mnda
motor neurone disease
association

Research Awarded in 2022

Research

We are a leader in the funding and promotion of cutting-edge motor neuron disease (MND) research, both within the UK and across the world. All of the research projects we fund have clear clinical relevance and/or therapeutic potential. You can find out more about the **research funding we have awarded in 2022** on the following pages, in order of their funding type. Research studies that involve animals (e.g. fruit flies, zebrafish, mice) are marked with **A**.

What types of research projects do we fund?

Our research projects are categorised into four themes that range from 'bench to bedside'. This means that some projects try to identify the causes of MND and develop functional models to study the disease, others aim to find unique biomarkers in people with MND to help speed up diagnosis and track progression of the disease, some hope to turn the most promising compounds into drugs that are safe and will treat the disease, and others are aiming to improve the quality of life and care of people living with MND.

Identifying therapeutic targets

Understanding the causes of MND, focusing on the pivotal biochemical processes involved in the disease that will provide a starting point for the development of new treatments.

Developing treatment pipeline

Turning the most promising scientific discoveries into potential new treatments. New treatments that have been proven safe and effective by all other methods are then carefully tested in people.

Understanding clinical progression

Developing a detailed understanding of how the disease manifests and progresses in humans to ensure that fundamental laboratory research can be clearly linked to the 'real world' events occurring in people with MND.

Improving standards of care

Ensuring that the clinical management of MND is informed by the priorities of people living with the disease and their families, and is supported by a strong evidence base.

How do we decide what research we fund?

Peer review (scrutiny by experts in the field) is essential in research and is used to ensure all projects we fund are of the highest calibre and can realistically achieve the aims of the project. Decisions to award research grants are made following rigorous peer review, and guidance from the MND Association's Biomedical Research Advisory Panel (for biomedical and clinical research) and Healthcare Research Advisory Panel (for healthcare research). The types of research we support are listed below:

Project grant (Biomedical or Healthcare)

We are committed to playing a key role in ending MND. Our **biomedical** research programme delivers significant and measurable advances in understanding and treating the disease. We only fund research of the highest scientific excellence and greatest relevance to MND.

The MND Association has a longstanding record of supporting **healthcare** research and therapeutic trials. Our goal is that healthcare research we fund will lead to improvements in treatment, disease management and quality of life for people with MND, their families and carers and strengthen the case for statutory funding of high-quality MND care. Some of our healthcare projects are co-funded by Marie Curie.

Grants are offered for up to **3 years** to allow for an in-depth investigation of an area of research.

PhD Studentship

We have a track record of attracting and funding promising young, or early career stage, scientists to develop their careers in MND research through our successful PhD studentship programme. Grants are offered for up to **3 years**. This is a cost-effective method that allows high calibre candidates to undertake PhD training in MND-related projects.

Small grant

We offer small grants that are of variable amounts to facilitate the rapid follow-up of important new findings. Small pump-priming grants are considered on an 'ad-hoc' basis.

The Lady Edith Wolfson Fellowship Programme

Clinical Research Fellowship

Jointly funded by the Medical Research Council (MRC), these grants support clinicians wishing to pursue scientific research and aim to strengthen the links between laboratories and clinics.

Non-Clinical Fellowship

Since 2015, the MND Association has awarded non-clinical fellowships to nurture and retain the best post-doctoral researchers at early and mid-career levels, usually conducting biomedical research, with the aim to develop them into MND research leaders of the future. Fellowships are awarded at two levels, depending on the experience of the applicant: **Junior** or **Senior**. Our non-clinical fellowships are currently funded with support from a number of donors.

Investigating the role of C9orf72/SMCR8 in motor neuron communication in MND (884-791) **A**		**Therapeutic targets**
Lead investigator	Prof Kurt De Vos	
Lead institution	University of Sheffield	
Co-investigators	Dr Matthew Livesey, Dr Andrew Grierson, Dr Emma Smith and Ian Coldicott	
Cost: £187,946	**Type of grant:** Project grant (Biomedical)	August 2023 - July 2025

There is evidence that C9orf72 protein helps to regulate the amount and location of GABAA receptor proteins, which are an essential part of communication between neurons. It is thought that mutations in the C9orf72 gene can lead to a reduction in the amount of GABAA receptor proteins in MND. This project will use cells from people with MND and animal models of the disease to investigate how the C9orf72 protein regulates GABAA receptors and how this impacts on the function of the neurons. It will also test existing drugs that interact with the receptors, which are currently used for other conditions, to see if these have an effect on the neurons and if they could be beneficial for those with MND.

The role of microglia in C9orf72-related MND (889-791)		**Therapeutic targets**
Lead investigator	Prof Kevin Talbot	
Lead institution	University of Oxford	
Co-investigators	Dr Björn Friedhelm Vahsen and Dr Sally Cowley	
Cost: £285,000	**Type of grant:** Project grant (Biomedical)	October 2022 - September 2025

Microglia are one of the types of 'support cells' in the central nervous system and are specifically involved in inflammatory responses, removing damaged cells and maintaining the connections between neurons. There is increasing evidence that changes in the function of the microglial cells may be one factor in the development of MND. The C9orf72 gene mutation is the most common genetic cause of MND, and the protein made from this gene is found in high amounts in microglia, suggesting that the mutation may contribute to the alterations in microglial cells. This project aims to investigate the role that changes in microglia may play in the disease and whether these changes are a result of the C9orf72 mutation. It will use stem cells from those with MND who have a C9orf72 mutation to create both motor neurons and microglia to observe how microglia with mutant C9orf72 initiate problems in motor neurons. Investigating the role that microglia play in the development and progression of C9orf72 MND may help to identify new therapeutic targets for future treatments.

Resolving the link between cell processes and axon length in a cell model of MND (885-791)		**Therapeutic targets**
Lead investigator	Dr Andrea Serio	
Lead institution	King's College London	
Cost: £289,911	**Type of grant:** Project grant (Biomedical)	November 2022 - October 2025

Motor neurons (MNs) are the longest nerve cells in the body and this can cause challenges with transporting essential resources from one end of the cell to the other. It has been found that there are some cell adaptations that might be related to the length of the neuron and it is thought that these adaptations could be linked to some processes that are affected in the early stages of the disease. This project will examine the relationship between neuron length and the processes of RNA and protein production, using motor neurons derived from people with different genetic forms of MND. The project will provide new insights into understanding early disease processes, and it will help to establish a better platform to test potential new therapies that are focused on correcting these processes that go wrong in the early stages of MND.

Therapeutic modulation of TDP-43 mechanisms in MND (886-791)		**Therapeutic targets**
Lead investigator	Prof Jernej Ule	
Lead institution	King's College London	
Co-investigators	Dr Martina Hallegger	
Cost: £298,133	**Type of grant:** Project grant (Biomedical)	November 2022 - October 2025
TDP-43 protein clumps in neurons are a feature of nearly all cases of MND, making this protein a key target for the development of new therapies. However, as TDP-43 has many different roles within neurons, it is very difficult to target this protein. Several mechanisms that normally control the properties of the TDP-43 protein have been identified and these help to maintain the function and amount of TDP-43. Mutations in TDP-43 that cause MND might be interrupting these mechanisms and causing clumps of the protein to form. This project will use cell models of MND to look at whether these mechanisms could be promising therapeutic targets. It also aims to identify new therapeutic strategies to restore the mechanisms and limit the formation of TDP-43 clumps.		

Investigating the role of adenosine deaminase in MND (887-791)		**Therapeutic targets**
Lead investigator	Dr Scott Allen	
Lead institution	University of Sheffield	
Cost: £278,722	**Type of grant:** Project grant (Biomedical)	December 2022 - November 2025
Previous research has shown that motor neurons are not the only type of brain cell damaged in MND, and that astrocytes (cells which support the function of motor neurons) also become dysfunctional. It has been found that a mutation in the C9orf72 gene causes energy production to be reduced in the astrocytes which causes the astrocytes to be less supportive towards motor neurones leading to increased cell death. It is thought that this reduced energy production may be due to the loss of a protein called adenosine deaminase (ADA), but it is not yet clear how this goes wrong in astrocytes in MND. This project will use cell models of MND to observe the underlying biological mechanisms of the loss of ADA and increase understanding of the role this plays in MND. It also aims to uncover ways in which the loss of ADA might be corrected, through testing whether purine nutritional supplementation or targeted gene therapy can increase levels of ADA in astrocytes.		

Dissecting the genetic determinants of cognitive and behavioural subphenotypes in MND (979-799)		**Therapeutic targets**
Lead investigator	Dr Ross Byrne	
Lead institution	Trinity College Dublin	
Co-investigators	Dr Russell McLaughlin and Professor Orla Hardiman	
Cost: £284,583	**Type of grant:** Non-Clinical fellowship (Junior)	September 2023 - August 2026
Some people with MND experience cognitive or behavioural symptoms, with about 15% of people suffering from frontotemporal dementia (FTD). These cognitive and behavioural symptoms can limit the success of life-prolonging treatments such as feeding tubes and breathing support. Understanding more about these symptoms might help to improve the wellbeing of people with MND and recent research has suggested these symptoms may have a genetic basis. However, currently little research has been done to identify which genes and pathways are involved. This project will analyse data from the largest studies of genetic factors contributing to MND and cognitive symptoms to identify shared genetic factors (which contribute to both cognitive decline and MND) and distinct genetic factors (which contribute purely to motor symptoms in MND). It is hoped that this could help with grouping people with MND for clinical trials, and in understanding the causes of cognitive symptoms in MND.		

Dissecting FUS' cytoplasmic toxic gain-of-function in MND (911-792) **A**		**Therapeutic targets**
Lead investigator	Dr Marc-David Ruepp	
Lead institution	King's College London	
Co-investigators	Professor Helene Plun-Favreau	
Cost: £114,856	**Type of grant:** PhD Studentship	October 2023 - September 2026
MND is known to be associated with changes in a gene called Fused in Sarcoma (FUS). These mutations cause the FUS protein to be lost from the cell nucleus, where it is meant to reside, and to mislocate to the cell cytoplasm. In the cytoplasm of the cell, the FUS protein has a toxic function that damages and kills motor neurons. However, it is not clear what causes cytoplasmic FUS to be toxic. This project aims to develop new FUS-linked MND cell models to understand more about the interactions that FUS has with other proteins in the cell cytoplasm and how these may be involved in the disease. This could lead to help to determine how toxic FUS is responsible for damaging motor neurons and identify new targets for future therapy development for FUS-linked MND.		

Analysing axonal transport changes in MND (908-792) **A**		**Therapeutic targets**
Lead investigator	Dr Giampietro Schiavo	
Lead institution	University College London	
Co-investigators	Dr James Sleigh	
Cost: £110,702	**Type of grant:** PhD Studentship	October 2023 - September 2026
In our neurones, we have a process that facilitates long-range transfer of information and nutrients from one end of the neurone to the other and back again. This process is called axonal transport. Evidence suggests that at the very beginning of MND, this process is impaired. With little knowledge of the mechanisms that control axonal transport, this project aims to (1) find whether the regulation of axonal transport is impaired in different types of MND; (2) identify whether substances identified in a previous project are able to rescue transport in diseased neurones in MND. If researchers can restore healthy axonal transport, they may be able to block the process leading to motor neurone cell death and stop disease progression.		

Investigating the effects of multiple gene mutations in the onset of MND (913-792)		**Therapeutic targets**
Lead investigator	Prof Majid Hafezparast	
Lead institution	University of Sussex	
Co-investigators	Dr Johnathon Cooper-Knock	
Cost: £108,930	**Type of grant:** PhD Studentship	October 2023 - September 2026
Previous research has suggested that in the majority of cases of MND, where no single gene is responsible, the disease may be a collective result of several gene mutations. However, there is little evidence to explain how variations in these genes, when they are inherited together, may contribute to the development of MND. It has been found that variations in two genes which produce proteins called dynein and TBK1, may act together to contribute to MND. These proteins have crucial roles in clearing toxic abnormal proteins in neurons. Variations in these genes are thought to be involved in neuron damage and death. This project will use cell models of MND to analyse the impact of mutations in these genes on the cell's clearance of abnormal proteins and stress response. It also aims to explore ways that these effects may be reversed and to help identify new potential therapies for MND.		

Understanding the role of NEAT1 in energy metabolism in TDP-43 associated MND (910-792)		**Therapeutic targets**
Lead investigator	Dr Tatyana Shelkovnikova	
Lead institution	University of Sheffield	
Co-investigators	Dr Scott Allen	
Cost: £114,917	**Type of grant:** PhD Studentship	October 2023 - March 2027
NEAT1 is an RNA molecule present in most cells in our body. NEAT1 exists in two forms which have different structures and functions. In most cases of MND, there is a loss of function of a protein called TDP-43. TDP-43 controls the amount of different types of NEAT1 and the loss of function can lead to more of one form of NEAT1 and less of the other form. It is thought that this imbalance in forms of NEAT1 might be the link between abnormal energy balance and metabolism in MND. This project aims to investigate the role that one form of NEAT1 plays in MND using cell models of motor neurons and astrocytes (another type of brain cell). This study may help to establish whether NEAT1 may be a promising therapeutic target in MND.		

Investigating mechanisms underlying the impaired hypoxia response in C9Orf72-related MND (909-792) **A**		**Therapeutic targets**
Lead investigator	Dr Ryan West	
Lead institution	University of Sheffield	
Co-investigators	Dr Scott Allen	
Cost: £114,907	**Type of grant:** PhD Studentship	October 2023 - March 2027
A mutation in a gene called C9orf72 is the most common genetic cause of MND. This mutation results in the build-up of 5 toxic proteins, called dipeptide-repeats (DPRs), in the nervous system of people living with MND. However, how DPRs cause motor neurone death remains unclear. Previous evidence suggests one these DPRs, often considered to be the most toxic, impairs the ability of nerve cells to respond to reduced levels of oxygen (hypoxia). These low oxygen levels are known to occur during MND because of a weakened respiratory system, however it may also occur before people show symptoms. This can be due to environmental stresses such as intense exercise, sleep apnea or smoke inhalation, which have all been observed as MND risk factors. This project aims to investigate how DPRs cause nerve cells to no longer respond to oxygen deprivation and how this may lead to MND.		

Developing a novel cell therapy approach to restore lost muscle function in MND (994-797) **A**		**Treatment pipeline**
Lead investigator	Dr Barney Bryson	
Lead institution	University College London	
Co-investigators	Prof Linda Greensmith	
Cost: £165,971	**Type of grant:** Project Grant (Biomedical)	August 2022 - July 2024

In MND, the specialised connections between motor neurons and muscles break down and this causes weakness and paralysis. A new strategy has been developed to create new connections between motor neurons and muscles using stem cells which are engineered to respond to pulses of light. These have been shown to enable muscle contraction to be artificially controlled using light signals. This project is focusing on adapting this therapy for use in humans by creating genetically engineered motor neurons that are suitable for use in people. These human motor neurons will then be tested in rat models to see if they can be activated by light signals, initiate muscle contraction and help to prevent muscle wasting which occurs in the disease.

Funded by the Motor Neurone Disease Translational Fund
Supported by funds raised by Kevin Sinfield through his extraordinary challenges

MND Association Collaborative Partnership: United2EndMND - Phase 1 (992-797)		**Treatment pipeline**
Lead investigator	Prof Ammar Al-Chalabi and Prof Chris McDermott	
Lead institution	King's College London	
Cost: £1,000,000	**Type of grant:** Project Grant (Biomedical)	August 2022 - January 2025

This collaborative partnership has been awarded to six UK universities to help accelerate the development of treatments for MND. This is helping to fund a 3-year project that aims to resolve two problems which are currently slowing progress in developing effective treatments for MND and will bring the research community together to discover new ways in which treatments can be found and tested. MND affects everyone differently and this means it is hard to measure disease progression and the effectiveness of potential treatments. The project aims to overcome this problem by improving ways that we can measure disease progression and treatment response. We also cannot take tissue samples from those with MND, and this makes testing new treatments on diseased cells very difficult. This problem will be addressed using blood cells from people with MND to generate motor neurons, and other types of brain cells, that are designed to behave in the same way as cells in someone with MND. This partnership will not only help to combat these barriers surrounding the drug discovery process, but it will also build a foundation for a UK MND research community.

Supported by funds raised by Kevin Sinfield through his extraordinary challenges

Developing a gene therapy for mutant FUS MND (993-797) **A**		**Treatment pipeline**
Lead investigator	Dr Younbok Lee	
Lead institution	King's College London	
Co-investigators	Professor Chris Shaw	
Cost: £250,000	**Type of grant:** Project Grant (Biomedical- LifeArc)	October 2022 - September 2025

In some cases of MND, people may have changes in the FUS gene which cause a faulty FUS protein to be made that builds-up in the wrong area of the neuron. This disturbs the production of other proteins that are essential to motor neuron health and survival, leading to motor neuron damage. Previous research has shown that reducing the activity of the altered FUS gene leads to less of the faulty FUS protein being made and may be able to prevent further damage to motor neurons. This project focuses on developing a potential gene therapy that aims to reduce the activity of the faulty FUS gene. The therapy will use a compound called an Antisense oligonucleotide (ASO) which is a piece of DNA that is designed to bind to the faulty FUS RNA (photocopy of the gene used to make the protein) and cause it to be destroyed. This potential new ASO therapy will be designed to work long-term with only one treatment needed and, if successful, could help prevent further motor neuron loss.

Supported by the Heaton Ellis Trust

The role of TBK1-dependent immune signalling pathways in MND (883-791) **A**		**Treatment pipeline**
Lead investigator	Dr Valeria Gerbino	
Lead institution	Fondazione Santa Lucia	
Co-investigators	Dr Thomas Maniatis	
Cost: £185,000	**Type of grant:** Project Grant (Biomedical)	November 2022 - October 2025

The progression of MND is thought to be influenced by cells in the nervous system called microglia. Previous research has shown that a gene called TBK1, which is involved in the immune response, becomes overactive in microglia in MND and this may contribute to disease progression. This project aims to use cell and mouse models of MND to investigate whether reducing the activity of TBK1 in microglia could lead help to slow disease progression. The researchers will also test gene therapy approaches in these models to determine if targeting the activity of TBK1 could be a good therapeutic target for future therapy development.

Developing and testing a new gene therapy approach for TDP-43 associated MND (995-797) **A**		**Treatment pipeline**
Lead investigator	Prof Pietro Fratta	
Lead institution	University College London	
Co-investigators	Dr Loic Roux	
Cost: £164,291	**Type of grant:** Project Grant (Biomedical)	January 2023 - December 2025

Previous research has shown that a protein called TDP-43 is faulty in around 97% of people with MND. This faulty TDP-43 function has been found to cause a mistake to occur in the genetic instructions for another protein called UNC13A. The UNC13A protein plays an important role in allowing neurons to communicate with each other using chemical signals and, if the protein is not working as it should this could contribute to the neuron damage that occurs in MND. It has been suggested that the mistake in the instructions for the UNC13A protein might be corrected using small DNA-like molecules. This project aims to test small DNA-like molecules in cell and mice models of MND to see if they might be effective at correcting the mistake and identify one that might be the most promising for use as a potential gene therapy for MND.

Funded by the Motor Neurone Disease Translational Fund
Supported by funds raised by Kevin Sinfield through his extraordinary challenges

Identifying the underlying biology of gene mutations in Kennedy's disease (978-799) **A**		**Treatment pipeline**
Lead investigator	Dr Wooi Fang (Catheryn) Lim	
Lead institution	University of Oxford	
Co-investigators	Professor Matthew wood and Professor Carlo Rinaldi	
Cost: £273,792	**Type of grant:** Non-Clinical Fellowship (Junior)	April 2023 - March 2026

Kennedy's disease (KD) is a disorder of motor neurons caused by a mutation in the gene encoding for a protein called the androgen receptor. Despite the genetic basis of KD being known for a long time, there is a lack of understanding of the biological mechanisms underlying the disease. This project will use animal and cell models of Kennedy's disease to improve current understanding of how gene changes in the androgen receptor may lead to altered function of the receptor and the role this might play in the disease. Dr Lim will also screen for anti-sense oligonucleotides (short sequences of genetic material that can be used as gene therapies) to identify one that could reverse the changes and be a new potential therapy for the disease.

The Lady Edith Wolfson Fellowship Programme

Investigating individualised effects of low-dose interleukin-2 throughout the MIROCALS Clinical Trial (969-794)		**Clinical progression**
Lead investigator	Prof Janine Kirby	
Lead institution	University of Sheffield	
Co-investigators	Prof Dame Pamela Shaw and Rachel Waller	
Cost: £69,130	**Type of grant:** Project Grant (Healthcare)	April 2022 - December 2023
Mirocals was a clinical trial testing whether injections of Interleukin-2 (IL-2) could help people with MND. As part of the trial, blood samples were taken from people with MND at certain time points throughout the trial and sent to Sheffield from all trial sites in the UK and France. This project will focus on taking the RNA (a photocopy of DNA) from these samples and using it to study participants responses to IL-2. This will help to improve current understanding about what causes the effect that IL-2 has on the immune system by looking for differences and patterns in RNA between those on IL-2 treatment and those on the placebo (dummy drug).		

Profiling Immune Responses to Low-Dose IL-2 in MND (970-794)		**Clinical progression**
Lead investigator	Prof Timothy Tree	
Lead institution	King's College London	
Cost: £133,832	**Type of grant:** Project Grant (Healthcare)	April 2022 - March 2024
There is evidence to suggest that there is a link between the immune system and disease progression in MND. The MIROCALS clinical trial tested whether injections of a compound called Interleukin-2 (IL-2) could extend survival in those with MND. This project will use blood samples from those with MND who took part in MIROCALS to further investigate whether IL-2 treatment leads to changes in the number and function of a specific group of immune cells, which help to regulate immune responses, and how changes may be related to disease progression. Alongside MIROCALS, this project will help to build on current knowledge of how immune system changes might contribute to the progression of MND and provide a greater understanding of the effects that treatment with IL-2 may have on those with the disease.		

Investigating connectivity between the brain and muscle in MND using High Density Surface Electromyography (888-791)		**Clinical progression**
Lead investigator	Dr Lara McManus	
Lead institution	Trinity College Dublin	
Co-investigators	Prof Orla Hardiman, Dr Bahman Nasseroleslami and Prof Madeline Lowery	
Cost: £177,089	**Type of grant:** Project Grant (Biomedical)	January 2023 - August 2025
This project proposes to combine an emerging technology, called High Density Surface electromyography, with electroencephalography ('brain wave') recordings to examine the flow of electrical activity between the brain and muscle. They will use this combination to observe changes in activity that occur in those with MND and assess whether these changes worsen as the disease progresses and motor neurons become more damaged. This will be the first study to use these combined techniques to quantify changes in the connections between the brain and muscle that occur in MND. These measurements are likely to be more sensitive than current methods and should therefore be able to pick up the earliest signs of motor neuron damage. This will help to diagnose MND earlier and mean that those with the disease can get earlier access to treatment and care. It will also aid in clinical trials as earlier diagnoses may enable more people with MND to take part in trials and potential treatments could have more benefit if they are given earlier on. This combination of techniques could also serve as a biomarker, helping to determine if new therapies are effective at slowing the progression of the disease.		

Characterising TDP-43 protein aggregates to identify biomarkers of MND (980-799)		**Clinical progression**
Lead investigator	Dr Rebecca Saleeb	
Lead institution	University of Edinburgh	
Co-investigators	Dr Matthew Horrocks and Dr Jenna Gregory	
Cost: £257,736	**Type of grant:** Non-Clinical Fellowship (Junior)	April 2023 - March 2026

Some cases of MND are caused by a build-up of a protein called TDP-43, which clumps together to form toxic "aggregates", leading to motor neuron damage and death. The differences in symptoms and severity between people with MND may be partly due to differences in the accumulation of TDP-43. Understanding the different forms of TDP-43 aggregates and developing ways to detect them early in the disease could help to identify the most appropriate clinical trial for each person and progress the development of personalised treatment. A custom-designed technology has been developed that allows the features of the aggregates to be seen in high levels of detail so that they can be characterised by similar features. This project will use this state-of-the-art technology to characterise the differences between TDP-43 aggregates in post-mortem tissue. This information will be used alongside knowledge of how the disease developed to identify different aggregate types and investigate their use as early prognostic markers.

The Lady Edith Wolfson Fellowship Programme

iDeliver MND: improving delivery of psychological care in MND (973-794)		**Standards of care**
Lead investigator	Dr Emily Mayberry	
Lead institution	University of Sheffield	
Co-investigators	Dr Elizabeth Coates, Dr Sian Hocking and Prof Chris McDermott	
Cost: £155,000	**Type of grant:** Project Grant (Healthcare)	June 2023 - May 2025

Some people with MND can experience changes in their thinking and behaviour that can affect their daily lives and their care. Psychologists can support people living with MND and their carers to manage these challenges and feedback from people living with MND, MND carers, and healthcare professionals shows that access to psychological support has been very useful. However, it is difficult to gather enough evidence about the difference access to psychology can make. This project aims to identify what is important for MND psychology services to deliver, how this care is being delivered, funded, and evaluated, what is working well, and what can be improved. The findings will be used to develop recommendations about how best to set up MND psychology services to provide the care people with MND and their carers need.

Home initiation and monitoring of non-invasive ventilation versus hospital-based care in people with MND (944-794)		**Standards of care**
Lead investigator	Dr Dariusz Wozniak	
Lead institution	Royal Papworth Hospital	
Co-investigators	Dr Michael Davis and Dr Ian Smith	
Cost: £210,398	**Type of grant:** Project Grant (Healthcare)	June 2023 - December 2025

People with MND who have breathing difficulties are offered a type of breathing support called Non-invasive ventilation (NIV). Typically, NIV is set up during a hospital visit and repeated visits to clinics are needed to monitor those with MND who use NIV. For some people, treatment may be able to be started and monitored at home, reducing the number of hospital visits needed. However, it is not yet known if home-based treatment is as safe and effective as hospital-based treatment. This trial will recruit 60 people with MND who need NIV and randomly assign them to either home-based or hospital-based treatment. The study will measure treatment effectiveness, patient and carer preferences, quality of life and cost effectiveness to assess whether home-based treatment may be more widely used for NIV for those with MND.

Developing remote monitoring tools for assessing disease progression in MND (912-792)		**Standards of care**
Lead investigator	Dr Emma Hodson-Tole	
Lead institution	Manchester Metropolitan University	
Co-investigators	Dr Gladys Pearson, Dr Amina Chaouch, Prof Yong Hong Peng and Prof Chris McDermott	
Cost: £101,470	**Type of grant:** PhD Studentship	October 2023 - September 2026

Currently there is a lack of methods to accurately and frequently measure changes in health and wellbeing as MND progresses. Recent advances in technology means that there are now methods of recording physical behaviour patterns in daily life. These measures of physical activity have been shown to indicate progression and response to treatment in other neurodegenerative diseases, such as Parkinson's disease. However, there have only been two studies that have explored the use of these measures in people with MND. This project will investigate whether MND causes unique changes in physical behaviour that can be used to identify if someone has MND and their stage of the disease, and whether changes in physical behaviour can be used to predict how quickly the disease will progress in people with MND. Improving measurement of the effects of MND will enable more informed decisions about personalised care to be made and the effects of new potential treatments to be better evaluated.

mnda
motor neurone disease
association