mnda
motor neurone disease
association

MND EnCouRage UK

10 July 2024

Staverton Park Hotel and Golf Club
Daventry, Northamptonshire

PROGRAMME

Foreword

Welcome to MND EnCouRage UK 2024

MND EnCouRage is as unique event, where passion meets purpose, and we celebrate the important work carried out by early career researchers (ECRs) who have chosen to investigate MND.

What makes MND EnCouRage truly special is its diversity of participants. The brightest and best ECRs meet with their peers and senior researchers, industry representatives and those living with and affected by MND to form a community united by a singular mission – to drive MND research forward to find effective and accessible treatments and, one day, a cure.

This year's programme includes panels to spark dialogue, workshops that nurture skills, presentations to inform and inspire, and activities that lay the groundwork for collaborations and friendships that will last long into the future. With topics ranging from genetics to clinical trials, and our 'Ask the Experts' panel – where curiosity meets expertise – EnCouRage UK provides the perfect opportunity for people from all backgrounds to learn about the MND research that is being carried out now.

An exciting part of the event is the Lightning Talks. Twenty-two ECRs get three minutes each to impress, inform, and inspire. These quick but remarkable talks bring their research to life. It's top-notch science communication, showing how simplicity and passion can be truly captivating.

MND EnCouRage is more than just a meeting. Every connection made and every idea shared brings us closer to our goal – a world free from MND.

"I always love attending MND EnCouRage. It is a wonderful combination of early career researchers full of enthusiasm, more established scientists, and people living with and affected by MND, all able to share their experiences, ask questions and provide insights. I strongly recommend it for anyone at the start of their journey in research into motor neurone disease, helping us accelerate the search for a cure." *Prof Ammar Al-Chalabi, King's College London.*

We wish you a very informative and enjoyable experience.

Mandy Spencer
Research Engagement Officer
MND Association

Dr Nick Cole
Head of Research
MND Association

Agenda *(subject to change)*

Wednesday 10th July

12.45 – 13.15 LUNCH		
	Please join us for lunch in the County Suite foyer	

13.45 – 16.15 Lightning Talks		
13.45	Welcome to MND EnCouRage UK 2024	*Mandy Spencer, MND Association*
13.50	Lightning Talks – Part 1	
14.30	Q&As	***Chairs** – Dr Nick Cole, MND Association and Dr Scott Allen, University of Sheffield*
14.45	**BREAK**	
15.00	Lightning Talks – Part 2	
15.40	Q&As	***Chairs** – Dr Nick Cole, MND Association and Prof Janine Kirby, University of Sheffield*
15.55	**BREAK**	

16.15 – 19.00 Ask the Experts and research updates		
16.15	Introduction	*Mandy Spencer, MND Association*
16.20	Controversy in clinical trials *A round-table discussion about the design and purpose of clinical trials*	*Prof Ammar Al-Chalabi, King's College London*
17.20	**BREAK**	
17.40	Ask the Experts *Put your research questions to our panel of leading MND researchers and clinicians*	***Chair** – Dr Nick Cole, MND Association*
18.10	Genetic testing and research *(TBC)*	*Prof Martin Turner, University of Oxford*
18.30	Patient engagement in early drug discovery	*Dr Paul Wright, LifeArc*
18.50	Thank you and feedback	*Mandy Spencer, MND Association*
18.55	Closing remarks	*Tanya Curry, CEO, MND Association*

Please join us for drinks in the County Suite Braz Bar followed by dinner at 19.30

Lightning Talks Part 1

1 Miss Katie Bowden, University of Sheffield

Astrocytes & neurones: From friend to foe

It is the role of astrocytes – a support cell in the brain – to maintain a healthy environment and support neurones by providing nutrients and clearing debris. However, in MND it has been shown that these cells become toxic, damaging the neurones and contributing to their degeneration. I am therefore looking to determine what changes occur in astrocytes which cause them to become toxic and I then plan to identify whether a drug can reduce this toxicity and promote motor neurone survival.

2 Miss Lexie Urquhart, Newcastle University

Targeting mitochondria as a treatment in motor neurone disease

Motor nerves (MNs) travel from the brain, via the spinal cord, to muscles and carry messages telling them to move. Motor neuron disease (MND) is a devastating disease in which MNs die leading to paralysis and death, typically within 5 years of diagnosis. There are currently no treatments. I am trying to understand why MNs die in MND using motor nerves (grown from stem cells) to study the connection between MNs and muscles, known as the neuromuscular junction 'in a dish'. I am interested in whether mitochondria (which provide energy) at this connection could be a therapeutic target in MND.

3 Dr Ben Middlehurst, University of Liverpool

Improving the quality of life for people with MND using genomic analysis within the TONiC study

We aim to improve the quality of life for people with MND by using a combination of clinical questionnaire data within the Trajectories of Outcome in Neurological Conditions (TONiC) study and genomic analysis. Participants within TONiC complete multiple questionnaire packs over time which allows us to identify groups of participants into different severity groups. We then take blood samples to measure changes in biological signatures over time and compare this with the information from the TONiC questionnaires, spanning disease severity, progression and well-being (disability, mood and symptoms), to help shape individualised care and therapies from the first visit to clinic.

4 Ms Abby O'Sullivan, UKDRI/University of Edinburgh

Beyond the single fix: Establishing models of ALS/MND to identify new combination drug therapies

By the time people present with symptoms of ALS/MND, multiple key processes essential for maintaining a healthy nervous system are dysfunctional. Research focused on single compounds targeting only one feature of ALS/MMND has resulted in high failure rates in clinical trials. We have performed high-throughput screening to identify existing drugs that may be therapeutic for ALS/MND. Now, we are seeking to identify drug treatments or combinations that can target multiple pathways simultaneously. We have developed disease-relevant models that can be used to test whether these treatments could be helpful in slowing or stopping ALS/MND.

5 Miss Alya Masoud Abdelhafid, UCL Queen Square Institute of Neurology

Analysing nerve transport changes in Motor Neurone Disease

There is currently a lack of effective therapies aiming to slow down progression of motor neurone disease (MND). Particularly, our knowledge of how MND develops and affects the survival of motor neurones is incomplete. Our findings indicate that axonal transport, which ensures long-range transfer of information between the neuronal periphery and the cell body, is impaired at the beginning of disease. We believe that the restoration of healthy long-range transport will block the process leading to nerve cell death and slow disease progression. We aim to identify whether novel substances can rescue transport in diseased neurones across the MND spectrum.

6 Dr David O'Brien, University of Sheffield

How does exercise affect the risk of MND in people with changes in the C9orf72 and SOD1 genes?
We know that carrying changes in the C9orf72 and SOD1 genes increases your risk of developing MND. The aim of this study is to assess if exercise plays a role in causing disease. Using a questionnaire of exercise history, we are interviewing those with the C9orf72 and SOD1 change, including people with MND and those who carry these genes but do not have MND. We have done 21 interviews so far, and are aiming to recruit 100 participants in total. We hope this study will improve our understanding about factors affecting the development of MND in people at genetic risk.

7 Mrs Modupe Aggreh, King's College London

The MND Register for England, Wales and Northern Ireland
Knowing where people with Motor Neuron Disease (MND) live, their age and their gender is important. It helps us learn more about MND and provides information about ease of access to care. That is why we created the MND Register for England, Wales and Northern Ireland. It currently covers 23 care centres participating across the country and there are over 8000 participants on the register with various age groups. There are more than 5000 men and 3000 women on the register and work is underway to complete the capture. The register is the largest one in the world by population covered.

8 Miss Uroosa Chughtai, Cardiff University

Investigating the role of MND/FTD genes in microglia
Neuroinflammation is a hallmark feature of motor neurone disease (MND) and related disorder frontotemporal dementia (FTD), with increasing evidence suggesting that the immune system plays a key role in MND/FTD onset and progression. Using cells in a dish, my research aims to investigate how genes associated with MND/FTD affect the function of the resident immune cells of the brain ("microglia") and how this may contribute to the death of neurons. So far, my research has shown that the loss of MND/FTD gene TBK1 in microglia is associated with an inability of microglia to perform some of their key functions.

9 Miss Razan Alomosh, Manchester Metropolitan University

Employing an in vitro human neuromuscular junction model to investigate the effects of the immune system on ALS involvement
The way that connections are formed between nerves and muscles, called neuromuscular junctions (NMJs), is influenced by certain substances in the body known as cytokines and growth factors. When the immune system malfunctions, it can cause the breakdown of these connections, leading to muscle loss and weakness, which is characteristic of Motor Neuron Disease. This research project focuses on studying how the proteins produced by T-lymphocytes from patients with Amyotrophic Lateral Sclerosis (ALS) affect the regeneration and function of motor neurons, NMJs, and muscle cells. According to the findings, the proteins produced by T-lymphocytes from ALS patients have harmful effects on motor neuron axons and the development of myotubes and motor neurons. These results could help to identify specific treatments for ALS patients by identifying targets for therapy.

10 Miss Samantha Rodrigues, University of Lancashire

An in-depth analysis of Prolonged Grief Disorder among informal MND caregivers in Northwest England and the impact of supportive care services
This study explores the impact of informal caregivers of individuals with Motor Neuron Disease (MND) on the psychological well-being, social support networks, service accessibility, utilisation of advanced care planning, and end-of-life circumstances for bereaved caregivers. Employing a mixed-methods approach with 63 participants, the findings highlight the importance of support infrastructure and psychological resilience in preventing the formation of prolonged grief disorder. The need of personalised support mechanisms tailored to the individual needs of grieving carers is emphasised, as is the recognition of study limits imposed by pandemic-related constraints.

11 Dr Yiran Wang, University College London

Targeting messaging glitches in motor neurone disease
Through induced pluripotent stem cell (iPSC) technology, we can generate highly pure and functional motor neurones that show signature MND features, including the misplacement of proteins in different cellular compartments. We identified a widespread form of corruption in generating RNA 'message' from the DNA 'blueprint' in MND motor neurones. Specifically, a part of the message that should be omitted remains within the final message, a process called intron retention, which could contribute to faulty positioning and/or impaired functioning of proteins and the development of disease. Identifying potential RNA targets serves as a new therapeutic avenue for MND treatment.

Lightning Talks Part 2

12 Dr Rebecca Saleeb, University of Edinburgh

Developing new tools to detect disease
Toxic clumps of protein are an early feature in several forms of MND, including ALS. Screening patients for these so-called "aggregates" could provide a much-needed early diagnostic, enabling clinicians to place patients in clinical trials earlier and improve the chances of therapeutic success. However, these aggregates are difficult to detect as they are extremely small (10,000 times smaller than the width of a human hair), and extremely rare. To overcome this, I have been developing advanced imaging tools that allow us to capture aggregates from patient samples and analyse them in unprecedented detail.

13 Dr Yasmin Ali, University of Sheffield

Creating an online system that improves access to Motor Neurone Disease research for people with MND: Telehealth in MND Research (TiM-R)
People with MND (pwMND) are faced with barriers to take part in research as their condition progresses. Telehealth in MND (TiM) is an online platform, created to enable pwMND access to participate in research regardless of where they live, and with minimal burden. It will act as an intuitive consenting and data collecting platform. Our research explores the needs of pwMND, carers, MND researchers, Healthcare practitioners, and industry representatives (from organisations conducting clinical research), through semi-structured interviews, to understand how TiM-R can be best used. Results will inform the final version of TiM-R and ensure its accessibility and usefulness.

14 Alicia Northall, University of Oxford

How can we combine different types of brain imaging data to understand MND?
At face value, routine MRI scans tell us little about brain changes in MND. However, detailed analysis of brain imaging data reveals widespread changes. Using MRI, we can measure how connected brain regions are to each other, based on their structure (anatomy) and function (brain activity). Another brain imaging method, magnetoencephalography (MEG), provides even more information about function-based connectivity. We can combine these methods to make use of their complementary strengths. This approach provides a more detailed understanding of brain changes in MND, which could be used to predict disease progression or test the effectiveness of drugs in clinical trials.

15 Mr Ayodeji Ijishakin, University College London

Prognostication of ALS disease with normative diffusion autoencoders
Predicting how long someone with Amyotrophic Lateral Sclerosis (ALS), will live is difficult. This is because not many people have it, so there is limited access to data. Additionally, the disease's effects on the brain are very subtle making them hard to detect with traditional techniques. Our approach uses an AI model that learns what healthy brains look like from a big group of healthy people. It then spots slight changes in patients with ALS, in-order to predict how long they may live for. We outperform previous approaches, demonstrating the utility of the approach.

16 Miss Milena Contreras, University of Edinburgh

Understanding how people living with MND make treatment decisions

Half of people living with MND may experience changes in their thinking and behaviour, with some developing a form of dementia. Such changes may include problems with planning, organisation and decision-making. However, it is currently unknown whether these changes have an impact on a person's ability to consent to medical treatments. This study found that the decision-making process involved in consenting to medical treatments (feeding tube) is affected in some people with MND. The use of specific support strategies was found helpful in enabling the person to maintain the capacity to make treatment decisions.

17 Miss Sophie Breen, University of Liverpool

Understanding the mechanism of action of new drugs for the treatment of C9orf72 related amyotrophic lateral sclerosis (ALS)

A mutation in a gene named C9orf72 is the most common cause of ALS. Previous work has shown that drugs targeting this mutation improve the hallmarks of disease, however, have negative side effects. Our work aims to use C9ALS/FTD patient samples to test if we can efficiently target this mutation with use of new drug technologies called antisense oligonucleotides. Drugs like these are currently being trialled for SOD1 ALS and have proven safe and effective. We wish to use a similar strategy for targeting the proteins that have been demonstrated to control C9orf72 to accelerate the development of new therapies.

18 Mr Ruaridh Lang, Sheffield Institute for Translational Neuroscience

Understanding the role of NEAT1 in altered energy metabolism in ALS, and development of NEAT1-targeting drugs

NEAT1 is a ribonucleic acid (RNA) molecule found in most cells of our bodies. It has recently been found to regulate glucose metabolism and is predicted to be important in cells of the nervous system - astrocytes (support cells) and neurons. Changes in the levels of NEAT1 are thought to contribute to abnormal energy balances commonly seen in ALS. I will explore this by using astrocytes and neurons growing in a dish, including genetic manipulations, and mouse model tissue. This should establish whether NEAT1 is a promising drug target in ALS - with drug development already underway in our lab.

19 Miss Laura Aiwanse Odemwingie, King's College London

Investigating the molecular basis for selective vulnerability in FET-linked amyotrophic lateral sclerosis (ALS) and fronto-temporal dementia (FTD)

FUS, EWSR1 and TAF15 are conserved RNA-binding proteins that make up the FET family and are involved in maintaining genomic stability. In ALS, mutations in the FUS gene lead to FUS cytoplasmic mislocalisation and toxic accumulation in neurons (inclusions). However, in Frontotemporal dementia (FTD), inclusions are made up of all three FET proteins with no causing mutation and including their nuclear import receptor TNPO1. We aim to characterise spatial and temporal production of FET proteins in the central nervous system of non-genetically modified mice throughout aging, providing insights into the differential and cell-specific vulnerability seen in FUS-ALS and FET-FTD patients.

20 Ms Avril Mc Tague, Trinity College Dublin

Connected rehabilitation in motor neurone disease – development of a digital platform

Digital technology may help people living with MND to access expert care in their homes. These technologies can connect people living with MND to the clinic between, or instead of visits. My research will develop an online platform with a range of advice for MND. The platform will support occupational therapists and physiotherapists to provide individually tailored advice and exercise for people living with MND.

21 Dr Ben Clarke, University College London

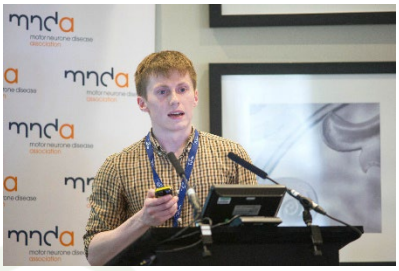
Human microglia from ALS patients display immune system defects

The main aim of my project is to investigate molecular changes in microglia, non neuronal cells that may contribute to motor neurone death in MND. I make microglia from stem cells which are created from skin cells taken from MND patients. With this "disease in a dish" approach, we have found molecular changes in microglia from MND patients related to their immune responses, which we hope may represent new drug targets for therapy.

22 Ms Sarah Gornall, University of Sussex/University of Sheffield

Investigating co-inheritance of rare variants in amyotrophic lateral sclerosis

In sporadic ALS- ALS where there is no family history- we are unsure as to what causes the disease. However, it may be due to inheritance of multiple specific changes to DNA carried by less than 1:1000 people (rare variants). By exploring data from Project MinE (a whole-genome sequencing database), and looking for patterns of inheritance in people with ALS, it may be possible to find a trend of rare variants in ALS-associated genes. We hope to establish if there is a clear correlation between carrying multiple rare variants in different genes, and ALS risk or age of onset.



"The presentations were so diverse and so exciting and so interesting. I've loved every second of it."

Person affected by MND, MND EnCouRage UK 2023

mnda
motor neurone disease
association

MND EnCouRage UK

Date: Tuesday 15 and Wednesday 16 July 2025

Abstract submission opens: February 2025

General registration opens: April 2025

Venue: Burleigh Court Hotel, Loughborough University (West Park), Loughborough, Leicestershire

Email: encourage@mndassociation.org

For the latest research news, visit our web pages:
www.mndassociation.org/research

If you have any questions about MND research, please email us at **research@mndassociation.org**

If you have any comments about MND EnCouRage UK, or suggestions for future events, please email us at **encourage@mndassociation.org**

If you have any concerns or issues relating to your MND journey or care, please contact our MND Connect Helpline:

Telephone: 0808 602 6262
Email: **mndconnect@mndassociation.org**
Website: **www.mndassociation.org/support-and-information/our-services/mnd-connect**