mnda
motor neurone disease
association

Research we fund
2020

Research

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 motor neuron disease (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.

We are a leader in the funding and promotion of cutting-edge 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 we fund on the following pages.

How do we decide what research we fund?

Peer review 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 grants (Biomedical or Healthcare)

Grants up to **£255,000** for **up to 3 years** to allow an in-depth investigation of an area of research. Some healthcare projects are co-funded by Marie Curie.

PhD Studentships

Grants up to **£100,000** for **up to 3 years**. A cost-effective method that allows high calibre graduates to undertake PhD training in MND-related projects.

Small grants

Grants 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 Fellowships

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. Our contribution differs for each fellowship and are for **up to 5 years**.

Non-Clinical Fellowships

Grants up to **£270,000** (Junior Fellowship) or **£440,000** (Senior Fellowship) for **up to 4 years** with the aim to retain and develop early and mid-career MND researchers, usually conducting biomedical research.

In the following pages we give a brief summary of the active research we fund or are committed to fund in 2020. Research studies that involve animals (e.g. fruit flies, zebrafish, mice) are marked with **A**. Co-investigators also include PhD students, post-doctoral researchers, research assistants, and technicians.

Nuclear magnetic resonance and TDP-43 aggregation (882-792)		**Therapeutic targets**
Lead investigator	Prof John Christodoulou	
Lead institution	University College London	
Co-investigators	Dr Lisa Cabrita and Sarah Alam (PhD student)	
Cost: £91,970	**Type of grant:** PhD Studentship	February 2017 - January 2020

The project investigates the detailed structure of TDP-43 using nuclear magnetic resonance (NMR), a state-of-the-art technique providing information about the arrangement of the atoms comprising the protein. The findings will help us understand how and why TDP-43 protein forms clumps and the role of these clumps in the disease process. This information will eventually be used to design and develop small molecules that may stop or reverse this process.

The Tolworthy PhD Studentship

Regulation of neuronal transport system by TBK1 (880-792) **A**		**Therapeutic targets**
Lead investigator	Prof Giampietro Schiavo	
Lead institution	University College London	
Co-investigators	Dr Pietro Fratta and David Villarroel-Campos (PhD student)	
Cost: £92,842	**Type of grant:** PhD Studentship	February 2017 - January 2020

The internal transport system of motor neurons ensures that they have fuel, maintenance materials, and nutrients in the right place at the right time in order to transmit messages from the spinal cord to muscles. This research is investigating how a protein called Rab7, involved in organising motor neuron transport, is affected in MND. Specifically, it is thought that faults in a TBK1 protein, known to malfunction in MND, have an indirect effect on the correct function of Rab7.

The Kerry Memorial PhD Studentship

The ALS Online Genetics Database (ALSoD) (911-793)		**Therapeutic targets**
Lead investigator	Prof Ammar Al-Chalabi	
Lead institution	King's College London	
Cost: £40,000	**Type of grant:** Small grant (Biomedical)	October 2017 - January 2020

Genetics is advancing very rapidly, with the number of new MND genes doubling every four years. The ALS Online Genetics Database (ALSoD) aims to be a continuously updated listing of gene variations associated with MND, linking to information about the clinical features that occur in people carrying specific gene variations, links to other online resources for researchers, and tools that allow MND researchers to analyse genetic information in detail.

Role of glycosphingo-lipids in MND (883-792) **A**		**Therapeutic targets**
Lead investigator	Prof Frances Platt	
Lead institution	University of Oxford	
Co-investigators	Dr David Priestman and Carla de Silva Santos (PhD student)	
Cost: £104,752	**Type of grant:** PhD Studentship	October 2016 - March 2020

There is an unexplored link between MND and rare diseases called lysosomal storage diseases. Lysosomes are a part of the cell where larger molecules, no longer required, are broken down for 'recycling and disposal'. One type of molecule that the lysosomes break down are glycosphingo-lipids (GSLs). The team has recently found a link between GSLs and MND. This project will investigate the role of a specific GSL in MND, using patient blood samples, cell lines and post-mortem tissues, as well as various samples from mouse models. The team will also test whether they can delay MND progression by targeting GSLs with therapies.

Supported by the PF Charitable Trust, the Newby Trust and the Inman Charity

Toxic protein accumulation in C9orf72-related MND/FTD (889-792)		**Therapeutic targets**
Lead investigator	Prof Kevin Talbot	
Lead institution	University of Oxford	
Co-investigators	Dr Ruxandra Dafinca and Paola Barbagallo (PhD student)	
Cost: £98,526	**Type of grant:** PhD studentship	April 2017 - March 2020

The researchers will use iPSC technology to create motor neurons from skin cells of healthy people and people with C9orf72 mutation. They will then introduce a virus causing protein accumulation and observe for the location and function of the clumps within neurons. Specific drugs will then be tested for their potential to remove the toxic virus from the neurons, findings of which could lead to identification of a new therapy.

Supported by the Childwick Trust

Dissecting the pathobiology of MND using FUS Delta14 mouse model (867-791) **A**		**Therapeutic targets**
Lead investigator	Dr Anny Devoy	
Lead institution	King's College London	
Co-investigators	Dr Marc-David Ruepp, Dr Helene Plun-Favreau and Annora Theong	
Cost: £100,000	**Type of grant:** Project grant (Biomedical)	January 2019 - June 2020

The aim of this study is to identify and investigate the earliest disease-specific changes that occur in MND in order to identify key cellular changes that contribute to the death of motor neurons. The project will take advantage of a new FUS mouse model of MND to investigate the interaction of mutant FUS with two important cellular structures – the endoplasmic reticulum and mitochondrion – which are essential for maintaining energy, and thus the health of cells, especially neurons.

Supported by the Hornby Lonsdale Charitable Trust

A Drosophila model for an Annexin gene causing MND (855-791) **A**		**Therapeutic targets**
Lead investigator	Dr Manolis Fanto	
Lead institution	King's College London	
Co-investigators	Dr Brad Smith, Prof Chris Shaw and Jodi Parslow	
Cost: £125,421	**Type of grant:** Project grant (Biomedical)	September 2017 - June 2020

Mutations in the ANXA11 gene are associated with about 1% of MND cases. This project will look at the fruitfly equivalent of the ANXA11 gene and investigate how mutations may damage the neurons. Findings from other studies show that mutations of this gene are likely to lead to defects in autophagy, a process by which a cell gets rid of its waste. If successful, the project may lead to ways of testing potential therapies.

Cellular and molecular mechanisms of C9orf72 neurodegeneration (948-795)		**Therapeutic targets**
Lead investigator	Dr Arpan Mehta	
Lead institution	University of Edinburgh	
Co-investigators	Prof Siddharthan Chandran and Prof Giles Hardingham	
Cost: £138,566	**Type of grant:** Clinical Research Fellowship	August 2017 - July 2020

One of the cellular pathways that might be affected in people with MND might also be associated with the length of projections coming from motor neurons (neurites), and the way this defect is coded in the DNA. Using iPSC technology, the researchers will investigate motor neurons of people with C9orf72-related MND and of healthy controls to see whether motor neurons of people with MND have a reduced neurite length and, if so, whether this might be due to a common mistake in the way DNA is transcribed into RNA.

Lady Edith Wolfson Fellowship

Is reduced dynein function a cause and a risk factor of MND? (852-791) **A**		**Therapeutic targets**
Lead investigator	Prof Luc Dupuis and Prof Majid Hafezparast	
Lead institution	University of Strasbourg	
Co-investigators	Dr Fabio Simoes	
Cost: £240,000	**Type of grant:** Project grant (Biomedical)	July 2017 - August 2020

This project is exploring the effect of the dynein protein on disruptions of the axonal transport system by introducing different amounts of dynein into mice. The mice will then be observed for changes in movements and muscle strength, indicating expression and progression of the disease. Results will provide information about the role of dynein in developing MND and whether it can be targeted as a potential therapeutic mechanism.

The role of RNA processing and long gene regulation in MND (885-792)		**Therapeutic targets**
Lead investigator	Dr Vincent Plagnol	
Lead institution	University College London	
Co-investigators	Dr Pietro Fratta, Prof Adrian Isaacs and Seth Jarvis (PhD student)	
Cost: £92,843	**Type of grant:** PhD Studentship	September 2017 - February 2021
This project is looking into the role of RNA dysregulation in order to identify key genes and pathways involved in developing MND. A technique called 'RNA-Seq' can be used to study all the RNA in a specific cell type. The student will analyse RNA-Seq data from data already generated by the team from human material and various animal models.		

Mechanisms and therapeutic entry points of C9orf72-related MND (856-791)		**Therapeutic targets**
Lead investigator	Dr Jean-Marc Gallo	
Lead institution	King's College London	
Co-investigators	Prof Franca Fraternali and Dr Sarah Mizielinska	
Cost: £82,765	**Type of grant:** Project grant (Biomedical)	February 2018 - September 2020
Mutations in the C9orf72 gene have a negative effect on many normal functions within a cell, leading to development of MND. The aim of this project is to investigate which mechanisms cause disruptions in the cells as a result of the C9orf72 mutation. The team will use mathematical and computational analyses to work out the most likely mechanisms altered in MND as a result of the mutation. Findings will provide more information on the toxic mechanisms involved in MND.		

Targeting disease pathways in a novel model of MND (851-791) **A**		**Therapeutic targets**
Lead investigator	Prof Linda Greensmith	
Lead institution	University College London	
Co-investigators	Prof Rickie Patani and Dr Bilal Malik	
Cost: £197,346	**Type of grant:** Project grant (Biomedical)	January 2017 - December 2020
Mutations in the SETX gene cause a rare form of juvenile MND (ALS4). This project will work with mice with the SETX mutation and human motor neurons reprogrammed from stem cells of people with ALS4. The researchers will observe disruptions in the neuronal transport system and formation of stress granules and compare the findings from mice and human stem cells. The findings should help determine a common cause of neuronal death in SETX-related MND.		

A genetic study of phenotypic modifiers in C9orf72 gene carriers (864-791)		**Therapeutic targets**
Lead investigator	Prof Chris Shaw	
Lead institution	King's College London	
Co-investigators	Prof John Powell and Dr Isabella Fogh	
Cost: £149,500	**Type of grant:** Project grant (Biomedical)	January 2019 - December 2020
Previously this team found evidence for 'modifier genes', genetic variants that influence age and site of onset of disease, survival and expression of behavioural FTD symptoms in MND patients with a C9orf72 mutation. This project will find more of these variants. By finding and understanding the role of these variants, this study will find novel targets and pathways for treatment that may delay onset or slow progression.		

C21orf2 as a risk factor for MND - the link between cilia and MND (866-791) **A**		**Therapeutic targets**
Lead investigator	Dr Vasanta Subramanian	
Lead institution	University of Bath	
Co-investigators	Dr Ross Ferguson	
Cost: £139,473	**Type of grant:** Project grant (Biomedical)	January 2019 - December 2020
The gene C21orf2 is a genetic risk factor leading to the development of MND. However, not much is known about the function of C21orf2 in the nervous system. It is believed to be important in making cellular structures called cilia that help the cell to sense signals and play a role in cell movement. This study will use a mouse model of MND and stem cells which carry the C21orf2 MND variants to improve understanding of the functions of C21orf2, disease mechanisms and develop therapeutic interventions.		

The role of Annexin A11 and Calcyclin in MND (888-792) **A**		**Therapeutic targets**
Lead investigator	Dr Brad Smith	
Lead institution	King's College London	
Co-investigators	Dr Salvatore Adinolfi, Prof Corinne Houart and Valentina Marchica (PhD student)	
Cost: £95,746	**Type of grant:** PhD Studentship	February 2018 - January 2021
The recently identified new gene ANXA11 accounts for a modest (~1%) proportion of familial and sporadic MND cases. In ANXA11 MND cases, tissue from MND patients, and SOD1 MND model mice, there is extra calcyclin protein (a small calcium binding protein) in astrocytes of the spinal cord, during the disease. This suggests calcyclin may be a signature of MND. The project will understand if calcyclin is toxic and/or protective and understand the functional role of this molecule in MND.		

Mechanism of disease onset of C9orf72 ALS/FTD (890-792) **A**		**Therapeutic targets**
Lead investigator	Dr Frank Hirth	
Lead institution	King's College London	
Co-investigators	Manpreet Atwal	
Cost: £81,175	**Type of grant:** Project grant (Biomedical)	February 2019 - February 2021
The two biggest areas of research into why motor neurons die in MND are studies of the C9orf72 gene and clumps or depositions of the TDP-43 protein. Using a fruitfly model of MND with the faulty gene, this project will examine what is happening in the early stages of the disease by looking at how faulty C9orf72 affects the accumulation of the TDP-43 protein.		

Functional characterisation of ANXA11 mutations in iPS-neurons (80-893-792)		**Therapeutic targets**
Lead investigator	Prof Chris Shaw	
Lead institution	King's College London	
Co-investigators	Erin Hedges (PhD student)	
Cost: £50,000	**Type of grant:** PhD Studentship	April 2019 - March 2021
A previous major project grant to the applicant funded a post-doc and a technician to generate and characterise a set of induced pluripotent stem cell lines (iPSCs) from stored frozen lymphoblasts originally from people with MND. While working on that project, the technician was registered for a part-time PhD. This grant provides funds to enable her to become a full-time student for up to two years and therefore complete enough independent work for a PhD. She will use iPSCs generated in the previous project to generate and study neuronal cells carrying a specific genetic mistake that has only recently been identified as a cause of some cases of inherited MND. This gene codes for a protein called Annexin A11.		

Role of immune-related autophagy and inflammation in C9-ALS/FTD (862-791) **A**		**Therapeutic targets**
Lead investigator	Dr Kurt De Vos	
Lead institution	University of Sheffield	
Co-investigators	Dr Andrew Grierson and Dr Emma Smith	
Cost: £216,197	**Type of grant:** Project grant (Biomedical)	September 2018 - August 2021
This project will investigate MND caused by a C9orf72 defective gene which results in inflammation when the waste removal system of the cell, a process called autophagy, is not working properly and causes a build-up of toxic waste. The researchers will test a number of drugs that increase the autophagy process using zebrafish and in cells donated by patients, to see if these potential treatments reduce inflammation which it is hoped might benefit MND patients.		

Unravelling TDP-43 autoregulation: routes to therapy for ALS-FTD (865-791)		**Therapeutic targets**
Lead investigator	Dr Jemeen Sreedharan	
Lead institution	King's College London	
Co-investigators	Dr Michael Niblock	
Cost: £218,600	**Type of grant:** Project grant (Biomedical)	October 2018 - September 2021
At the centre of almost all cases of MND is an imbalance in a protein called TDP-43. This work will find ways to correct this by testing thousands of potential gene therapies at the same time to potentially reduce TDP-43 to normal levels. These studies could yield targets for therapy that will be important for most people with ALS.		

Connecting microRNA and autophagy disturbances in MND (887-792)		**Therapeutic targets**
Lead investigator	Prof Rob Layfield	
Lead institution	University of Nottingham	
Co-investigators	Dr Federico Dajas-Bailador and Sophie Foggin (PhD student)	
Cost: £89,500	**Type of grant:** PhD Studentship	October 2018 - September 2021
This project will look at the interplay of disturbances in microRNA and dysfunction of the cells' waste disposal system, and investigate how these two adverse processes together contribute to the death of motor neurons. The researchers will transform skin cells from people with MND with TDP-43 gene mutation into motor neurons and observe which microRNAs are critical in neuronal death, and if these have a negative impact on other MND related genes implicated in autophagy.		

Endoplasmic reticulum-mitochondria axis in MND and FTD (967-799) **A**		**Therapeutic targets**
Lead investigator	Dr Patricia Gomez-Suaga	
Lead institution	King's College London	
Co-investigators	Prof Chris Shaw and Prof Chris Miller	
Cost: £259,997	**Type of grant:** Non-clinical Fellowship (Junior)	May 2018 - October 2021
A number of adverse processes in the cells of people with MND are caused by inadequate communication between two cellular structures – mitochondria (producing energy for the cell) and endoplasmic reticulum (ER; involved in creating proteins). A lack of contact between these structures in certain types of MND can then lead to selective death of motor neurons. Using cell and animal models, this project will investigate whether abnormalities in the C9orf72 gene cause damage to the communication between mitochondria and ER, potentially establishing a target for intervention. ***Lady Edith Wolfson Fellowship***		

Investigating ALS as a disease of the Tripartite Synapse (863-791) **A**		**Therapeutic targets**
Lead investigator	Dr Gareth Miles	
Lead institution	University of St Andrews	
Co-investigators	Prof Siddharthan Chandran and Dr Matthew Broadhead	
Cost: £236,987	**Type of grant:** Project grant (Biomedical)	December 2018 - November 2021

Changes in the connections between neurons, called synapses, and dysfunction of the main supportive cells of the nervous system, called glial cells, contribute to motor neuron loss in MND. This project will investigate the changes in synapses and glial cells in MND in mouse models, post-mortem tissue obtained from people with MND and combinations of motor neurons and glial cells from skin samples of people with MND.

Supported by Robert Barr's Charitable Trust

'MND's next top model: iPSC models according to protein aggregation (971-799)		**Therapeutic targets**
Lead investigator	Dr Dezerae Cox	
Lead institution	University of Cambridge	
Co-investigators	Prof Sir David Klenerman and Prof Chris Shaw	
Cost: £155,052	**Type of grant:** Non-clinical Fellowship (Junior)	TBC

Preventing toxic protein aggregates being formed or preventing them causing damage are possible ways to treat MND, and the presence of these aggregates could be used for early disease diagnosis. However, detailed understanding of the shape, size and properties of these aggregates has been hampered by their low abundance and the fact they can form many different types of clumps. Therefore, it remains unclear how well the cellular models used in MND research best represent the real disease. This project aims to use sensitive imaging techniques to enhance understanding of these aggregates. It will also characterise the protein aggregates formed in cellular models and compare them to the aggregates formed in patient-derived tissue, to determine which cell model is most realistic. This will help understand the fundamental biology underlying MND, particularly the role of aggregates, as well as assist in designing more realistic cell models.

Lady Edith Wolfson Fellowship

TDP-43 and p62 in ALS-FTD: when a molecular handshake goes wrong (970-799) **A**		**Therapeutic targets**
Lead investigator	Dr Daniel Scott	
Lead institution	University of Nottingham	
Co-investigators	Prof Rob Layfield, Prof James McInerney and Barry Shaw	
Cost: £254,115	**Type of grant:** Non-clinical Fellowship (Junior)	August 2019 - July 2022

A recently discovered interaction or 'molecular handshake' between TDP-43 protein that builds-up in and is toxic to diseased motor neurons, and another protein called p62 which controls key cellular 'waste-disposal' systems, indicates that this handshake could be harmful in affected individuals. The purpose of this fellowship is to understand the effect this might have on motor neurons and to investigate the utility of targeting p62 to prevent the build-up of toxic TDP-43 as a potential therapeutic strategy in MND.

Lady Edith Wolfson Fellowship

Understanding the role of NEAT1 in MND (968-799) **A**		**Therapeutic targets**
Lead investigator	Dr Tatyana Shelkovnikova	
Lead institution	Cardiff University	
Co-investigators	Prof Vladimir Buchman, Prof Dame Pamela Shaw and Camille Robesahala De Meritens	
Cost: £389,513	**Type of grant:** Non-clinical Fellowship (Senior)	September 2018 - August 2022
An RNA molecule called NEAT1 forms the scaffolding of small compartments in a cell's nucleus (the paraspeckle). It has been suggested the way NEAT1 is created may be altered and that these changes might be common to both sporadic and familial MND and differentiate them from FTD. This project will model NEAT1 in human motor neurons and fruit flies and observe how it responds to stress and toxicity within neurons. Understanding the adverse processes regulated by NEAT1 might provide a potential target for therapy. ***Lady Edith Wolfson Fellowship supported by the Wolfson Foundation***		

Investigating early stage protein translation deficits with mice/iPSC (868-791) **A**		**Therapeutic targets**
Lead investigator	Dr Pietro Fratta	
Lead institution	University College London	
Co-investigators	Dr Thomas Cunningham, Prof Elizabeth Fisher, Dr Bernadett Kalmar, Prof Rickie Patani, Prof Giampietro Schiavo and Dr Maria Secrier	
Cost: £209,295	**Type of grant:** Project grant (Biomedical)	October 2019 - September 2022
A new mouse line bearing mutations in the FUS gene develops an aggressive MND phenotype over 3 months. This project will thoroughly characterise these mice and their motor neuron loss to make the novel tool available to the MND research community. Secondly, these mice and patient-derived cells will be used to determine whether the making of new proteins is impaired and if it is an early mechanism of disease. The findings of the project could help in development of new therapeutic strategies to modify disease progression.		

Predicting disease course in the C9orf72 BAC mouse model of MND (871-791) **A**		**Therapeutic targets**
Lead investigator	Dr James Alix	
Lead institution	University of Sheffield	
Co-investigators	Dr Johnathon Cooper-Knock, Dr Richard Mead, Prof Visakan Kadirkamanathan, Dr John Day	
Cost: £220,001	**Type of grant:** Project grant (Biomedical)	October 2019 - September 2022
An extremely valuable mouse model has been developed to display many of the hallmarks of the human condition, including its unpredictability. This project will examine the mice in detail using a variety of tests that look at how different parts of the brain and spinal cord work. Advanced mathematical methods will be used to develop a way to detect when the disease starts and predict how it is going to progress. The results will enable scientists to better understand the disease and how it develops to enable better research studies to be designed and develop new treatments.		

Understanding RNA dysfunction through novel RNA-seq technologies (20-893-792) **A**		**Therapeutic targets**
Lead investigator	Dr Pietro Fratta	
Lead institution	University College London	
Co-investigators	Prof Giampietro Schiavo, Dr Maria Secrier, Dr Thomas Cunningham, Dr Vincent Plagnol and Samuel Bryce-Smith (PhD student)	
Cost: £100,000	**Type of grant:** PhD Studentship	November 2019 - November 2022

Correct processing of RNA (molecules that carry information to make proteins from DNA) is crucial for survival. Proteins called TDP-43 and FUS are important for the processing of RNA. Novel mouse models carrying disease-causing mutations allow the study of presymptomatic stages of MND. This project will help understand how changes in TDP-43 and FUS impact on motor neuron RNA and survival. Molecular changes occurring in early stages of disease can be identified using RNA-sequencing (RNA-seq) technology. This knowledge will be invaluable for developing effective therapeutics and the project will allow application of cutting-edge technology to numerous MND mouse and human cell models.

The Masonic Charitable Foundation PhD Studentship

Converging minor intron splicing defects in MND (872-791)		**Therapeutic targets**
Lead investigator	Dr Marc-David Ruepp	
Lead institution	King's College London	
Co-investigators	Dr Sarah Mizielinska	
Cost: £223,386	**Type of grant:** Project grant (Biomedical)	January 2020 - December 2022

The aim of this project is to identify which specific defects in minor intron splicing are shared between FUS, TDP-43 and C9orf72 gene mutations. To do this, human stem cells will be exposed to the various MND causing gene mutations and then will be grown into nerve cells. Cells with mutations in FUS (which can cause a very aggressive form of MND) and TDP-43 (the protein most commonly aggregated in MND) have already been created and now cells with the most common gene mutation (C9orf72) will be created. The project will look for changes in the minor intron splicing process to find potential new targets for drug development across all MND types.

Natural and synthetic chaperones for SOD1-related MND (969-799)		**Therapeutic targets**
Lead investigator	Dr Gareth Wright	
Lead institution	University of Liverpool	
Co-investigators	Prof Samar Hasnain and Prof Malcolm Jackson	
Cost: £289,590	**Type of grant:** Non-clinical Fellowship (Senior)	April 2019 - March 2023

SOD1 is a protein found in all human cells but sometimes it misfolds into abnormal shapes that are toxic to motor neurons, leading to their death. This project will search for drug molecules that help it fold properly and create synthetic proteins that will remove it using the cellular recycling system. Ultimately the project will help us understand what causes those instances of MND where SOD1 misfolding is present and find therapeutic applications.

Lady Edith Wolfson Fellowship supported by the Wolfson Foundation

Identifying disease modifying interactors of FUS at synapses (894-792) **A**		**Therapeutic targets**
Lead investigator	Dr Caroline Vance	
Lead institution	King's College London	
Co-investigators	Dr Anny Devoy and TBC (PhD Student)	
Cost: £97,310	**Type of grant:** PhD Studentship	October 2020 - September 2023
The project will investigate how FUS protein functions normally in the brain by identifying proteins that it interacts with at synapses (point of contact for brain cells) and seeing how these differ in disease. Two different and well-characterised mouse models of MND-FUS will be used to identify common pathways affected in disease. One recapitulates an early-onset aggressive fatal model of the human disease and the other models non-fatal late-onset. Advanced imaging will also be used to investigate how manipulating the FUS-interacting proteins within brain cells in a dish can reverse a known cellular defect (transport of proteins). This will identify potential therapeutic pathways for intervention in relevant disease cell types.		

Role of repetitive proteins in C9orf72-MND waste disposal dysfunction (896-792) **A**		**Therapeutic targets**
Lead investigator	Dr Sarah Mizielinska	
Lead institution	King's College London	
Co-investigators	Dr Patricia Gomez-Suaga and TBC (PhD Student)	
Cost: £97,311	**Type of grant:** PhD Studentship	October 2020 - September 2023
Defects in the C9orf72 gene can produce repetitive proteins which disrupt waste disposal (process called autophagy). If waste is not cleared effectively from brain cells, it builds up and clumps together affecting cell function and eventually leading to cell death. Autophagy requires certain proteins to be transported between the nucleus and cytoplasm. This project will investigate 1) how repetitive proteins disrupt autophagy and how this is related to the dysfunction of transport, 2) how that overlaps with loss of the C9orf72 protein and how the autophagy disruption affects the clearance of key disease-related cargo and 3) the therapeutic potential of autophagy inducers. This will hopefully help design new therapies to prevent the death of brain cells and thus the normal functioning in C9orf72-related MND.		

Investigating the role of NEK1 in ALS (895-792) **A**		**Therapeutic targets**
Lead investigator	Dr Kurt De Vos	
Lead institution	University of Sheffield	
Co-investigators	Dr Andrew Grierson and TBC (PhD Student)	
Cost: £88,475	**Type of grant:** PhD Studentship	October 2020 - September 2023
Mutations in the NEK1 gene are predicted to cause less NEK1 protein to be produced, thus not enough to do its job. The aim of this project is to understand why loss of NEK1 function causes MND by investigating precisely what NEK1 does and how it might connect to the cellular waste disposal process called autophagy. This knowledge could be used to correct the defects.		

Role of microglia-released microRNA in ALS Pathology (897-792) **A**		**Therapeutic targets**
Lead investigator	Prof Majid Hafezparast	
Lead institution	University of Sussex	
Co-investigators	Prof Nigel Leigh, Dr Lisa Mullen, Prof Sarah Newbury and TBC (PhD Student)	
Cost: £88,153	**Type of grant:** PhD Studentship	October 2020 - September 2023

Microglia (immune cells in the brain) are activated to release a number of proteins and chemicals which modulate the function of neighbouring motor neurons but at high levels can damage these cells. Recent data show that cultured microglia also release a group of molecules known as microRNAs (miRNAs) with different expression in non-activated and activated states. There is increasing evidence that miRNAs released from microglia play an important role in cell-to-cell communication by modulating gene expression in adjacent cells. This PhD project will use normal and mutant mouse models of MND, cell and molecular biology techniques alongside bioinformatics tools to identify the key disease-associated miRNAs and the genes targeted by these miRNAs.

Spatiotemporal diversity of cellular and molecular mechanisms in MND (950-795) **A**		**Therapeutic targets**
Lead investigator	Prof Rickie Patani	
Lead institution	University College London	
Cost: £150,000	**Type of grant:** Clinical Research Fellowship	May 2019 - February 2024

To understand precisely what goes wrong in MND and where, this project uses iPSC technology. This is where skin cells from patients are 'tricked' into becoming stem cells and are then transformed into motor nerves. New problems are identified within messages that normally make the protein, also with misplacement and malfunction of these proteins. As well as the motor nerves, 'supporting' cells called astrocytes are found to be co-conspirators in MND. Another major aspect of the proposed work is understanding how ageing makes these cells vulnerable to MND. Studying these aspects will help to identify key processes that can then guide new therapy development.

Lady Edith Wolfson Fellowship

Impact of TDP-43 on translation and response to axonal damage in ALS (951-795) **A**		**Therapeutic targets**
Lead investigator	Dr Pietro Fratta	
Lead institution	University College London	
Cost: £175,000	**Type of grant:** Clinical Research Fellowship	October 2019 - September 2024

TDP-43 is a protein important for the specific transport of RNA to different locations in the axons and in the response of cells to stress and damage. This project will combine novel mouse models and patient cell lines to investigate how TDP-43 impacts the response of motor neurons to damage in the axons, and the relevance of this response pathway in ALS. It will help to understand how changes in TDP-43 impact motor neuron survival. This information will be essential to develop effective therapeutics.

Lady Edith Wolfson Fellowship

C9orf72 zebrafish model to investigate disease modifying therapy (854-791) **A**		**Treatment pipeline**
Lead investigator	Dr Tennore Ramesh	
Lead institution	University of Sheffield	
Co-investigators	Dr Guillaume Hautbergue, Prof Dame Pamela Shaw and Dr Alex McGown	
Cost: £248,143	**Type of grant:** Project grant (Biomedical)	August 2017 - July 2020
Changing the levels of SRSF1, a natural part of cellular transport, has the potential to reduce toxicity in C9orf72-related mutations, a genetic mistake known to cause MND. In this project, Dr Ramesh and colleagues will use a new zebrafish model of C9orf72 to test effectiveness of altering SRSF1. This model was chosen as studying the effects in the zebrafish system is relatively inexpensive, efficient and quick.		

Developing strategies to promote muscle reinnervation in MND (965-799) **A**		**Treatment pipeline**
Lead investigator	Dr Barney Bryson	
Lead institution	University College London	
Co-investigators	Prof Linda Greensmith and Prof Giampietro Schiavo	
Cost: £272,579	**Type of grant:** Non-clinical Fellowship (Senior)	August 2017 - July 2020
This project uses stem cells from mice transformed into motor neurons which will be used to create new muscle neuron connections. These will be implanted back into the mice and observed for how well the neurons connect with muscles. The researchers will then identify the chemicals that promote successful innervation. This study has the potential to contribute to the development of a new therapy by replacing damaged motor neurons and restoring lost muscle function. ***Lady Edith Wolfson Fellowship supported by the Wolfson Foundation***		

CDNF and CDNF variants - novel therapy for ALS (859-791) **A**		**Treatment pipeline**
Lead investigator	Prof Mart Saarma	
Lead institution	University of Helsinki	
Co-investigators	Prof Michael Sendtner	
Cost: £37,500	**Type of grant:** Project grant (Biomedical)	October 2017 - September 2020
Stress in the endoplasmic reticulum (ER) was found to be one of pathogenic processes in ALS. Cerebral dopamine neurotrophic factor (CDNF) is a newly-discovered protein that regulates stress in the ER and has the potential to protect and restore neurons. Unlike other neurotrophic factors, CDNF's ease of passage through the blood-brain barrier allows it to spread throughout the brain. This project will test the therapeutic effect of CDNF in motor neuron cells, in mice and using iPSCs from people with ALS.		

Generation and validation of Open Access antibodies for MND research (988-797)		**Treatment pipeline**
Lead investigator	Dr Opher Gileadi	
Lead institution	University of Oxford	
Cost: £150,000	**Type of grant:** Project grant (Biomedical)	January 2018 - January 2021
Researchers purchase or generate their own antibodies, substances needed to study specific chemical reactions, to study MND in their labs. However, it is estimated that up to half of these don't work as they should, possibly yielding questionable study results. This initiative will bring together the experts in the field to create a standardised procedure to characterise all the antibodies used by MND researchers worldwide. Once created, researchers can consult the database and be more assured that the results they generate will be of the highest quality.		

Manipulating the heat shock response pathway for ALS therapy (858-791)		**Treatment pipeline**
Lead investigator	Dr Han-Jou Chen	
Lead institution	University of York	
Co-investigators	Prof Chris Shaw and Dr Hon Kwan (Anita) Ho	
Cost: £245,370	**Type of grant:** Project grant (Biomedical)	August 2018 - May 2021
By increasing levels of the heat shock factor (HSF1), the tendency of the TDP-43 protein to clump together, accumulate and cause death of motor neurons decreases. HSF1 was already found to be reduced in spinal cords of people with MND, suggesting that lack of HSF1 contributes to accumulation of TDP-43. Dr Chen will apply a specialised gene therapy technique in a mouse model to investigate the effectiveness of increasing HSF1 levels on reducing disease symptoms. The findings could lead to identification of new drugs that might act on HSF1.		

MIROCALS: Efficacy and safety of low-dose Interleukin-2 (940-794)		**Treatment pipeline**
Lead investigator	Prof Gilbert Bensimon and Prof Nigel Leigh	
Lead institution	University Hospital Centre of Nîmes & University of Sussex	
Cost: £590,387	**Type of grant:** Project grant (Healthcare)	February 2019 - July 2021
The Modifying Immune Response and Outcomes in Amyotrophic Lateral Sclerosis (MIROCALS) study aims to investigate Interleukin-2 as a potential treatment for MND. Interleukin-2 has been used for many years to treat cancer. However, at low doses it is much safer but still effective against a number of immune diseases. Because the immune system is thought to be involved in causing damage in MND, the researchers believe it may be beneficial in treating MND too. This study aims to recruit 216 people living with MND in the UK and France. ***Supported by the Garfield Weston Foundation, J P Moulton Charitable Foundation and the Batchworth Trust***		

Validation of non-coding biomarkers (861-791) **A**		**Clinical progression**
Lead investigator	Prof Majid Hafezparast	
Lead institution	University of Sussex	
Co-investigators	Prof Nigel Leigh, Prof Sarah Newbury, Prof Martin Turner and Dr Greig Joilin	
Cost: £ 158,299	**Type of grant:** Project grant (Biomedical)	September 2018 - August 2020

There are currently no robust biomarkers to detect MND, with diagnosis being based on clinical examination. This project will build on Dr Hafezparast's previous work where several molecules, called non-coding RNAs, were shown to be present at abnormal levels in the blood and cerebrospinal fluid of people with MND. They will now test the levels of these molecules in a larger number of people as well as in post-mortem brain tissue. Validation of these molecules as biomarkers would allow earlier diagnosis and tracking of disease progression in clinical trials.

Energy expenditure in people with ALS (921-793)		**Clinical progression**
Lead investigator	Prof Ammar Al-Chalabi	
Lead institution	King's College London	
Cost: £9,000	**Type of grant:** Small grant (Healthcare)	October 2017 - September 2020

Understanding how much energy is expended by people with MND is important as there is increasing evidence that the weight loss most people experience is in excess of what can be accounted for by muscle loss or reduced calorie intake. This project will repeatedly measure muscle mass and energy expenditure in people with MND to examine changes in metabolism as the disease progresses, and how these relate to prognosis and feelings of fatigue.

A Multicentre Biomarker Resource Strategy in ALS: AMBRoSIA (972-797)		**Clinical progression**
Lead investigator	Prof Martin Turner	
Lead institution	University of Oxford	
Co-investigators	Prof Andrea Malaspina and Prof Dame Pamela Shaw	
Cost: £ 2,006,834	**Type of grant:** Project grant (Biomedical)	August 2016 - July 2021

This project will collect blood, urine and skin cells from 900 people with MND and over 400 people without the disease. The blood and urine samples will be subjected to an extensive analysis to search for MND biomarkers. Skin cells can be used to reprogramme into motor neurons using iPSC technology. These are used to test the effects of new drugs on motor neurons. It also allows researchers to explore the possibility that different drugs may work for different subtypes of MND. The extensive collection of samples will also act as a resource for future research.

Supported by the Linbury Trust in memory of Annette Page, ballerina, the London City Swim Foundation and the PF Charitable Trust

NECTAR - Screening component of AMBRoSIA (974-797)		**Clinical progression**
Lead investigator	Prof Janine Kirby and Dr Pietro Fratta	
Lead institution	University of Sheffield and University College London	
Cost: £382,000	**Type of grant:** Project grant (Biomedical)	November 2016 - July 2021
The NECTAR project will use the blood samples collected as part of the AMBRoSIA programme and conduct genetic analysis on these samples, looking for genetic mutations and variations known to be linked to MND. The results of these analyses will be used for research, to see if there are specific biomarkers that characterise the genetic forms of MND. There will also be the option for the person with MND, their families and future family members to find out the results of their genetic analysis - in other words, whether they are carriers of MND-related genes.		

A new strategy for clinical trials and personalised therapy in MND (870-791)		**Clinical progression**
Lead investigator	Prof Ammar Al-Chalabi	
Lead institution	King's College London	
Co-investigators	Dr Ahmad Al Khleifat	
Cost: £119,767	**Type of grant:** Project grant (Biomedical)	August 2019 - July 2021
Analysis of MND clinical trial data generally assumes it is one disease, rather than multiple diseases representing different underlying pathologies, but knowing how to subgroup patients for targeted trials is essential. Imaging based subgrouping methods such as brain scanning do not exist, and subgrouping based on disease hallmarks from brain and spinal cord tissue is not feasible while the affected person is alive. The propose of this project is to generate a DNA fingerprint for each person in an ongoing clinical trial 'MIROCALS' to understand why some people are likely to respond to treatment and others are not. The analysis will also extend to the biggest MND genetic project in the world (Project MinE) to ensure observations are not biased.		

Cognitive and behavioural impairment in MND-FTD (892-792)		**Clinical progression**
Lead investigator	Prof Laura Goldstein	
Lead institution	King's College London	
Co-investigators	Prof Ammar Al-Chalabi, Dr Silia Vitoratou and Lyndsay Didcote (PhD student)	
Cost: £95,574	**Type of grant:** PhD Studentship	October 2018 - September 2021
Assessment of changes in thinking and behaviour in people with MND is done using screening tools which offer a fast evaluation in the clinic. Due to the variety of tests there are and their different rules and criteria, various conclusions might be drawn from the different tests, potentially leading to people with MND being offered inadequate care. This project will compare different screening tools and see how they agree in terms of diagnosing behavioural and cognitive change in people with MND. Findings from this project will inform clinicians and researchers about the implications of using different measures.		

Statistical models and machine learning to find MND subgroups (869-791)		**Clinical progression**
Lead investigator	Dr Alfredo Iacoangeli	
Lead institution	King's College London	
Co-investigators	Prof Ammar Al-Chalabi and Prof Richard Dobson	
Cost: £166,383	**Type of grant:** Project grant (Biomedical)	October 2019 - September 2023
Current classifications of MND do not readily translate to relevant subgroups for treatment, nor do they reliably predict clinically important factors like survival. Machine learning is a method to use computers to find patterns in data. A particular form of machine learning, latent class cluster analysis, was previously applied to clinical information from neurologists and showed that MND can be considered as five subtypes. These subtypes strongly predicted survival, and more recently were the basis of a genetic study that found two genes that predict disease progression rate. Biological information can now be used to refine the subgrouping further to find new subtypes of MND for personalised medicine.		

Determining the gut microbiota in early ALS patients (860-791)		**Clinical progression**
Lead investigator	Dr Nikhil Sharma	
Lead institution	University College London	
Co-investigators	Dr Pietro Fratta, Dr Andrea Malaspina, Dr Jane Macnaughtan, Dr Vincenzo Libri, Dr Ian Jeffery	
Cost: £100,015	**Type of grant:** Project grant (Biomedical)	August 2019 - July 2022
It has recently been discovered that a functional link exists between the brain and microbes in the gut (microbiota). As microbiota have the ability to control immune cells in the brain (microglia) and the intestines, they have the potential to regulate cellular inflammation. Therefore, it is possible that manipulating the microbiome of people with MND might lead to reduction of inflammation in the central nervous system. This project will explore the association between the microglia and microbiome to establish it as a potential route for therapy.		

Advancing therapy development in MND - Martin Turner Professorship (989-797)		**Clinical progression**
Lead investigator	Prof Martin Turner	
Lead institution	University of Oxford	
Cost: £1,000,000	**Type of grant:** Project grant (Biomedical)	December 2018 - November 2023
This 5-year plan offers an important advance in understanding the core systems-level neurobiology of MND. For a multi-factorial, complex disorder of cortical dysfunction, it is clear that combinations of biomarkers are needed. Neuroimaging is a leading approach to develop more sensitive trial outcome measures, with the added value of biofluid analysis to clarify clinical variation. The aim of this professorship is to exploit the unique insights of neuroimaging, integrated with targeted analysis of cerebrospinal fluid (CSF), to develop sensitive outcome measures for the therapeutic era in MND.		

DeNDRoN MND Co-ordinator (933-794)		**Standards of care**
Lead investigator	Prof Chris McDermott	
Lead institution	University of Sheffield	
Co-investigators	Prof Dame Pamela Shaw and Stacy Young	
Cost: £108,001	**Type of grant:** Project grant (Healthcare)	August 2015 - January 2020

The Dementias and Neurodegenerative Disease Research Network (DeNDRoN) was established in 2005 to facilitate recruitment of patients into neurodegeneration research studies. In recent years around 12% of participants in DeNDRoN-registered studies have been recruited into an MND research project: a remarkable figure given that MND represents around 0.5% of neurodegenerative disease. A key reason for this success is the important role of the DeNDRoN Co-ordinator. This post is a wide-ranging role supporting clinical research from funding application stage through to study completion by assisting ethics submissions, supporting recruitment at individual centres and ensuring regular communication across the network.

Trial of home monitoring for Ventilatory Failure in people with MND (906-793)		**Standards of care**
Lead investigator	Dr Ian Smith	
Lead institution	Papworth Hospital NHS Foundation Trust	
Cost: £13,400	**Type of grant:** Small grant (Healthcare)	August 2017 - February 2020

This trial will test a hand-held device to diagnose the onset of breathing failure in people with MND. This would allow more remote and more frequent measurements of respiration, reduce the number of hospital attendances, and help the patients' doctor to identify start of breathing deterioration and guide the process to initiate non-invasive ventilation to support breathing. This support is known to improve quality and duration of life for people with MND.

A prospective observation of secretion problems in MND (ProSec) (960-794)		**Standards of care**
Lead investigator	Prof Chris McDermott	
Lead institution	University of Sheffield	
Co-investigators	Prof Stephen Walters and Dr Sarah Boddy	
Cost: £124,728	**Type of grant:** Project grant (Healthcare - Marie Curie)	November 2017 - April 2020

As many as half of people with MND may have problems with excess saliva and for most of those, the symptom is not well managed. This project will be collecting information on how excess saliva is treated and how well the treatment worked. The need for more research into the management of excess saliva was highlighted by the MND NICE guideline and a recent research priority setting exercise.

Optimising quality of living throughout the course of MND (Opt-Life) (929-794)		**Standards of care**
Lead investigator	Prof Carolyn Young	
Lead institution	Walton Centre Liverpool	
Co-investigators	Prof Dyfrig Hughes and Dr Alan Moore	
Cost: £296,703	**Type of grant:** Project grant (Healthcare)	April 2016 - December 2020

This project aims to develop patient-reported outcome measures and a model of quality of life for people with MND. It is part of a wider study called TONiC, and participants will be asked to fill out a questionnaire pack in order to identify factors affecting quality of life. As the researchers are also looking at the health costs associated with MND, the project will help with future economic evaluations of new medicines and interventions in MND.

Improving early recognition of MND in primary care (939-794)		**Standards of care**
Lead investigator	Prof Julia Hippisley-Cox	
Lead institution	University of Oxford	
Co-investigators	Prof Carol Coupland	
Cost: £72,001	**Type of grant:** Project grant (Healthcare)	January 2020 - January 2021

This project aims to identify and quantify the 'red flag' symptoms associated with a diagnosis of MND. These will then be included in the electronic health record system used by General Practitioners across the UK to ensure that people with MND are identified early but without too many alerts being generated for people who do not have the disease.

The MND Register of England, Wales and Northern Ireland (926-794, 200-421)		**Standards of care**
Lead investigator	Prof Ammar Al-Chalabi and Prof Kevin Talbot	
Lead institution	King's College London and University of Oxford	
Co-investigators	Andrea Bredin, Sarah Opie-Martin and Lynn Ossher	
Cost: £519,027	**Type of grant:** Project grant (Healthcare)	October 2014 - February 2021

MND affects around 5,000 people in the UK at any one time, but the true figure is not known. The MND Register aims to capture this information across England, Wales and Northern Ireland. The number of people living with MND could give important clues to the cause of the disease and identify gene-environment interactions, and give us an accurate number of how many people within the UK are affected to help co-ordinate better care.

Supported by the Betty Messenger Charitable Foundation and a family trust that wishes to remain anonymous

Evaluation of post-gastrostomy management in MND (PostGas) (935-794)		**Standards of care**
Lead investigator	Prof Chris McDermott	
Lead institution	University of Sheffield	
Co-investigators	Dr Sarah Boddy, Dr Theocharis Stavroulakis	
Cost: £198,308	**Type of grant:** Project grant (Healthcare)	June 2017 - February 2021
Gastrostomy was found to be an effective way to manage malnutrition and resulting weight loss. However, research suggested that lack of information on nutrition after gastrostomy leads to continuing weight loss. This study will review current practices of post-gastrostomy nutritional care and explore reasons why some patients continue to lose weight after gastrostomy. This study is a continuation of the ProGas project, investigating the best gastrostomy methods in MND.		

Practical management of cognitive symptoms in MND - MiND Toolkit (934-794)		**Standards of care**
Lead investigator	Prof Eneida Mioshi	
Lead institution	University of East Anglia	
Co-investigators	Prof Michael Hornberger, Prof Lee Shepstone, Dr Godwin Mamutse and Dr Ratko Radakovic	
Cost: £199,957	**Type of grant:** Project grant (Healthcare)	May 2017 - April 2021
This project aims to develop a new toolkit to help patients and their carers to deal with behavioural and cognitive symptoms, including general loss of interest and empathy. The toolkit will be based on input from MND patients and their carers and subjected to clinicians' use in practice. The final step of this project is to create a set of guidelines to act as an official document helping patients, carers and professionals to manage behavioural and cognitive changes in MND. ***Supported by the John Jarrold Trust***		

Building the evidence base in MND (905-793)		**Standards of care**
Lead investigator	Dr Michael Lunn	
Lead institution	Cochrane Neuromuscular Disease Group	
Cost: £8,000	**Type of grant:** Small grant (Healthcare)	June 2017 - May 2021
The aim of this grant is to support publishing of research reviews into MND via the Cochrane Neuromuscular platform. This platform provides accessible, credible information to support informed healthcare decision-making, and aims to stimulate future work by highlighting evidence gaps and providing information for funding organisations and researchers as they plan to undertake clinical research.		

Web-based psychological intervention to reduce distress in MND (891-792)		**Standards of care**
Lead investigator	Prof Lucy Yardley	
Lead institution	University of Southampton	
Co-investigators	Dr Laura Dennison, Dr Adam Geraghty and Cathryn Pinto (PhD student)	
Cost: £79,612	**Type of grant:** PhD Studentship	October 2018 - September 2021

Emotional distress often leads to poor quality of life and potentially a poor prognosis. To support people with MND and their carers who are going through a great deal of emotional distress, this project aims to review existing therapy interventions and create an internet-based therapy intervention. As these interventions are web-based, they would be more practical for people with MND as they can access them from home.

Acceptance and COMmitment therapy for people with MND (COMMEND) (936-794)		**Standards of care**
Lead investigator	Dr Rebecca Gould	
Lead institution	University College London	
Co-investigators	Prof Chris McDermott and Prof Laura Goldstein	
Cost: £80,000	**Type of grant:** Project grant (Healthcare)	December 2017 - November 2021

People with MND experience distress due to the disease's nature and impact and, so far, there isn't enough evidence for effective ways to improve their psychological health. This study will adapt Acceptance and Commitment Therapy (ACT), a psychological intervention based on mindfulness, for people with MND to help them learn how to live with difficult emotions, thoughts and bodily sensations.

Supported by the Pixel Fund

Developing a web-based decision aid for gastrostomy in MND (963-794)		**Standards of care**
Lead investigator	Dr Sally Wheelwright	
Lead institution	University of Southampton	
Co-investigators	Dr Anne Hogden, Dr Alejandra Recio-Saucedo, Prof Claire Foster, Prof Karen Morrison and Prof Chris McDermott	
Cost: £94,576	**Type of grant:** Project grant (Healthcare - Marie Curie)	December 2018 - December 2021

Gastrostomy is offered to people with MND as a palliative care intervention when weight loss becomes problematic, with the assumption that it is the best method to provide long-term nutritional support. However, there is currently little evidence on increased survival, and the impact on patient and carer quality of life. As the decision about whether to undergo gastrostomy is a difficult one, this project aims to support this decision-making process by developing a patient decision aid.

Understanding experiences of inherited MND to develop Healthtalk (941-794)		**Standards of care**
Lead investigator	Prof Louise Locock	
Lead institution	University of Aberdeen	
Co-investigators	Prof Martin Turner, Prof Sue Ziebland, Adam Barnett and Ruth Sanders	
Cost: £44,420	**Type of grant:** Project grant (Healthcare)	October 2019 - March 2022
This study will interview families affected by inherited forms of MND to help build a new section on the research-based website "Healthtalk". The interview will include investigating how families make decisions around issues including predictive genetic testing and reproductive choices, how families communicate around the disease, and how they deal with genetic information. The resource will be a lasting source of information used to help support families affected by inherited MND, others going through similar experiences, and help train doctors, nurses, GPs and other health professionals to understand inherited MND.		

Task force to provide analysis of Diaphragm Pacing Studies in MND (937-794)		**Standards of care**
Lead investigator	Prof Chris McDermott	
Lead institution	University of Sheffield	
Cost: £15,000	**Type of grant:** Small grant (Clinical)	TBC
Weakness of the breathing muscles is a common feature of MND causing poor quality of life, breathlessness, recurrent chest infections and eventually death. The most effective treatment is a non-invasive ventilator (NIV) which can be difficult for individuals to use so there is a need for additional and alternative options. Another option is to use Diaphragmatic Pacing (DP), however, the results about its safety and effectiveness have been conflicting. The aim of this project is to assemble a task force to oversee an independent analysis of all the available data on DP in MND to understand the differing results and explore if there are potentially people who may benefit from DP.		

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Bold = Principal investigator; PhD = PhD student; CF = Clinical Research Fellow; NF = Non-Clinical Fellow

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We also fund research in
Australia, France, Finland, Germany

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