Coordinating Investigator: Dominic

Rowe, AM (Faculty of Medicine & Health Sciences Macquarie University)

**3 Sites: Dominic Rowe, MD,** Macquarie University (Sydney NSW);

**Susan Mathers, MD,** Calvary Healthcare Bethlehem (Melbourne VIC);

**Robert Henderson, MD,** Royal Brisbane and Women's Hospital.

Potential fourth site in WA. Number of Subjects: 80 subjects will be randomized

1:1 (40 Cu(II)ATSM: 40 placebo)

#### 3. PHASE I TRIAL OF MEPHA4-FC IN MND PATIENTS

#### Background

The molecule EphA4 plays an essential role in both the formation and function of the locomotor system where nerve cells connect with muscles to control movements. Work from Prof Bartlett's laboratory has shown that blocking EphA4 with a drug called mEphA4-Fc improved functional performance and life span in an MND mouse model by preventing the death of motor neurons. Researchers propose the drug mEphA4-Fc may be able to slow disease and protect motor neurons in MND patients.

In 2017, FightMND awarded Prof Perry Bartlett's team a grant to prepare this new compound for testing in a phase I trial. This project included scaling up the manufacturing of mEphA4-Fc, quality control to ensure the drug is high-quality and suitable for clinical testing as well as safety and toxicology studies and mEphA4-Fc is now ready for testing in a phase I trial.

#### The Project: Phase I mEphA4-Fc trial

This project, led by Prof Perry Bartlett at the Queensland Brain Institute, is a phase I safety trial that will examine the safety and tolerability of mEphA4-Fc in MND patients. This study is the first time that mEphA4-Fc will be tested in humans. The study is expected to begin in the middle of 2019 and be completed in late 2021. Positive outcomes from this trial will support mEphA4-Fc to be progressed through to the next phase of testing.

Lead Researcher - Prof Perry Bartlett Affiliations: Foundation Professor in Molecular Neuroscience, The Queensland Brain Institute, University of Queensland

**Expected outcome:** A successful outcome will support the testing of this therapy in a Phase 2 Clinical trial in 2021/2022.



# FUNDED RESEARCH SUMMARY (CONT.).

# **DRUG DEVELOPMENT PROJECTS**

In 2018 FightMND funded 2 pre-clinical Drug Development projects. These were selected through our Translational Research Grant (TRG) Scheme.

#### TRG 1. V-SMART® NANOMEDICINE FOR THE TREATMENT OF ALS/MND (LAUR-301)

#### Background

GDNF is a protein that supports the health of neurons and has been shown to protect dying motor neurons in MND mice. However, GDNF does not have good drug-like properties for treating MND as it cannot penetrate the brain and reach its target cell, the diseased motor neurons.

Lauren Sciences LLC, a private New York biotechnology company, has developed an innovative nanovesicle platform technology, called V-Smart®, to encapsulate and deliver non-brain penetrant molecules across the bloodbrain-barrier (BBB), target sites in the brain and selectively release molecules at these target sites. Importantly, V-Smart® nanomedicines developed with this technology can be administered noninvasively.

Lauren Sciences has shown that their V-Smart® Nanomedicine LAUR-301: encapsulates GDNF, maintains GDNF activity, targets cells, delivers and selectively releases dose-dependent amounts of GDNF in the central nervous system (CNS, i.e., brain and spinal cord) of normal mice, without toxicity.

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

The researchers will now test whether LAUR-301 can deliver GDNF in MND mice, protect dying motor neurons, reverse or slow down progression of MND disease and increase lifespan. Successful results from this project will lead directly to future development of LAUR-301 to be progressed towards a phase I clinical trials. One of the other key benefits of this project is that the V-Smart® Nanovesicle technology can be utilized to deliver other non-brain penetrating therapeutic agents into the brain and spinal cord to target the motor neurons in MND.

Lead Researcher - Prof Eliahu Heldman Affiliations: Director of Biology, Lauren Sciences LLC and Professor Emeritus, Ben-Gurion University, Israel Expected outcome: This project is expected to demonstrate true bench-to-bedside applicability within 24-36 months after completion.





#### TRG 2. INVESTIGATING THE THERAPEUTIC POTENTIAL OF GRT-X IN HUMAN AND MOUSE MODELS OF MND

#### Background

This project brings together 3 academic researchers with differing but internationally acclaimed expertise in MND and a pharmaceutical company with a unique a promising drug, GRT-X.

GRT-X is a promising therapeutic as it acts simultaneously on two neuroprotective mechanisms that can reduce the rate of motor neurone loss, which will hopefully slow the progression of the disease. GRT-X has been shown to reduce hyperexcitability, commonly seen in MND motor neurons, and reduces inflammation and inflammatory pathways.

# The Project: Pre-clinical testing of GRT-X in human and mouse models of MND

This project will test the ability of this new drug GRT-X, to slow MND disease progression in MND mice. It will also investigate how the drug is having protective effects on motor neurons and determine if GRT-X is a good drug to be advanced into the clinic.

**Lead Researcher –** Associate Professor Mark Bellingham

Affiliations: University of QLD

**Expected outcome:** This project will determine if GRT-X should be further developed for testing in MND patients.

## NATIONAL PRECISION MEDICINE PROGRAM

This is a large scale national collaborative project that aims to accurately classify/group MND patients according to their genetic, molecular and clinical profiles using innovative stem cell models and systems biology approaches to predict and tailor treatment options for each individual patient. This project involves a vital collaboration between:

- » MND patients and clinics
- » the Centre for Eye Research (CERA) led by Associate Professor Alice Pebay
- » the Australian MND Registry (AMNDR) led by Associate Professor Paul Talman
- » the Sporadic ALS Australia Systems Genomics Consortium (SALSA-SGC) led by Professor Naomi Wray, and
- » the FightMND Drug Screening Program at the Florey Institute of Neuroscience and Mental Health led by Associate Professor Brad Turner

#### The Project workflow

MND patient and control subject blood will be collected for genomic analysis by SALSA SGC. Skin cells will also be collected and reprogrammed into stem cells which are differentiated into motor neurons in the dish. MND and healthy control motor neurons will be profiled using genetic, protein and metabolism approaches to construct disease pathways and networks. Genetic, molecular and clinical data obtained from AMNDR will be integrated using systems biology and big data analysis. Disease signatures will be generated and used to subtype MND patients according to genetic, molecular and clinical profiles. Patient motor neurons will then be subject to targeted and personalised drug screening guided by disease signatures and subtypes, in an effort to advance drug candidates to clinical trials in MND patients.

**Expected outcome:** This project will lead to a better understanding of the Australian MND population and improved recruitment of patients into clinical trials: the right drug for the right patient at the right time.

This project is supported by the Australian Government through the Medical Research Future Fund.



# FUNDED RESEARCH SUMMARY (CONT.).

# **MND BIOMARKER FACILITY**

FightMND provided the funding for the purchase of cutting-edge robotics to fast-track the assessment of MND biomarkers in patient samples from both Australian and international Clinical Trials. Biomarkers help to track disease progression and aid in the development of therapies by providing a read out of whether or not the therapy is effective. Flinders University has developed a world-first urine test (biomarker) that can reliably be used to determine MND disease progression.

**Expected outcome:** This will establish a high-through screening facility to assess MND patients' response to new therapeutics.

## FIGHTMND DRUG DEVELOPMENT PIPELINE

	DISCOVERY RESEARCH	DRUG DEV	/ELOPMENT	$\rangle$	CLINICA	L TRIALS		APPROVAL
THERAPEUTIC CANDIDATE	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			$\rightarrow$					
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 & FUNDRAISING**

## **BIG FREEZE 5 JUNE 10, 2019**

The fifth edition of the famous Big Freeze at the MCG on June 10 again went to new heights in 2019 with a record number of Big Freeze beanies sold throughout the campaign.

The six-week fundraising campaign raised \$5M and we have the Australian public, the Federal Government and our campaign partners to thank for achieving this outcome.

The Australian community once again rallied behind us as they have for the past four years and supported the campaign like never before donating so incredibly generously to help the fight to beat Motor Neurone Disease.

Donations rolled in and beanies were bought throughout the campaign but as the campaign reached its crescendo, all eyes, as always, were on the Melbourne Cricket Ground on June 10 for the fifth Big Freeze at the MCG.

The Big Freeze in 2018, when all 18 AFL coaches slid into Australia's coldest pool was always going to be a hard act to follow but 12 months later, the event delivered its usual brilliant entertainment factor again.

Fourteen sliders, including past AFL champions and sporting legends, were invited by Neale Daniher to take the plunge into Australia's most famous 'ice bath'.

AFL games record-holder Brent Harvey joined members of the AFL 300-game club, Brownlow medallists and premiership players and gold medalists in netball, cycling and basketball at the top of the, and bottom, of the Big Freeze slide.

Big Freeze 5 was watched by over 700,000 people live through Channel 7

#### **2019 SLIDERS**

Nick Riewoldt Anna Meares Dane Swan **Bob Murphy** Chris Judd **Brent Harvey Bianca Chatfield** 

Sam Mitchell **Jimmy Bartel** Cyril Rioli Brendan Fevola Jobe Watson Lauren Jackson

Liam Picken







## **DANIHER'S DRIVE OCTOBER 11 - 14, 2018**

The fourth edition of Daniher's Drive, which raised an incredible \$2.6M began in Melbourne and ventured across the border to South Australia for the first time in 2018.

With the magnificent sunrise backdrop of Government House in Melbourne, the convoy of 106 cars and 366 participants set off for the annual four-day journey that visits regional townships of Australia amid some the country's most magnificent landscapes.

The 2018 event included community and lunch stops in Woodend, Davlesford, Stawell, Nhill, Apslev, Penola, Coleraine & Dunkeld throughout each day before settling in each night at Horsham, Mount Gambier (SA) and Geelong on nights one, two and three respectively.

Night two featured a Gala Auction and Comedy night with entertainment provided by two of our great comics, Tom Gleeson and Cal Wilson before a Woodstock themed fancy-dress night concluded the event on the final night.

The Australian community continue to support us in vast numbers and the Daniher's Drive presents an opportunity for FightMND to go to the regional communities of Australia and thank them for the support they provide.



## SOCKIT2MND JUNE 15 & 16, 2019

The second Sockit2MND round in 2019 yielded our most successful year yet, with a significant rise in participation and sock purchases from previous the inaugural year in 2018.



The SockIt2MND round is a fundraising round for grassroots and community sporting clubs to join the fight against MND. The round aims to generate awareness of MND throughout sporting club and association communities by wearing blue FightMND socks in the dedicated SockIt2MND round.

In 2019, the campaign raised \$223,710, a 41% increase on the year prior with 14,000 pairs sold compared with 9,500 in 2018.

A record number of 234 clubs and associations purchased socks in 2019 with 196 of those comina from Victoria including 10 clubs from the VFL competition. For the first time in 2019, we received wonderful support from the South Australian National Football League (SANFL) with four clubs wearing socks in two league matches.



# CAMPAIGNS & FUNDRAISING (CONT.).



## BUILD IT, FIGHT IT – HOME FOR FIGHTMND MARCH 2019

For the first time ever, a brand new family home was built, furnished and donated to FightMND to auction and raise funds for MND research.

The fully-furnished four-bedroom property at Clyde North in Melbourne's south-east, was built by Henley on land provided by Brown Property Group in its Meridian community with furniture provided by Guests Furniture.

The home went under the hammer at a no reserve auction on Saturday, March 1 and after some energetic bidding from a number of interested buyers, the hammer fell and the property sold for \$700,000.

FightMND also extends its gratitude to the hundreds of locals trades and suppliers that donated materials and labour to the project as well as Harcourts Narre Warren South Real Estate for marketing and selling the magnificent home.



## COLES & AUSSIE PORK FARMERS MAY & JUNE 2019

Coles and Australian pork farmers partnered with FightMND again in 2019 with a unique national fresh pork sales campaign that delivered an outstanding fundraising outcome in the fight against MND.

Coles donated 10 cents from the sale of all fresh pork products sold in over 800 supermarkets nationally to help fund more vital research into the disease.

The campaign, in just its second year, raised an amazing \$520,000 and following the success of the first campaign in 2018 that raised in excess of \$330,000, the support from Coles and the farmers has returned a total of over \$850,000.

As a result of the incredibly successful campaign, Coles are the largest corporate donor to FightMND.

We thank Coles and our Australian pork farmers for this generous contribution.



## COMMUNITY FUNDRAISING

#### COMMUNITY BIG FREEZE EVENTS

At FightMND, we are extremely proud of what the Big Freeze at the MCG has grown from since its inception in 2014 and replicating the incredibly fun and engaging concept has become more and more popular among thirdparty fundraisers over the past 12 months.

In 2018/19, our most successful community fundraising events, the majority of which were held within sporting clubs, TAFE, school, university and hospital communities, were DIY Big Freeze related fundraising events.

A number of these clubs hosted their second or third Big Freeze events during this year, illustrating the popularity of the concept. FightMND is both enthused and excited that the Big Freeze campaign is expanding into the wider Australian community and in particular in small rural towns such as Yeppoon in Queensland and Boxwood Hill in Western Australia, shows the strength of this particular campaign and of the appetite for the Australian community, no matter where, to support our cause and trying to 'freeze MND', driven by their want for their funds to go towards further research.

Highest community Big Freeze fundraisers in 2018/19:

- » Newcastle Big Freeze (NSW) \$218,000
- » Echuca Moama Big Freeze (Vic) \$85,000
   » Yeppoon Big Freeze (QLD) \$65,000
- Boxwood Hill Big Freeze (WA) \$78,000
   South West (Cobden) Big Freeze (Vic) -
- South West (Cobden) Big Freeze (Vic) -\$34,000

#### **FUN RUN EVENTS**

FightMND's participation in several fun run events also proved extremely successful fundraising activities.

In 2018, FightMND entered Run Melbourne in July and Sydney's iconic City2Surf in August 2018, successfully gathering a group of fit and fun fundraisers under the banner of TeamFightMND.

TeamFightMND has raised more than any other charity in Run Melbourne history which is something we are both proud of and appreciative of. Our inspiring team of runners has grown in size each year with over 300 runners now representing us in the early hours of a Sunday morning through the streets of Melbourne. A free FightMND Runners Pack was sent to participants that raised over \$1000.

Over 400 runners, walkers and rollers competed in these two events in 2018, raising an extraordinary \$487,000 indicating the active peer-to-peer sporting events we participate in continue to go from strength to strength.

Thank you to everyone who took part and fundraised for FightMND at these events in Sydney and Melbourne.

FightMND understands that planning for and staging major fundraising events requires a lot of people to invest a great deal of time and for that we appreciate the efforts our supporters make.

To the many thousands of members of the FightMND Army that fundraise, large or small, to contribute to the fight against MND, the Foundation sends its heartfelt gratitude.



# FINANCIAL REPORT.

IN 2019, FIGHTMND INCOME GREW AT 25% FOR THE YEAR, TO A TOTAL OF \$17.0 MILLION, REFLECTING THE INCREDIBLE SUPPORT RECEIVED FROM OUR SPONSORS, DONORS AND VOLUNTEERS. IN TURN, AN EVEN LARGER SUM OF \$17.4 MILLION WAS INVESTED INTO CURE MEDICAL RESEARCH AND CLINICAL TRIALS TO PURSUE A TREATMENT AND A CURE FOR MOTOR NEURON DISEASE ALONG WITH PROVIDING EQUIPMENT AND AIDS IN CARE FOR THOSE WHO SUFFER FROM MND.

As at 30 June 2019, FightMND had cash reserves of \$26.5 million up from \$17.8 million as at 30 June 2018.

The 2020 Budget was approved by the Board and reflects ambitions of yet further growth in our major fundraising campaigns. For the year ending 30 June 2020 we expect growth in net fundraising income to be no less than 15%.

I thank my colleagues for their dedicated commitment and support in overseeing appropriate financial management and governance of the foundation. I also thank our sponsors, donors and volunteers who have helped us achieve a strong financial outcome for 2019.

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

<sup>†</sup>Revenue from Donations, Gifts & Grants and Fundraising Events, less Fundraising Events Expense and Administrative Expense

## WHERE OUR MONEY COMES FROM



## WHERE OUR MONEY GOES



## **FINANCIAL TABLES**

#### **INCOME STATEMENT**

# REVENUE Donations, Gifts & Grants Fundraising Events Other Revenue Other Revenue Total Revenue EXPENSES Investment Medical Research Clinical Trials Care Equipment Expense Fundraising Events Administrative

#### **OPERATING SURPLUS / (LOSS)**

#### **BALANCE SHEET**

#### ASSETS

Current Assets

Non-Current Assets

**Total Assets** 

LIABILITIES Current Liabilities

Non-Current Liabilities

Total Liabilities

NET ASSETS

MEMBER'S FUNDS

	2010
11,116,749	9,567,499
5,072,367	3,513,968
765,950	446,675
16,955,066	13,528,142
8,208,106	13,000,433
6,758,522	5,279,093
2,467,083	1,365,864
2,178,107	1,131,485
433,611	882,927
20,045,428	21,659,802
(2 000 262)	(8,131,660)
(3,090,363)	(0, 131, 000)
(3,090,363)	(0,131,000)
(3,090,383) 2019	2018
2019	2018
<b>2019</b> 28,190,035	<b>2018</b> 20,398,013
<b>2019</b> 28,190,035 5,214	<b>2018</b> 20,398,013 5,560
<b>2019</b> 28,190,035 5,214	<b>2018</b> 20,398,013 5,560
2019 28,190,035 5,214 28,195,249	2018 20,398,013 5,560 20,403,572
<b>2019</b> 28,190,035 5,214 <b>28,195,249</b> 12,364,862	20,398,013 5,560 20,403,572 6,302,127
<b>2019</b> 28,190,035 5,214 <b>28,195,249</b> 12,364,862 8,798,526	2018 20,398,013 5,560 20,403,572 6,302,127 3,979,222

2019

2018



# **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 5 AND THE 2018 DANIHER'S DRIVE.





# **MAJOR PARTNERS**



# **EVENT SUPPORTERS**

**AQUATECHNIC POOLS BELLS ICE** HARRY THE HIRER **INFUSION 121 KING'S FIBREGLASS** 

MACHSHIP **MSC SIGNS NET NINJAS TOKEN ARTISTS** 

## **SUPPORTING** PARTNERS



# OUR **DONORS**

WE WISH TO ACKNOWLEDGE AND OFFER OUR SINCERE THANKS TO THE FOLLOWING DONORS WHO ALL CONTRIBUTED \$30,000 OR MORE TO FIGHTMND DURING THE YEAR.

**JOHN & BETTY LAIDLAW ESTATE OF JENNIFER DAWN** KERR **DOUG BARLOW** LITTLE FOUNDATION TOM BARR SMITH



IXOM THE VFL CLUB FOUNDATION **EVANS FAMILY FOUNDATION THE ALBURY SS&A CLUB** 

