

The MND Collective

A collective approach to research to enable better outcomes for people living with MND

EXECUTIVE SUMMARY

Solving a complex problem is an enormous and almost impossible task for an individual or individual organisation to achieve. What better example of a complex problem is there than Motor neurone disease (MND), a rapidly progressive neurodegenerative disease with no known cause, no effective treatments, and no cure. Considered a rare disease, MND has not received the attention and funding needed to enable researchers, and healthcare practitioners to advance their understanding of the disease, develop and provide access to promising treatments, and ensure delivery of equitable best practice standard of care. Since 2014, commencing with the success of the ice-bucket challenge in both raising the profile and funding of MND both here and worldwide, there has been an incredible influx in research investment and a burst of momentum and optimism. This presents a unique opportunity to bring together key stakeholders across the MND landscape, with the voices of people with MND at the centre, to work together in effective and impactful ways. Through shared goals and objectives, we propose an opportunity to drive meaningful change in the sector through the establishment of an MND Collective.

KEY CONTACTS

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BACKGROUND

The Impact of MND in Australia

Motor neurone disease (MND), also termed Amyotrophic Lateral Sclerosis (ALS), is an insidiously progressive neurodegenerative disease resulting in progressive weakness, swallowing and speech disturbance, respiratory failure, and death. Memory and thinking can be affected in over 50% of sufferers, while in many, the mind and intellect remain intact while sufferers are left motionless, mute, and trapped within their once active bodies.

Two Australians die every day from MND and two more are diagnosed, with around 2000 people living with the illness, with an average life expectancy of only 27 months from diagnosis in Australia.

The economic impact of MND is significant, with costs of \$2.4 billion estimated in 2015 (Deloitte Access Economics)¹. The lifetime risk of developing MND is 1 in 300 and global forecasts predict a 69% increase in the number of people diagnosed in the next 25 years (Arthur et al., 2016)².

Despite the first description of MND over 150 years ago, it remains a terminal diagnosis with no effective treatments or cure. The only drug approved to treat MND in Australia was approved over twenty years ago, and offers only modest benefits. While research to find an effective drug or treatment has had limited success, improvements and developments in best

practice standard of care have been able to improve the quality of life of people living with the disease and extend survival, giving people with MND more time with families and loved one. Thus, there exists an urgent need for effective therapies to treat this devastating disease and equivocal access to best practice standard of care for all who are diagnosed.

MND is an incredibly complex disease and presents an enormous challenge for the MND research community. The causes the disease or what controls the progression remains unknown. Together with the lack of effective treatments, it is a problem that cannot be solved in isolation, but rather will take a collective approach of the brightest minds across the research and health care landscape working together with people with MND to bring an end to the disease.

Research momentum in Australia

The resources and support for MND research have expanded considerably over the last few years both in Australia and internationally. Here in Australia, the entrance of FightMND into the MND Research scene, in addition to the established presence of MND Research Australia (MNDRA), MND and Me and Racing for MNDi (see appendix 1 for the Australian MND organisation landscape), has resulted in a momentum in the MND research space that has never been seen before, supported by well over \$100 million of research funding. These significant increases in investment have already begun to enable the building of research resources, infrastructure and enhanced research capacity, particularly in the clinical research space.

While this has provided an opportunity, it is paired with a strong responsibility and obligation to people living with MND, to ensure funding is used effectively. To deliver meaningful and sustainable impact, FightMND and MNDRA are working to mobilise a first of its kind collaborative approach that;

- enables critical stakeholders to identify priorities and create valuable shared resources;
- puts people living with MND at the centre of decisions;
- engages the whole system to produce better outcomes for those living with MND.

The effective development of a collective approach to tackle MND requires input from key stakeholders across the MND landscape with a central voice of people with lived experience (PLEx) of MND. To develop and subsequently put into action a collective approach to tackle MND, FightMND and MNDRA co-hosted the first ever Australian National MND Research Summit.

AUSTRALIAN NATIONAL MND RESEARCH SUMMIT (“THE SUMMIT”)

The Summit

In November 2020, MNDRA and FightMND engaged with PwC’s The Impact Assembly, to host the Summit, a 2-day virtual event that brought close to 60 key stakeholders from across the MND sector together to address the question of how to enable better outcomes for people living with MND through research.

The objectives of the Summit were to:

- Connect hearts and minds around a collective purpose, vision and outcomes
- Understand what success means for people with MND, their families, carers and loved ones
- Explore adaptive and collaborative approaches to research, how these are working in clinical trials, genetics and care and how these can be applied in similar approaches
- Understand how to incubate collectives and develop a high-level model for MND including;
 - Working together with people with lived experience;
 - High-level governance model;
 - Eco-system engagement.
- Build a draft 12-month road map, clarify the next steps and ensure momentum is maintained

Discussions at the Summit were focused on looking beyond the specific research priorities of individuals, thinking differently and challenging ways of past-thinking, and keeping people with MND at the forefront of decision making. A key objective of the Summit was to form the foundation of a broader strategy and approach to mobilise the Collective.

Key Stakeholders and Outcomes

The Summit was attended by 60 key stakeholders within the MND sector including:

- People living with MND
- Genetic carriers
- Carers
- Researchers
- FightMND
- MND Research Australia (MNDRA)
- MND Australia
- Federal and State Associations:
 - MND Association (MNDA)
 - MND State Associations
- MND and Me Foundation
- Neurologists
- Allied health practitioners
- Industry representatives
- Federal Government representative
- Other disease association/foundation representatives

Outcomes from the Summit included strong support for the development of an MND Collective. Together, participants drafted the mission, values and direction of a collective approach to research. Such an approach has created the foundations of a framework for working together to beat MND which will maximise the impact of funding investment and keep the voices of people with MND at the forefront of decisions.

WHAT IS A COLLECTIVE?

A collective is formed when a group of stakeholders come together to form a centralized structure that share a common goal and focus, and shared outcomes and measurement of these outcomes. A key component of the success of a collective is continuous communication to discuss outcomes and next steps and to reinforce the common objectives and goals of the collective. The goal of a collective is to think more holistically, to drive collaboration and to reduce duplication of efforts or activities happening in silos.

The Stanford Social Innovation Review ([Kania & Kramer, 2011](#)) describes the five conditions for collective success as a common agenda, shared measurement systems, mutually reinforced activities, continuous communication and backbone support organisations. The collective itself is not a new organisation, but rather a commitment and framework to allow the key stakeholders and established organisations and initiatives to each play their role and contribute in effective and impactful ways towards the common goal/s and drive meaningful change in the sector.

Key points

- A collective is not a new entity or organisation, but rather the coming together of existing groups, organisations and stakeholders under a shared focus and vision, and a common agenda.
- From this shared goal and focus, a collective creates a joint approach to solving a complex problem.
- A collective is not a fundraising initiative. Rather it is a framework to drive collaboration and collective impact in research.
- Each stakeholder makes a commitment to contribute to the overarching plan of the collective, by playing their specific role and contributing based upon their capabilities and areas of expertise.
- Each individual organisation will be treated fairly and have a voice.
- Decisions within the collective will be made based on objective evidence and best possible solutions to the problem, not to favour the priorities of any one organisation over another.
- Through commitment to regular communication, meetings and sharing of information, stakeholders within the collective will hold each other accountable, measure impact and outcomes, solve complex problems and implement solutions.

THE MND COLLECTIVE

The “MND Collective” is a concept co-designed with 60 experts from lived experience, medicine, and research. During the co-design process a purpose, vision and values were developed from which the collective framework and objectives were developed.

OUR PURPOSE

To sustain hope through collaborative research and improve the lives of people living with MND

OUR VISION

Through research, collectively accelerate our understanding of MND and fast track the discovery, delivery of effective treatments and improve care for people living with MND across Australia

OUR VALUES

Voice - People with MND are at the heart of what we do

Collaboration - We work together to innovate and amplify impact

Impact – We empower collective members to challenge the system to accelerate meaningful change

Urgency - Save time, save neurons, save lives - tomorrow is not soon enough

Equity - Equitable access to the continuum of care and research

- The Collective will bring together everyone in the MND community with an interest in how research can improve the lives of people living with MND. This will include those with lived experience, care providers, researchers, medical and allied health practitioners, funding bodies, government and industry.
- The MND Collective was developed to tackle the question; how can we create better outcomes for patients through research?
- The purpose of the collective is to maximise our impact through collaborative research and improve the lives of people living with MND.
- Our vision is to collectively accelerate our understanding of MND and fast track the discovery, delivery of effective treatments for people living with MND across Australia.
- Within the MND Research Collective, people with lived experience of MND are at the core of everything that we do.
- The collective will be led by a governance model that includes a governance team (Board) and driving teams.

Importantly, the collective is a collaborative initiative of the two major funders of MND research in Australia, MNDRA and FightMND, both of which encourage involvement of all MND researchers across Australia.

MND Collective Roadmap

To begin to shape the direction and work towards the objectives of the Collective an initial governance structure and focused leadership and driving teams need to be established as well as the recruitment of a lived experience (PLEx) panel to participate in all early discussions and decisions.

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The table below details aims of the Collective for the first 6 months of the project and current progress of aims (as at October 2021).

Aims		Status
1. Establish	1.1 A Board with diverse representation	Model drafted
	1.2 PLEx advisory panel to provide vital input on early decisions	Model drafted
	1.3 Driving Teams to ensure the momentum from the Summit is not lost	In progress
2. Develop	2.1 A Collective prospectus/narrative and governance model	Draft completed
	2.2 A Stakeholder map	Completed
	2.3 A Resource Map including basic/clinical/care research resources	In progress
3. Deliver	3.1 Support for and recruitment of a Project Manager	Under discussion
	3.2 Development of the framework for a national clinical trial network.	Not yet developed

APPENDIX 1

AUSTRALIA'S MND LANDSCAPE

1. MND AUSTRALIA AND STATE ASSOCIATIONS

MND Associations in Australia were formed during the early 1980's to meet the varying and complex support, equipment and information needs of people living with MND and their families. MND Australia was established in 1991 to represent the State and Territory MND Associations nationally.

MND Australia, its research arm, MND Research Australia, and members, the State MND Associations, form a national network focused on improving the lives of all Australians living with motor neurone disease (MND) and advancing research to end MND. For over 35 years this national network has helped increase understanding of the disease and advocated for improvements in its treatment and care to ensure people living with MND have the best quality-of-life possible.

One of the major roles of MND Australia is to promote and support best practice and evidence based care and support for people living with MND and their families throughout Australia. MND Australia is the national voice for people living with MND.

2. MND RESEARCH AUSTRALIA (MNDRA)

MNDRA is a national organisation, established in 1984 to promote medical and scientific research into MND and sits under the umbrella of MND Australia. MNDRA supports high-quality MND research to discover the causes, improve care and find treatments and ultimately a cure for MND.

Objectives;

- Promote research excellence by supporting only the best research that has the greatest chance of finding effective treatments and improving the care of people living with MND;
- Attract and develop outstanding researchers by supporting researchers at all stages of their careers;
- Partner for impact, drive collaboration and innovation along the research pipeline and the healthcare system;
- Advance research evidence to inform healthcare policy and practice improvement.

Achievements;

- Funded > \$40M in MND research across the research spectrum;
- Our fellowship programs running for over 20 years have supported early-career researchers to develop into senior leadership roles;
- Provided the funding to establish the Sporadic ALS Australian Systems Genomics Consortium (SALSA-SGC) that has now become an integral part of MiNDAUS;
- Funded a number of proof-of-concept and pilot studies that have gone forward to clinical trial and clinical practice including;
 - Supported the development of the Stentrode, a world-first minimally invasive brain-computer interface that wirelessly transmits brain signals, that is currently being trialled in Melbourne;
 - Identified significant mental health needs and service usage of people with MND leading to the production of Fact Sheets for people with MND; their families, friends, and carers; and for health professionals;

- Developing decision-making tools to help people with MND make decisions about care – these tools have now been adapted for use internationally;
- Discovering that PMX205 slows MND progression in rodent models of MND – this drug has now gone into clinical trial;
- Discovering copper-ATSM diminishes the severity of MND symptoms and extends survival of MND model mice, which led to Phase I and II copper-ATSM clinical trials;

3. FIGHTMND

Formed in 2014, FightMND's vision is a world without MND. FightMND is the largest independent funder of MND research, new drug development, and clinical trials in Australia. Since forming in 2014, FightMND has committed over \$55.9 million into funding the best and brightest researchers in Australia and abroad in the pursuit of new treatments and ultimately a cure to this devastating disease.

Our investments to date include;

- 12 Australian Clinical Trials giving MND patients across Australia access to try potential new treatments
- 22 Drug Development projects aimed at developing new treatments for MND
- 25 IMPACT grants
- FightMND High-throughput Drug Screening Program to help fast-track research discoveries through to clinical trial
- Precision Medicine Program to improve the targeting of treatments for patients
- Support for the Sporadic ALS Australian Systems Genomics Consortium (SALSA-SGC) at 8 sites across Australia
- 5 FightMND Career Fellowships/Scholarships to support future leaders of MND research in Australia
- 19 other research initiatives including:
 - financial support for the Australian MND Registry (AMNDR)
 - on-going financial support for the Victorian Brain Bank
 - FightMND Research Symposium
 - Australian National MND Research Summit

In addition to our research investments, FightMND is committed to ensuring that Australian's diagnosed with the disease are enabled to live as independently as possible for as long as possible. To support this vision, over the last 4 years we have been the single largest funder of vital new assistive equipment for people living with the disease across the country. We have committed over \$7.3 million for new equipment, directly improving the quality of life for Australian MND patients.

4. MND AND ME FOUNDATION (QLD)

The MND and Me Foundation was established by Scott Sullivan, a husband and father of two children who was diagnosed with Motor Neurone Disease (MND) in 2010 at the age of 38, and sadly passes away in April 2014.

The Foundation's mission is To Care and To Cure: The Foundation funds MND research and treatment initiatives to improve the lives of people diagnosed with MND but until a cure is found, the Foundation provides the right solutions at the right time throughout the cycle of pre-diagnosis, diagnosis, living with MND and following a loved ones' passing.

MND and Me Foundation is a significant financial contributor towards research into finding a cure for MND. Scott saw the importance of collaboration and communication in research and he understood the importance of research into both the underlying cause of MND and the need for clinical trials. He also recognised the importance of new ideas and youthful enthusiasm.

By the end of 2021, the MND and Me Foundation will have provided \$2.2 million in MND Research funding across a number of projects.

In 2015 the Scott Sullivan Research Fellowship was established with the initial Fellowship awarded to Dr Shyuan Ngo at UQ. The three-year Fellowship is aimed at a Queensland based, mid-career researcher with a focus on clinical research and the next Fellowship will commence in January 2022.

The MND and Me Foundation has been growing their research grant funding over the past five years. Since 2018, the Foundation has funded three named grants through MNDRA. The Col Bambrick, NTI and Fat Rabbit Research Grants are all funded through philanthropic donations and supporter fundraising. For 2022 the Scott Sullivan Research fellowship will be jointly administered by MND and Me and MNDRA.

Individual Queensland based projects are also funded on a needs basis.

- Home improvement and Care grants – improving quality of life
- Carer services – facilitating mental health and wellbeing for adults and children

5. RACING FOR MNDI

Racing for MNDi was established with a specific focus on familial MND. Racing for MNDi's vision is for a world without MND, sooner. To achieve this, they believe in funding interdisciplinary partnerships, collaborations, and to fast-track the research pathways most likely to translate to clinical benefits for people with MND.

Currently, the MNDi Foundation funds the Murdoch MND Research Partnership headed by Professors Sue Fletcher and Merrilee Needham. The partnership is a multi-institutional collaboration that brings together research and clinical expertise to accelerate the development of genetic drugs that directly target pathways involved in MND pathology and motor neuron disruption. The teams that are currently funded are exclusively focussed on understanding mechanisms in MND and developing RNA therapeutics for inherited and acquired MND. This means therapies are developed specifically to target pathways that are disrupted in motor neurons and supporting cells.

6. MiNDAUS PARTNERSHIP

The MiNDAUS Partnership was formed in 2018 and is funded through a partnership grant from National Health and Medical Research Council of Australia (NHMRC) and support either in cash or in kind from MND Research Australia, Australian MND Registries, MND Association of WA, The Thomas MND Research Fund, MND Australia, and MND &Me. Fight MND is also a partner. Total funding support is \$2.2M.

The Partners are leading research scientists, clinicians, front line service providers, people with lived experience of MND, and philanthropy.

The Project entitled **“Motor Neurone Disease: Patient centred care for a progressive neurological disease – evidence driven policy”** has three core themes:

- **Empowering patients and their carers** through the development of patient and carer registries. The **Patient Registry**, as well as recording personal details and preferences, allows the patient and carer to monitor the progression of the condition in an objective and qualitative way and to report this to their MND service coordinator and clinic, thus allowing timely and relevant support in an efficient manner. Such self-management has been shown to be a critical component of patient and carer wellbeing. The **Clinical Registry** provides a record more medically related data, including genetic data arising from patients, who give consent, to broader, more research related, involvement.
- **Integration of Data Collection in MND** involved the bringing together data from the Australian MND Registry and the sporadic ALS Systems Genomics Consortium into a single platform which can be readily accessed by scientists and others under strict governance provisions. The patient and carer registry data are part of this very rich collection of information to inform research, the provision of better care, and policy.
- **Integrating Evidence to Inform Policy.** There are many policy improvements needed to effectively respond to the unique needs of those living with MND. This must be facts based and requires reliable data and its transformation into areas where change is most needed, the development of policy and implementation, with its translation into practice.

Progress to date:

- The Patient Registry has been developed and is currently being rolled out in several clinics with the engagement of MND associations and patients themselves. Patient and carer feedback is very positive. The Carer Registry is in the early stages of development.
- The Data Bases have been combined and the necessary governance provisions established to protect patient confidentiality, and integrity of data use. Requests are now being received from research scientists for access to this valuable source of factual patient information.
- Areas of critical policy need have been identified along with the necessary data, in order to enable changes which support improved service delivery (such as skill development of those working in MND, and telehealth), and for continued research.
- A pool of people living with MND (PLeX), along with the necessary supports, is being established to ensure grass roots input into future research and service delivery.
- The future of the MiNDAUS Partnership at the end of the current project is being explored including diverse funding sources, and a closer working relationship with MND/MNDRA.
- The MiNDAUS Partnership is already recognised nationally and overseas for its achievements in a patient centred approach. It is seen to provide a roadmap – see Vucic S et al. MiNDAUS partnership: a roadmap for the cure and management of motor neurone disease. *Amyotroph Lateral Scler Frontotemporal Degener.* 2021 Sep 30;1-8. doi: 10.1080/21678421.2021.1980889.
- The outcomes of MiNDAUS have and will continue to be publicised as part of a “marketing” approach to MND research, service providers, the MND community, government, and the general community.

APPENDIX 2
Governance model

The MND Collective

