



### ***FightMND to invest \$20.2 million in MND research and care in 2023***

FightMND will announce that this year, we will invest a further \$20.2 million into Motor Neurone Disease (MND) research and care initiatives for people with MND.

In 2023, FightMND will commit a further \$16.5M into MND Research, including support of 23 projects and 6 career development awards:

- 1 Clinical Trial
- 7 Drug Development Projects;
- 4 Discovery Projects;
- 7 IMProving and Accelerating Translation (IMPACT) Projects;
- 1 Clinical Investigator award
- 2 Mid-Career Research Fellowships;
- 2 Early Career Research Fellowship; and
- 1 Angie Cunningham PhD Scholarship and Grant-in-Aid;

Additional funds invested in 2023 include:

- 2 Daniel McLoone Major Research Initiatives – co-funded with MND Australia
- Other research initiatives (Victorian Brain Bank, Massey Park grant, COVID-19 Impact support funding)

In addition, FightMND will also commit a further \$3.67 million into 22 MND Care Support projects for Australians living with and affected by MND. This funding will support projects that:

- Provide equipment, technology and at home needs;
- Support the development and delivery of MND education initiatives; and
- Support the establishment and growth of support groups in the MND community

## CURE RESEARCH PROJECTS

### 1x Clinical Trial

**Project:** Phase 2/3 Clinical Trial – A randomized, phase II/III trial on the biological and clinical effects of acetyl-L-carnitine in MND

**Principal Investigator:** Prof Steve Vucic (The University of Sydney, NSW)

**Amount funded:** \$1,799,816

**Summary:** This phase 2/3 clinical trial conducted in Australia and Italy tests a re-purposed drug called ALCAR in 250 MND patients. ALCAR showed early promise by slowing MND progression and prolonging survival in smaller studies, and this new trial will provide definitive data on ALCAR's potential to advance as an MND therapy.

## 7X DRUG DEVELOPMENT PROJECTS

**Project:** Discovery of STING inhibitors for the treatment of Motor Neuron Disease

**Project lead:** Prof Peter Crack (The University of Melbourne, VIC)

**Amount funded:** \$549,515

**Short summary:** Prof Peter Crack will lead a team to screen a library of drugs to find the most promising candidates to treat inflammation in MND, a major driver of disease progression. Prof Crack is a first-time recipient of FightMND funding.

**Project:** Selective blockade of microglial Kv1.3 with HsTX1[R14A] as a novel approach for the treatment of Motor Neurone Disease

**Project lead:** A/Prof Joseph Nicolazzo (Monash University, VIC)

**Amount funded:** \$549,638

**Short summary:** Increased inflammation in the brain is thought to contribute to the death of motor neurons in MND. This project tests if a new drug can block a key inflammatory pathway to reduce inflammation and prevent loss of motor neurons in MND.

**Project:** A blood-brain barrier permeable DHODH inhibitor for treating MND

**Project lead:** A/Prof Peter Crouch (The University of Melbourne, VIC)

**Amount funded:** \$475,085

**Short summary:** A/Prof Crouch and team will test if a new treatment developed for brain cancer can also slow disease progression in preclinical models of MND. Because this drug can reach and act on brain areas affected in MND, positive outcomes from this study may fast-track its advance to a clinical trial for MND.

**Project:** Novel axonal regenerative therapy using antisense oligonucleotides for sporadic and familial MND

**Project lead:** Dr Dunhui (Oliver) Li (Murdoch University, WA)

**Amount funded:** \$549,537

**Short summary:** This project tests a new strategy to repair and protect dying neurons and wasting muscles in MND using a gene therapy approach, hoping to improve function and survival outcomes in patients.

**Project:** Development of next-generation blood-brain barrier penetrating SOD1-targeting antisense therapy

**Project lead:** Dr Fazel Shabanpoor (The Florey/The University of Melbourne, VIC)

**Amount funded:** \$547,406

**Short summary:** Dr Shabanpoor's team is designing an advanced way to deliver gene therapies for treating MND. They aim to improve on the amount of gene therapy that can reach motor neurons and reduce the invasiveness of current methods. The team will test how effectively their new gene design reduces a form of a protein called SOD1, that is harmful to motor neurons.

**Project:** Validation of NC-B8 anti-CD38 antibody safety and efficacy using human MND samples

**Project lead:** Dr Damien Toulorge (ENCEFA, France)

**Amount funded:** \$505,583

**Short summary:** This project will gather evidence in preclinical models of MND to support the advance of a drug called NC-B8 to a clinical trial for MND. NC-B8 has a number of mechanisms of action to tackle MND in multiple areas.

**Project:** Translating a novel gene therapy for MND towards clinical testing

**Project lead:** Prof Lars Ittner (Macquarie University, NSW)

**Amount funded:** \$1,200,000

**Short summary:** This project will test the safety and effectiveness of a new gene therapy targeting TDP-43, a key protein in MND that accumulates in motor neurons and makes them unhealthy. Successful outcomes will bring the gene therapy closer to a clinical trial for MND. Prof Ittner is a first-time recipient of FightMND funding.

## **4X DISCOVERY PROJECTS**

*Discovery projects aim to resolve one or more current unknowns in the MND research sector, focused on discovering why MND occurs and what contributes to its progression. Outcomes should significantly advance our understanding of MND, and substantially increase the likelihood of accelerating the development of more effective treatments or cure for MND.*

### **Investigating neuronal support cells and their dysfunction in MND**

**Project:** Oligodendrocytes and TDP-43 pathology in MND

**Project lead:** Dr Adam Walker (The University of Queensland, QLD)

**Amount funded:** \$1,000,000

**Short summary:** Dr Adam Walker received the 2022 Bill Guest Mid-Career Fellowship. This project is part of his broader research program to understand the role of the MND-linked protein, called TDP-43, in MND.

### **Understanding the earliest signs of MND development**

**Project:** ACORN (Australian C9orf72 National Study)

**Project lead:** Dr Thanuja Dharmadasa (The Florey/The University of Melbourne, VIC) - *This is one of 3 funded projects for Thanuja this round*

**Amount funded:** \$999,294

**Short summary:** Dr Dhamadasa is a first-time recipient of FightMND funding. This project will harness collaborations between clinical researchers in Australia and the UK. who will study MND in people with the inherited form of MND before symptoms emerge, to understand the earliest signs of disease and to enable treatment for MND to begin much earlier than is currently possible.

## Understanding how TDP-43 regulates genes in MND

**Project:** Deciphering the role of TDP-43 regulation of cryptic exons in MND pathogenesis

**Project lead:** Prof Roger Chung (Macquarie University, NSW) – *This is one of 2 funded projects for Roger this round*

**Amount funded:** \$997,931

**Short summary:** This discovery project seeks to understand some of the fundamental molecular causes of motor neuron death and MND. It will study how a protein called TDP-43, that becomes harmful in MND, alters the make-up of genes in motor neurons, and how this genetic change causes MND.

## Retroviruses and MND

**Project:** How Does Human Endogenous Retrovirus Cause MND?

**Project lead:** A/Prof Mary-Louise Rogers (Flinders University, SA)

**Amount funded:** \$999,157

**Short summary:** Anti-retroviral therapy used to treat HIV is also showing promise as a potential treatment for MND in clinical trials. This project will seek to advance our understanding on how retroviruses may cause MND, and how therapies targeting retroviruses may slow progression of the disease.

## 7X IMPACT PROJECTS

*IMProving and ACcelerating Translation (IMPACT) projects support key areas of research focused on overcoming some of the hurdles and challenges in MND research that contribute to failed drug development or clinical trials. Outcomes from these projects will include:*

- *improvements in drug design and delivery*
- *treatments that target disease causing genes*
- *improved understanding of the variability in disease characteristics between individuals with MND*
- *the development of molecular markers to help diagnose MND, or predict if a drug is effective*
- *better models for studying MND in the laboratory*

## Disease heterogeneity

**Project:** Delving deep into the MND genome to reveal somatic mosaicism

**Project lead:** Dr Lyndal Henden (Macquarie University, NSW)

**Amount funded:** \$300,000

**Short summary:** This innovative project will perform an analysis of blood and brain samples from MND patients, searching for brain-specific genetic defects to help uncover new genetic causes of MND. Dr Henden is a first-time recipient of FightMND funding.

## Disease Biomarkers

**Project:** Lower Motor Neurone excitability as a new, and specific, biomarker of disease progression

**Project lead:** A/Prof Gabriel Trajano (Queensland University of Technology, QLD)

**Amount funded:** \$220,468 (co-funded with the MND and Me Foundation)

**Short summary:** A/Prof Trajano is developing a non-invasive technique to measure neuronal activity in MND patients. Successful outcomes will deliver a new and accurate way for clinicians to assess the progression of MND in patients. A/Prof Trajano is a first-time recipient of FightMND funding.

**Project:** Lipid dysregulation underlying MND – a new scope for biomarker development

**Project lead:** A/Prof Woojin Kim (The University of Sydney, NSW)

**Amount funded:** \$299,687

**Short summary:** A/Prof Kim is a first-time recipient of FightMND funding. This project will seek to develop a blood-based lipid test to diagnose MND more rapidly, accurately monitor disease progression and measure if treatments are successful.

## Gene therapies

**Project:** Developing novel gene expression control mechanisms for MND gene therapies

**Project lead:** Prof Roger Chung (Macquarie University, NSW) – *This is one of 2 funded projects*

**Amount funded:** \$299,668

**Short summary:** This project aims to fill a key gap in gene therapy, by developing a gene therapy that activates only when unhealthy forms of proteins are present in motor neurons.

**Project:** ASO-mediated reduction of UBQLN2 for X-linked MND

**Project lead:** Dr Emma Scotter (The University of Auckland, NZ)

**Amount funded:** \$300,000

**Short summary:** This collaborative project brings together teams from New Zealand and Australia to explore a gene therapy approach for treating a rare familial form of MND caused by a defect in the UBQLN2 gene.

## Disease models

**Project:** Generation of inducible and MND-sensitive genetic models for both basic research and drug discovery

**Project lead:** Dr Jean Giacomotto (Griffith University, QLD)

**Amount funded:** \$299,791

**Short summary:** This project will develop innovative preclinical models to advance studies in genetic causes of MND. The preclinical models will also be powerful tools for drug screening and the discovery of potential treatments for MND. Dr Giacomotto at Griffith University is a first-time recipient of FightMND funding.

## Drug Delivery

**Project:** Developing blood-brain barrier penetrating inhibitors of fatty acid binding protein 4 to reduce microglia-mediated neuroinflammation in Motor Neurone Disease

**Project lead:** A/Prof Joseph Nicolazzo (Monash University, VIC)

**Amount funded:** \$299,940

**Short summary:** A/Prof Nicolazzo will create and test a series of modifications to a promising drug targeting inflammation in MND. The team aims to improve the drugs ability to reach motor neurons in the brain and enhance its therapeutic potential for MND.

## CAREER DEVELOPMENT AWARDS

### 2x Mid-Career Research Fellowships

*FightMND Mid-Career Research Fellowships encourage outstanding researchers to choose or to continue to focus on MND as their primary area of research. The 4-year fellowship provides the opportunity for mid-career researchers to strengthen their research team and independent programs, build collaborations and embed themselves as key players in the MND research sector. The fellowship's research program is focused on causes of MND and elucidating disease mechanisms, with the ultimate goal of developing more effective treatments, and a cure, for MND.*

**Project:** Comprehensive disease gene discovery across familial MND, sporadic MND & MND twins

**Project lead:** A/Prof Kelly Williams – Bill Guest Mid-Career Research Fellow (Macquarie University, NSW)

**Amount funded:** \$680,000

**Key highlights:** A/Prof Kelly Williams is awarded the Bill Guest Mid-Career Research Fellowship in 2023, named in honour of inaugural FightMND board chairman Bill Guest AM. A/Prof Williams will lead a team to uncover new genetic causes underlying familial and sporadic MND.

**Project:** Can we tailor excitation therapy for MND?

**Project lead:** A/Prof Catherine Blizzard (University of Tasmania, TAS)

**Amount funded:** \$680,000

**Key highlights:** A/Prof Blizzard is a first-time recipient of FightMND funding. A/Prof Blizzard will lead a team to identify why motor neurons become overactive in MND, and map out how this overactivity spreads through the brain and spinal cord as MND progresses.

### 2x Early-Career Research Fellowships

*FightMND Early-Career Research Fellowships encourage researchers with outstanding ability to focus on MND as their primary area of research. The 4-year fellowship provides the opportunity for early-career researchers to establish their own independent research programs, build collaborations and further themselves as an MND researcher. The fellowship's research program is focused on causes of MND and elucidating disease mechanisms, with the ultimate goal of developing more effective treatments, and a cure, for MND.*

**Project:** Genetic markers and antisense oligonucleotides to restore axonal health in MND

**Project lead:** Dr Frances Theunissen (The University of Notre Dame, WA)

**Amount funded:** \$580,000

**Short summary:** During this fellowship, Dr Theunissen will work with mentors at the Perron Institute in WA and The Florey in VIC to identify genetic signatures that define subtypes of MND, and test new potential genetic therapies.

**Project:** Improving the likelihood of translation of novel Degradar technology for the treatment of MND

**Project lead:** Dr Stephanie Rayner (Macquarie University, NSW)

**Amount funded:** \$580,000

**Short Summary:** Dr Rayner will work to design and test a new type of MND therapy that seeks out and destroys unhealthy proteins which are damaging motor neurons, whilst ensuring healthy proteins remain intact. Dr Rayner is a first-time recipient of FightMND funding.



## **1x Angie Cunningham PhD Scholarship**

*The FightMND Angie Cunningham FightMND PhD Scholarship and Project Grant-in-Aid Award honours the life and qualities of Angie Cunningham wife of FightMND founder Pat Cunningham who died from MND in 2016.*

**Project:** Identification and characterisation of RNA-protein interaction in pathological aggregates of TDP-43 in MND

**Project lead:** Dr Albert Lee (Macquarie University, NSW)

**PhD Candidate:** Ms Flora Cheng

**Amount funded:** \$236,670

**Short summary:** The 2023 Angie Cunningham PhD scholarship is awarded to Ms Flora Cheng, working under the mentorship of Dr Albert Lee at the Centre for Motor Neuron Disease Research, Macquarie University. Ms Cheng will map out how known defects in TDP-43 cause it to misbehave in MND patients.

## **1x Clinical Investigator Award**

*This is the first year FightMND are offering Clinical Investigator Awards. Offered for a term of 1 year, these awards aim to assist an early-career clinical fellow to transition into a research appointment.*

**Project:** Unravelling the early cortical signature of MND in vivo

**Project lead:** Dr Thanuja Dharmadasa (The Florey/The University of Melbourne, VIC) *This is one of 3 funded projects*

**Amount funded:** \$99,813

**Short summary:** Dr Dharmadasa is a first-time recipient of FightMND funding. This project will use advanced imaging techniques to study “split limb syndrome”, one of the earliest clinical signs of MND. Study outcomes may lead to the development of imaging biomarkers that detect and diagnose MND.

## **2x McLoone Research Initiatives (Jointly funded with MND Research Australia)**

*The Daniel McLoone Major Research Initiative (MRI) aims to support an outstanding innovative and collaborative project that has the capacity to make a significant impact on Australian MND research. This award is a MND Research Australia initiative and this year two projects were selected that are jointly funded by FightMND and MND Research Australia.*

**Project:** Australian Preclinical Research MND (APRALS) Network: a roadmap for effective translation of therapeutics for sporadic MND

**Project lead:** Prof Bradley Turner (The Florey/The University of Melbourne, VIC)

**Amount funded:** \$1,000,000

**Short summary:** This project will establish Australian Preclinical Research ALS (APRALS), a national collaborative network of expert MND laboratory researchers, to fast-track the development and testing of potential new treatments for people living with MND.

**Project:** Exploring disease heterogeneity across MND clinical phenotypes using a multimodal, multicentre neuroimaging approach

**Project lead:** Dr Thanuja Dharmadasa (The Florey/The University of Melbourne, VIC) *This is one of 3 funded projects*

**Short summary:** This project will combine advanced brain images of MND patients with their clinical assessments to identify patterns or markers that can separate them into clinical subgroups. Study outcomes will allow clinicians and researchers to identify which subgroup a patient fits into (e.g. fast-progressor or slow-progressor), lead to better prediction of MND progression, and provide an earlier and more informed understanding of how best to manage the person's disease.

## OTHER RESEARCH INITIATIVES

**Project:** Victorian Brain Bank

**Project lead:** Prof Catriona McLean (The Florey/The University of Melbourne, VIC)

**Amount funded:** \$82,118

FightMND will provide support to strengthen operations of the Victorian Brain Bank. The Victoria Brain Bank is an important resource for Australian researchers, providing them with access to well-characterised post-mortem brains and clinical data that may give clues to why MND occurs and improve diagnosis.

**Project:** Turning Cells in Circuits: Putting the pieces together to solve the puzzle of MND

**Project lead:** Prof Tracey Dickson (The University of Tasmania, TAS)

**Amount funded:** \$45,688



## CARE – SUPPORT PROJECTS

Care Support projects are aimed at improving the quality of life for people living with, and affected by, MND, and building capacity and capability in the MND healthcare sector.

### 9 x Equipment technology and at home needs projects

*These grants will enable the purchase of essential care equipment and improve access to care services, to support the day-to-day needs of people living with MND across Australia.*

**Project:** MND equipment pool

**Organisation:** Barwon Health

**Amount:** \$99,395

**Summary:** Access to assistive care equipment in regional Victoria is limited, Barwon Health MND clinic will establish a pool of equipment to trial and loan for at-home use, providing much needed aids to people living with MND in Victoria.

**Project:** Driving for a Better Life

**Organisation:** Cavalry Health Care Bethlehem

**Amount:** \$98,496

**Summary:** Management of end of life care for MND patients at home is currently difficult. Cavalry Health Care Bethlehem will purchase two vehicles to transport allied health professionals to care for patients at home and offer the transport of patients to visit their loved ones or to a memorable location. This will provide support for the care of terminally ill patients across Victoria to delay the difficult transition into palliative care.

**Project:** Make Aged Care fair

**Organisation:** Motor Neurone Disease Association of QLD

**Amount:** \$150,000

**Summary:** If a person is diagnosed with MND over the age of 65 they are no longer eligible for NDIS funding and whilst they can apply for My Aged care packages these offer only a fraction of the financial support provided by the NDIS and are subject to long wait times. This project will address the inequity in funding and accessibility by providing (30) care support packages for people living with MND in Queensland who do not receive NDIS funding.

**Project:** Providing Equipment Services to People with MND

**Organisation:** Motor Neurone Disease Association of South Australia

**Amount:** \$248,244

**Summary:** This project will support the continued provision of specialised and critical equipment to people living with MND in South Australia and the development of new online resources and training programs for clients and carers.

**Project:** Electronic equipment library

**Organisation:** Motor Neurone Disease Association of Tasmania

**Amount:** \$150,000

**Summary:** This project will support the continued running of the MNDA Tasmania electronic equipment loan library to purchase new equipment for MND patients, provide technical training and support for effective use of complex equipment and circulate webinars to upskill local allied health professionals.

**Project:** Empowerment and Quality of Life through Assistive Technology

**Organisation:** Motor Neurone Disease Association of Victoria

**Amount:** \$250,000

**Summary:** Assistive technology is a core need for people living with MND. This project will support the continued provision of specialised assistive mobility equipment to people living with MND in Victoria.

**Project:** Equipment provisions for people with MND

**Organisation:** Motor Neurone Disease Association of Western Australia

**Amount:** \$250,000

**Summary:** Assistive equipment is a core need for people living with MND. This project will support the provision and timely access of free assistive technology for people living with MND in Western Australia who do not have access to appropriate government funding.

**Project:** Improved access to Assistive Technology

**Organisation:** Motor Neurone Disease NSW

**Amount:** \$248,175

**Summary:** Assistive technology is a core need for people living with MND. This project will support the continued provision of a comprehensive range of assistive equipment to people living with MND in NSW, NT and ACT.

**Project:** MND overwhelm reduction via technology

**Organisation:** MND and Me Foundation

**Amount:** \$125,000

**Summary:** As MND progresses, patients can lose the ability to speak. This project will support the continued provision of specialised communication devices designed for people living with MND, including new eye-gaze technology, so that patients can communicate effectively with their multidisciplinary team and loved ones.

## **10 x Education initiative projects**

***These grants will provide funding to support the design and development of care-focused informational resources for the MND community, in the form of online resources and/or workshops.***

**Project:** Innovative immersive mobile education to improve the quality of life for people living with Motor Neurone Disease (PlwMND), their families and carers

**Organisation:** Dementia Australia

**Amount:** \$244,000

**Summary:** Access to MND care across Australia is highly variable and services, particularly in remote areas, can be inadequate. Dementia Australia will develop and launch a free educational app available to all Australians, that will support and teach best practice care for patients with MND through highly engaging learning experiences.

**Project:** "Game on with MND": Improving quality of life for people living with Motor Neurone Disease (MND) through more fun and accessible digital games

**Organisation:** Motor Neuron Disease Association of Australia

**Amount:** \$146,696

**Summary:** Current gaming platforms do not meet the physical and social needs of people living with MND. This project will engage with MND patients to understand the social and technological challenges playing digital games and create new interfaces to improve access to games and the overall gaming experience for people living with MND.

**Project:** Carers' Can Project

**Organisation:** Motor Neurone Disease Association of Victoria

**Amount:** \$150,000

**Summary:** Carers are an essential part of the multidisciplinary team that cares for people with MND, but they are rarely given the support that they need. MND Victoria will develop a series of self-management support videos for carers aimed at providing practical guidance to increase confidence and understanding on how to manage and support people living with MND.

**Project:** MND Community Capacity Building

**Organisation:** Motor Neurone Disease Association of QLD

**Amount:** \$250,000

**Summary:** People impacted by MND in Australia do not always receive the same support and the advice given by healthcare professionals can be unsuitable and ineffective. This programme will offer educational learning resources and workshops in metropolitan and regional QLD to train and educate healthcare professionals on the complex needs of MND patients and empower clients and carers to feel well-informed on managing the disease and supported in periods of grief and bereavement.

**Project:** Caring for people with motor neurone disease: Education and training

**Organisation:** Motor Neurone Disease Association of Western Australia

**Amount:** \$150,000

**Summary:** People impacted by MND in Australia do not always receive the same support and the advice given by healthcare professional can be unsuitable and ineffective. This programme will develop and deliver three educational workshops in WA, to upskill and educate healthcare professionals and carers about the complex needs of MND patients and advise on the current MND and care strategies, to build capacity in the MND healthcare sector in WA.

**Project:** Increasing Support Capacity

**Organisation:** Motor Neurone Disease NSW

**Amount:** \$95,500

**Summary:** People impacted by MND in Australia do not always receive the same support and the advice given by healthcare professional can be unsuitable and ineffective. This programme will develop and deliver two educational workshops, to upskill and educate healthcare professionals and carers about the complex needs of MND patients and build capacity in the MND healthcare sector across NSW, ACT and NT.

**Project:** MND Massive Open Online Course (MOOC) Development

**Organisation:** Multiple Sclerosis of Queensland

**Amount:** \$250,000

**Summary:** Access to MND care across Australia is highly variable and services, particularly in remote areas, can be inadequate. MS Queensland will develop a web-based interactive learning course available to all Australians, that will provide in-depth information on the MND journey, from diagnosis to end of life care, and will help guide those impacted by MND to make informed decisions about MND care.

**Project:** A national person-centred approach to family carer needs assessment and support in MND community care: Translation into practice

**Organisation:** Perron Institute for Neurological and Translational Science

**Amount:** \$153,285

**Summary:** The practical, physical and emotional needs of family carers of people with MND are often overlooked. Researchers at the Perron Institute will develop and implement a web-based system 'Carers Alert Thermometer' in Australia that is responsive to the changing needs of family carers and coordinates with service providers to resolve these issues in a timely manner.

**Project:** A Roadshow of Care - Improving regional capability in MND care

**Organisation:** Royal Brisbane and women's Hospital Foundation

**Amount:** \$110,200

**Summary:** Access to specialist care in regional, rural and remote settings for people living with MND is often not available and it can be difficult for people to travel to metropolitan areas to receive this care. This project will support a multidisciplinary team of MND experts to deliver a roadshow of tailored workshops and educational sessions in disadvantaged areas of regional-rural QLD targeted at allied healthcare professionals, carers, GPs and nurse practitioners working in hospital, community or aged care facilities.

**Project:** Enhancing support for pabMND and upskilling psychological workforce on the needs of plwMND and pabMND

**Organisation:** The Australian Psychological Society

**Amount:** \$98,000

**Summary:** There are currently very limited resources in Australia focused on the psychological health and care needs of people living with, or affected by, MND. To address this, the Australian Psychological Society will develop a clinical practice guide for psychologists and allied health professionals that provides evidence-based recommendations on psychological care for people living with MND. In parallel, they will develop a webinar to support the psychosocial care needs and mental health of people impacted by MND throughout the disease journey.

### **3 x Building support groups in the community**

***These grants will provide funding to help build support groups in the MND community across Australia.***

**Project:** Development of a national lived experience model for people living with MND in Australia

**Organisation:** Motor Neuron Disease Association of Australia

**Amount:** \$205,859

**Summary:** There is a significant lack of involvement of the MND lived experience in targeted resources, policies and research for MND care. MND Australia will collaborate with the MND community to co-design a new initiative that will incorporate the patients voice in the development of new frameworks and structures that better represent people living with MND.

**Project:** Building Capacity of MNDSA's Volunteer Program

**Organisation:** Motor Neurone Disease Association of South Australia (MNDSA)

**Amount:** \$149,798

**Summary:** Volunteers provide essential support for the MND State Associations in Australia, however since the pandemic there has been a noticeable drop in the number of regular volunteers. This project will focus on improving the recruitment, training and retention of volunteers to support critical services provided by the MND Association of SA.

**Project:** A Friend's Place - specialist grief and bereavement care service for families impacts by MND (Pilot Program)

**Organisation:** National Centre for Childhood Grief

**Amount:** \$54,309

**Summary:** Children are highly vulnerable to developing life-long psychological challenges after living with and losing a parent to MND. This project will develop a grief and bereavement counselling programme to support families with children under 18 years of age who have a parent diagnosed with MND.