



MEDIA RELEASE

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FIGHTMND COMMITS \$9 MILLION TO 15 NEW MND RESEARCH PROJECTS

FightMND has today announced a major funding commitment to advance research into Motor Neurone Disease as the fight to find effective treatments and a cure for the disease continues.

This announcement represents FightMND's ongoing commitment to MND research with \$9 million being injected into world-leading research across 15 separate research projects, led by Australia's best and brightest researchers, with all projects commencing within the next six months.

This investment takes the total amount of funds invested by FightMND to \$37.6 million since 2014.

As a result of the extraordinary success of this year's Big Freeze 5 campaign, combined with the incredible support of the Australian public's community fundraising efforts, FightMND can make this significant commitment to additional research projects.

Among the new projects funded are three clinical drug trials, one drug development project, seven projects aimed at improving and accelerating the process of bringing new treatments to clinical trial, and early and mid-career Research Fellowships. This funding also provides on-going support for the Sporadic ALS Australian – Systems Genomics Consortium (SALSA-SGC), a national program that collects and analyses samples from MND patients at eight clinics across Australia.

In making the announcement, FightMND CEO Jamie Howden thanked the Australian public for its unwavering support and fundraising efforts which makes this level and scope of investment into vital research possible.

"FightMND is extremely fortunate to have our FightMND Army behind us every step of the way and we are continually humbled by how strongly our loyal and committed supporters respond when we ask them to donate to the fight, and we couldn't do it without them.

"This announcement is another major and progressive step in our quest to discover more effective treatments and a cure for Motor Neurone Disease and we are looking forward to seeing these projects commence and closely monitor their progress", Howden said.

"MND medical researchers and clinicians, both in Australia and abroad, are firmly committed to discovering positive outcomes for the treatment of MND. FightMND is pleased to be able to play a key role in funding this vital research work and is possible thanks to the generosity of all our donors, corporate partners, fundraisers and supporters. We also acknowledge and thank the Federal Morrison Government, Federal Health Minister, Hon. Greg Hunt and Victorian Premier, Hon. Daniel Andrews and his Government for their incredible support.

"We are now making an impact on fighting the disease and are seeing some early and potentially positive signs from clinical trials and drug development projects already underway. There is more momentum in global MND research than ever before, but the fight does continue in earnest with these exciting upcoming projects," Howden said.

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Background notes on each of the 15 projects below;

3 x Clinical Trials

Project: Phase 3 Clinical Trial – The Lighthouse trial 2 (Triumeq)

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

In this study researchers will investigate whether an ancient virus (HERV-K), hidden in the genome, may be responsible for MND, becoming activated and leading to the death of motor neurons. The study will investigate the safety and efficacy of the HIV medication, *Triumeq*, on blocking HERV-K in a large number of MND/ALS patients. The trial will be a large multi-national trial conducted on 363 patients in 17 centres across Australia, Europe and UK. It aims to enrol 75 Australian patients across 6 sites.

Project: Phase 2 Clinical Trial - Nanocrystalline gold (CNM-Au8)

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

This study will test the safety and efficacy of a novel drug, *Nanocrystalline-Gold (CNM-Au8)* in 42 MND patients at two clinical sites in Sydney, Westmead Hospital and the Brain and Mind Centre. CNM-Au8 acts by reducing a number of the cell's stress and toxic responses that occur in MND. A promising trial would lead to a larger Phase 3 trial in the next 2-3 years.

Project: Phase 1 Clinical Trial – Re-purposed medication Trimetazidine

Principal Investigators: Dr Shyuan Ngo (University of QLD)

About half of all patients with MND experience an increase in their energy consumption (termed hypermetabolic), which accelerates the spreading of ALS throughout the body and is linked to an increased risk of death and faster rate of progression in people with MND. The study will test the ability of the heart medication, *Trimetazidine*, to normalise metabolism in MND and determine if it can be safely administered to MND patients. This study will be conducted across 3 sites in the Netherlands, UK and one site in Australia at the Royal Brisbane and Women's Hospital. Positive outcomes from this study would lead to a Phase 2 study where the effect of Trimetazidine on the slowing disease progression would be investigated.

1x Drug Development Project

Project: Rescuing motor neurons using a novel drug that blocks HDAC6

Principal Investigators: A/Prof Anna King (University of Tasmania)

Motor neurons are nerve cells that create signals to communicate with and regulate the activity of muscles. The enzyme HDAC6 is involved in maintaining the structure of motor neurons, but in MND HDAC6 becomes damaging to motor neurons leading to their death and failure to communicate with muscles. This study will test if blocking HDAC6 with a drug, will protect motor neurons and rescue communication between motor neurons and muscles in 3 pre-clinical MND models.

7 x IMPACT Grants (IMProving and ACcelerating Translation of drugs to clinics)

Project: Assessing changes in breathing and muscle strength in MND – MND Biomarkers

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

This project will develop and validate a new way to diagnose MND by detecting abnormal breathing and weakening breathing muscles.

Project: Treating overactive immune defence systems in the brain – MND Disease Models

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

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.

Project: Enhancing drug delivery in MND – Drug delivery

(Project lead: A/Prof Joseph Nicolazzo, Monash University) - Victoria

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.

Project: Disease susceptibility, precision medicine and MND – Diversity of MND

(Project lead: Prof Julie Atkin, Macquarie University) - NSW

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.

Project: New biomarkers for MND – MND Biomarkers

(Project lead: Dr Fleur Garton, University of Queensland) - Queensland

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.

Project: Pre-clinical steps towards a stem cell trial for MND – Regenerative medicine

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

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.

Project: Establishing a new model of MND – MND Disease Models

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

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 cure MND.

Mid-career Research Fellowships

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.

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 Fellowships

Dr Rebecca San Gil (University of Queensland) - Queensland

This fellowship will support an up-and-coming MND researcher 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: Prof Naomi Wray (University of QLD)

In 2015, Prof 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 3 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.
- 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 provides continued support of this Program for the next 3 years. By investing in SALSA-SGC, FightMND will support researchers in the SALSA-SGC project and research nurses at 8 MND clinics across Australia, giving MND patients at each of these sites the opportunity to be involved in important research to advance treatment of MND.

About FightMND

FightMND is a not-for-profit registered charity, founded in 2014. It was established to raise the awareness of Motor Neurone Disease in Australia, to increase funding for research to find an effective treatment and cure and to provide care equipment for MND patients. We have a clear objective – to have a world free from MND.

FightMND is Australia's largest independent MND foundation focused on funding large-scale, collaborative research and clinical trials. The generous donations contributed by everyday Australians, right across the country, has enabled FightMND to raise and commit millions to cure and care initiatives.

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OUR IMPACT

A snapshot of how the money has been invested to fight MND since 2014:

