motor neurone disease association

MND EnCouRage UK 2023

27-28 June

Staverton Park Hotel and Golf Club

Daventry, Northamptonshire

PROGRAMME

Foreword

Welcome to MND EnCouRage UK 2023.

MND EnCouRage is a unique two-day event which aims to recognise, retain and encourage the important work of early career researchers (ECRs) who have chosen MND as their area of investigation.

It brings together the brightest and best ECRs in the UK with senior researchers and clinicians, and people living with and affected by MND for discussion, workshops, presentations, and activities focusing on the latest MND research.

A highlight of the event is the 'Lightning Talks' sessions where each of the ECRs are given three-minutes to present their work. This is a wonderful way for the ECRs to share their research, and passion, for the projects they have undertaken, and the perfect opportunity to learn more about the MND research that is being carried out now.

There are also plenty of opportunities for networking and building relationships that will last long into the future.

Now in its second year, MND EnCouRage UK is quickly becoming a hugely anticipated and popular event and we are very happy that you have chosen to be part of it. We wish you a very productive and enjoyable meeting.

Dr Nick Cole
Head of Research
MND Association

Mandy Spencer
Research Engagement Officer
MND Association

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We would like to thank our sponsors, LifeArc, for their support of MND EnCouRage UK 2023.

Programme

Tuesday 27 June (early career researchers)

09.00 – 09.35	**Networking and registration**	
09.00	Networking breakfast – join us for an informal breakfast and meet your fellow delegates and presenters	

09.35 – 15.05	**Communicating science to a non-scientific audience**	
09.35	Welcome to MND EnCouRage UK 2023	*Mandy Spencer, MND Association*
09.40	How to give brilliant talks *A 'presenter therapy' interactive workshop*	*Dallas Campbell, television and science presenter*
11.40	**BREAK**	
12.00	Lightning Talks – Part 1	*Mandy Spencer, MND Association*
12.40	Lightning Talks Feedback and Q&As	***Chairs** – Dr Nick Cole, MND Association and Dr David Taylor, ALS Society of Canada*
12.50	**LUNCH**	
13.50	Lightning Talks – Part 2	*Mandy Spencer, MND Association*
14.30	Lightning Talks Feedback and Q&As	***Chairs** – Dr Nick Cole, MND Association and Dr Caroline Vance, King's College London*
14.40	1-1 feedback	
14.55	**BREAK**	

15.05 – 16.10	**Real-world perspectives of MND**	
15.05	Introduction	*Dr Nick Cole, MND Association*
15.10	Real-world perspectives *Stephen Mallett, who is living with MND; Kirti Thakrar, who is an MND Association volunteer and former carer; and Prof Chris McDermott, Professor of Translational Neurology at SITraN, talk about their experiences of MND and current issues relating to MND research*	***Chair** – Dr Nick Cole, MND Association*
15.40	Q&As	***Chair** – Dr Nick Cole, MND Association*
15.50	**BREAK**	

16.10 – 18.00	**Navigating your career path**	
16.10	Introduction	*Dr Nick Cole, MND Association*
16.15	Working outside academia and industry (or in the middle)	*Dr Paul Wright, LifeArc*
16.35	Is there life outside the lab? Navigating non-academic routes	*Kristiana Salmon, QurAlis*
16.55	The trials and tribulations of MND research	*Dr Jacqueline Mitchell and Dr Caroline Vance, King's College London*
17.15	Differing pathways towards independence	*Prof Janine Kirby and Dr Scott Allen, University of Sheffield*
17.35	The global landscape of ALS/MND	*Dr David Taylor, ALS Society of Canada*
17.55	Looking forward to Day 2 and close	*Mandy Spencer, MND Association*

Please join us for a networking BBQ and drinks (finish approx. 20.30)

Programme

Wednesday 28 June (early career researchers from 10.15, other guests from 12.45)

10.15 – 11.00	**Networking breakfast**	
10.15	Join us for an informal breakfast and catch up with your fellow delegates and presenters	

11.00 – 13.45	**Media workshops**	
11.00	Welcome to Day 2 and introduction	*Mandy Spencer, MND Association*
11.05	Media Workshop 1 – Group A *Getting your work noticed responsibly and managing challenges* Media Workshop 2 – Group B *Sharing your news your way – a few tips to make you a great interviewee*	*Freya Robb, Science Media Centre and Dr David Taylor, ALS Society of Canada* *Suzanne Ostler, Head of Communications and Marketing, MND Association*
11.50	**BREAK**	
12.00	Media Workshop 1 – Group B *Getting your work noticed responsibly and how to manage challenges* Media Workshop 2 – Group A *Sharing your news your way – a few tips to make you a great interviewee*	*Freya Robb, Science Media Centre and Dr David Taylor, ALS Society of Canada* *Suzanne Ostler, Head of Communications and Marketing, MND Association*
12.45	**LUNCH**	

Delegates attending the afternoon and evening sessions only are welcome to join us in the County Suite for lunch

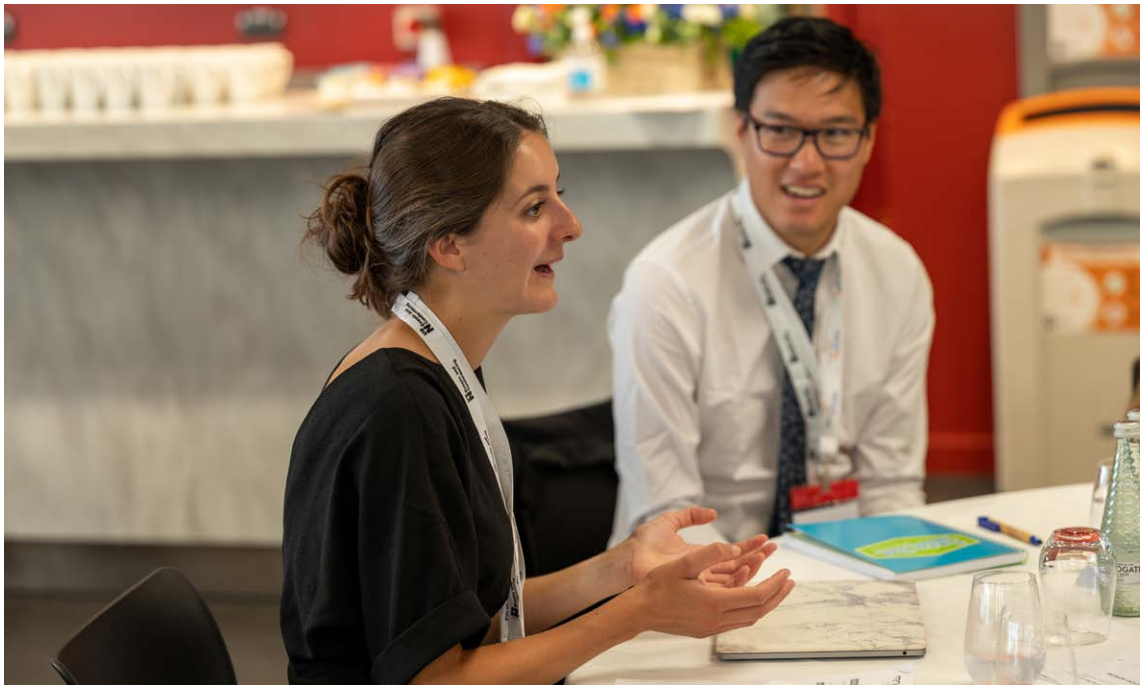
13.45 – 16.20	**Lightning Talks and Ask the Experts**	
13.45	Welcome to MND EnCouRage UK 2023	*Mandy Spencer, MND Association*
13.50	Lightning Talks – Part 1	
14.30	Q&As	***Chair*** *– Dr Nick Cole, MND Association and Prof Janine Kirby, University of Sheffield*
14.40	**BREAK**	
14.50	Lightning Talks – Part 2	
15.30	Q&As	***Chairs****– Dr Nick Cole, MND Association and Prof Ammar Al-Chalabi, King's College London*
15.40	Ask the Experts *Put your research questions to our panel of leading MND researchers and clinicians*	***Chairs*** *– Dr Nick Cole, MND Association* ***Panel*** *– Prof Ammar Al-Chalabi, King's College London* *Dr Caroline Vance, King's College London* *Dr Jacqueline Mitchell, King's College London* *Dr David Taylor, ALS Society of Canada* *Kristiana Salmon, QurAlis* *Prof Janine Kirby, University of Sheffield* *Dr Scott Allen, University of Sheffield* *Dr Paul Wright, LifeArc*
16.00	**BREAK**	

Programme

Wednesday 28 June (continued)

16.20 – 19.30	**Research updates**	
16.20	Introduction	*Dr Nick Cole, MND Association*
16.25	ALS Research: Media vs Data	*Dr David Taylor, ALS Society of Canada*
16.45	How to read a research paper: Why, How, What *A round-table workshop*	*Prof Ammar Al-Chalabi, King's College London*
17.45	**BREAK**	
17.55	Translating research to treatments and how to involve patients in drug discovery	*Dr Paul Wright, LifeArc*
18.15	Genetic testing for all? Lessons learned from instigating change in Canada	*Kristiana Salmon, QurAlis*
18.35	**Pre-dinner drinks in the County Suite Braz Bar**	
18.50	**DINNER**	
19.20	MND Community Research Advisory Network update and event feedback *Please take a few minutes to tell us what you thought of MND EnCouRage UK 2023*	*Mandy Spencer, MND Association*
19.30	Closing remarks	*Tanya Curry, CEO – MND Association*

Please continue to enjoy your dinner, then join us for drinks in the County Suite Braz Bar
(finish approx. 21.30)



Lightning talks Part 1

1 Identifying FUS interactions at the nerve terminal

My research focuses on understanding how a protein (FUS), which can be disrupted in some cases of MND, functions normally in the brain. I aim to identify the other proteins that FUS interacts with and then see how this differs in disease. I focus on the specific part of brain cells, where they connect to each other and information flows from one nerve cell to another. My research will increase our knowledge on why some mechanisms stop working during disease, why nerve connections are altered and provide new therapeutic targets.

Sara Tacconelli, King's College London

2 Developing a platform to improve the identification of therapies for Motor Neurone Disease (MND)

The project seeks to develop a highly reproducible cellular model of MND, amenable to large scale experimentation, to identify a cellular signature of the disease. Using machine learning and genetic engineering, this signature will be used to investigate genes linked to the disease. Validating these genetics would enable scientists to test potential new treatments for the disease at scale, transforming the fight against MND.

Finbar Gaffey, University of Sheffield

3 Studying new 'humanised' mouse models of ALS

Variations in the FUS gene cause particularly severe forms of ALS. The FUS gene is important for cells to function, which may explain why variations in this gene are so detrimental. I work with mice which have in their genetic code a human FUS gene variant which can cause ALS. It is hoped these 'humanised' mice more accurately represent disease mechanisms seen in patients. The mice have ALS-like symptoms including progressive muscle weakness, weight loss and hyperactivity making them useful tools to better understand what is happening in ALS, with the goal of preventing and slowing these changes in patients.

Georgia Price, University of Oxford

4 Targeting microRNAs in astrocytes to protect ALS motor neurones

Astrocytes are cells in the nervous system which protect motor neurones. However, in ALS, this protection is reduced, which worsens the neurodegeneration. It has been shown that increasing levels of the protein Nrf2 in astrocytes increases their protective ability. One way to alter levels of specific proteins is by targeting small RNA molecules called microRNAs. MicroRNAs are found throughout the body, therefore microRNA targeting is a possible therapeutic approach. We aim to increase Nrf2 in astrocytes by blocking specific microRNAs and investigate the effect this has on ALS motor neurones, to work towards a new therapeutic strategy in ALS.

Hannah Bailey, University of Nottingham

5 Developing a patient decision aid for genetic testing in MND

Genetic testing for people with MND is predicted to increase alongside advances in clinical trials. This could also see more family members facing decisions around pre-symptomatic testing. Our research explores experiences, decision-making and information/ support needs of people with MND and family members around genetic testing through semi-structured interviews and observations of clinic consultations. It also involves a survey to assess clinician views on MND genetic testing, confidence in carrying it out, and training priorities. Results will inform the development of a decision aid to support individuals with MND and family members in making informed choices around genetic testing.

Jade Howard, University of Sheffield

6 Evaluating models of Motor Neuron Disease molecule by molecule

A unifying characteristic of MND is the appearance of clumps of protein molecules, known as aggregates, in motor neurons. These aggregates are a leading candidate for causing motor neuron deterioration. However, aggregates are highly diverse and make up only a tiny fraction of the total molecules in motor neurons, making them extremely challenging to study. I am developing single-molecule methods that allow us to measure the number, shape and composition of individual clumps extracted from donated brain tissue. We can then use these aggregate characteristics to evaluate the accuracy of experimental models of MND used in the laboratory.

Dezerae Cox, University of Cambridge/ UK Dementia Research Institute

7 The Tale of Two Proteins in Motor Neuron Disease

Proteins must be located correctly and work normally to keep us alive. Two proteins are misplaced and aggregate abnormally in spinal cord neurons in motor neuron disease (MND). The most well-studied of these is TDP43. Comparatively little is known about the second, CystatinC, despite 86% of patients showing CystatinC aggregates at autopsy. We have shown a relationship between the two proteins: TDP43 only aggregates in neurons that have CystatinC aggregates. CystatinC normally promotes cellular survival; its aggregation likely causes the loss of this function. We aim to understand the implication of CystatinC aggregation and its link to TDP43 in MND.

Sarah Granger, University of Sheffield

8 Combining different types of data to help predict prognosis in motor neurone disease

Accurately predicting motor neurone disease (MND) prognosis can help to improve clinical trial design and efficiently manage patient care. In clinical practice, functional rating scales, blood tests, and more recently, brain imaging are routinely collected for monitoring MND. However, for predicting disease prognosis, using these types of data independently has been shown to be unreliable. My research focuses on using machine learning to combine these data sources, exploring their relationships, and assessing whether this leads to clinically useful prognosis prediction.

Florence Townend, University College London

9 Understanding cognitive and behavioural changes in people with MND

In addition to involvement of the nerve pathways controlling muscles and movement, some people with MND may also show changes in their thinking (cognition) and behaviour (e.g., difficulties with making decisions, finding words, apathy). However, we don't know why certain people experience these changes, when they first begin or how they develop over time. Some people with MND show cognitive difficulties when first assessed and continue to decline. This suggests that these symptoms may begin either around the same time, or perhaps even before, the appearance of physical symptoms. Our ongoing research aims to pinpoint when these symptoms first begin.

Caroline McHutchison, University of Edinburgh

10 Growing brain cells in 3D to study ALS

ALS is a disease that results in the death of cells called motor neurons, which signal for muscles to move, leading to paralysis. Researchers have discovered that the cells that surround motor neurons, called glia, contribute to the death of motor neurons. To find out how glia might be doing this, we need to investigate how motor neurons and glia interact. My project is therefore focussed on growing motor neurons and glia in 3D structures, to more closely replicate our nervous systems to help identify new treatments.

Marianne King, University of Sheffield

11 Disease mechanisms of C9orf72 ALS using human iPSC cultures and mouse models

A defect in a gene called C9orf72 is the most common cause of ALS, and our work seeks to understand how C9orf72 defects cause nerve cells to die in individuals with ALS. We focus on a specific class of molecules, called lipids, which makes up more than 50% of the brain. We found that C9orf72 defects change the levels of specific types of lipids in nerve cells and that restoring proper lipid levels can delay nerve cell death. We are now conducting experiments to test whether recovery of specific lipids is a viable therapeutic intervention for preventing nerve cell degeneration.

Alex Cammack, University College London

Lightning talks Part 2

12 Individualised information about your future with MND: developing a personalised prediction tool

MND progresses at different speeds in different people. As a result, it is challenging to give people with MND personalised information about their future, which can leave people feeling uncertain. Some parts of care, such as having a feeding tube inserted, have an optimum starting window. However, uncertainty about the future makes these complex decisions more difficult. We are developing a tool to offer people with MND personalised predictions about their future and help with care decisions. This tool is created using advanced computer algorithms that analyse data from 15,000 people with MND, looking for different patterns of MND progression.

Harry McDonough, University of Sheffield

13 Using extracellular vesicles to measure protein changes inside the brain

In diseases affecting the brain and spinal cord, such as MND, we are unable to look directly at the cells affected to identify changes that predict disease risk and progression. Extracellular vesicles are particles that are released from all cells in the body, including in the brain. From there, they enter bodily fluids such as cerebrospinal fluid (which bathes the brain and spinal cord) and blood, which we can access. Extracellular vesicles contain proteins that can tell us about the health of the cells that released them. By developing methods to separate brain vesicles from these fluids, we can quantify changes in protein levels that correspond to changes occurring inside affected cells in MND.

Elizabeth Dellar, University of Oxford

14 Using fruit flies to model cell structure in MND

The most common genetic cause of MND is a mutation in the C9orf72 gene. This mutation produces toxic proteins, called dipeptide-repeats (DPRs). Using our unique fruit fly models expressing DPRs of a size comparable to those observed in people living with MND we show DPRs disrupt the cytoskeleton, the cell's structural framework. Cytoskeletal-stabilising drugs reduce neurodegeneration in these flies.I am characterising how DPRs disrupt the cytoskeleton, causing neurodegeneration, by investigating interactions between DPRs and cytoskeleton regulators, as well as testing the potential of repurposing clinically approved cytoskeletal-stabilising drugs for MND.

Charlotte Gale, University of Sheffield

15 Mitochondrial function at the neuromuscular junction in motor neuron disease (MND)

Neuromuscular junctions (NMJs) are the specialised chemical synapses that form between motor neurons and their effector muscles. This process is energy demanding, and as such mitochondria - the organelles responsible for producing chemical energy - have been shown to accumulate at the NMJs. However, mitochondrial dysfunction at the NMJ sites has been implicated in the pathogenesis of MND. There is a significant need to understand this disease progression and to identify potential therapeutics for treating MND. Here, we aim to develop a human stem-cell-derived NMJ model to investigate the role of mitochondrial dysfunction in MND, which could offer potential targets for future clinical treatments.

Adam Creigh, Wellcome Centre for Mitochondrial Research, Newcastle University

16 Testing modified vitamin-A based potential new therapies in human-originated MND cell models

Motor neurone disease (MND) is a rapidly progressing neurodegenerative disease with no cure. Testing potential new drugs requires a laboratory-based model that mimics the disease conditions. While animal-originated cell models are often used, their ability to mimic the human condition is somewhat debatable and human-originated cell models circumvent these problems. I am developing a system, growing human brain and spinal cord cells from foetal tissue, where I apply stressors to imitate MND conditions to test potential new therapies. Presently tested is a therapy based on modified versions of the natural product vitamin-A, known to have neuroprotective, growth and regeneration properties.

Victoria Gorberg, University of Aberdeen

"AMAZING PRESENTATIONS GIVEN BY CARING AND COMMITTED PEOPLE"

Person affected by MND, EnCouRage 2022

17 How can the potential of existing technologies to monitor and support cough and secretion management be harnessed to improve outcomes for people with MND?

Saliva, secretion and cough problems are common in people with MND impacting quality of life, ability to implement respiratory interventions such as NIV and causing a risk of chest infections. Over 60% of patients attending our MND respiratory clinic experienced secretions enough to impact on their quality of life. Additionally, these patients reported difficulty accessing specialist care outside of their tertiary care centre as local teams lack the specialist knowledge and co-ordination required to manage these unique and complex issues. This project will work with people with MND and community therapy services to co-design a tool to support cough and secretion management closer to home using remote monitoring technologies.

Charlotte Massey, University of Sheffield

18 Measuring non-movement issues in ALS

ALS can cause issues with non-movement abilities such as thinking, paying attention and planning. I aim to find out what ALS does to the brain to cause these issues. I will measure non-movement issues over time in people with ALS using tasks which test these abilities. I will also directly measure activity in brain areas known to relate to these abilities, using electroencephalography (EEG). I will then look at what brain activity changes relate to the presence of non-movement issues. If we can detect these brain changes early, before non-movement issues appear, we could provide earlier treatment.

Serena Plaitano, Trinity College Dublin

19 Why did only one twin develop MND?

We collected skin biopsies from an athlete who had developed MND, early and later on in disease, and his healthy identical twin brother, who did not exercise. We converted the biopsies into helper cells called astrocytes, which usually maintain neuron health, but in MND, can damage neurons. The patients' astrocytes produced large amounts of harmful proteins early on in disease but did not kill neurons. Later in disease these proteins were reduced, but the astrocytes became toxic to neurons. The unaffected twin's astrocytes were comparatively healthy. Could exercise be responsible for these differences?

Allan Shaw, University of Sheffield

20 Profiling the actively synthesised proteins in motor neurons during different stages of a model of motor neuron disease

Although MND/ALS is a complex disease with mixed genetic and non-inherited causes, accumulation of TDP-43 in motor neurons is reported in over 95% of patients. Protein synthesis is also affected in ALS patients, which may be driven by TDP-43 accumulation. We are profiling the actively synthesised proteins at different stages of disease progression in a TDP-43 mouse model using a cutting-edge technique called Translating Ribosome Affinity Purification (TRAP). Correct protein synthesis is needed to maintain healthy motor neurons, so identifying novel proteins which contribute to ALS progression may be useful both for disease insight and further development as drug targets.

Hannah Smith, University of Edinburgh

21 Are we getting closer to developing a biological classification of ALS?

ALS is a complex disease which differs in terms of 1) symptom onset and progression, 2) the genetic factors involved, and 3) the underlying molecular processes which contribute to its development. This can present challenges to researchers and clinicians when recommending clinical trials and treatments which may slow disease progression and improve quality of life. My work focuses on grouping patients based on their biological features to increase our chances of finding genes and processes which could be used as personalised indicators of ALS progression and help to select people that are more likely to respond to certain treatments.

Heather Marriott, King's College London

22 Investigating the contribution of Stathmin-2 in MND

Axons are the projections extending from a neuron that signal between the nervous system and the rest of the body. During motor neuron disease (MND), these begin to degenerate. Stathmin-2 is a protein that supports axon growth and maintenance, but people with MND have decreased levels of Stathmin-2. This reduction occurs due to errors that take place in a specific part of DNA expression, known as splicing, where non-coding regions of genes are usually removed. This project aims to create a model of Stathmin-2's contribution to MND and then use this as a tool for drug screening.

Brittany Ellis, University of Sheffield

About our sponsor

LifeArc
Making life science life changing

LifeArc is a self-funded, non-profit medical research organisation. We take science ideas out of the lab and help turn them into medical breakthroughs that can be life-changing for patients. We have been doing this for more than 25 years and our work has resulted in five licensed medicines, including cancer drug Keytruda, and a diagnostic for antibiotic resistance. Our teams are experts in drug and diagnostics discovery, technology transfer, and intellectual property. Our work is in translational science – bridging the gap between academic research and clinical development, providing funding, research and expert knowledge, all with a clear and unwavering commitment to having a positive impact on patient lives. LifeArc is committed to spending £1.3 billion by 2030 in areas of high unmet medical need.

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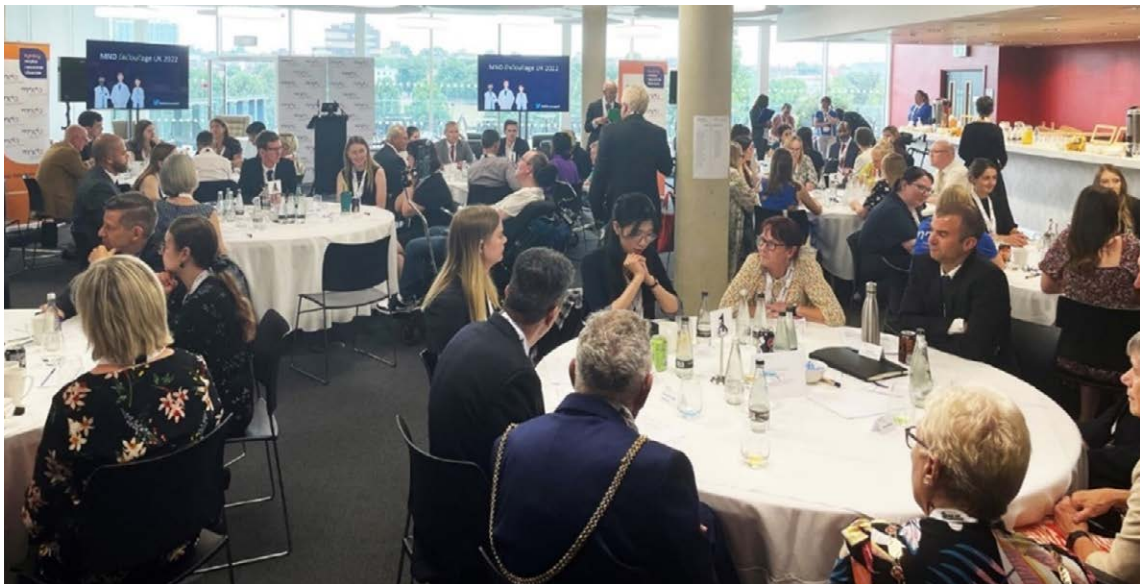
With grateful thanks to LifeArc for supporting MND EnCouRage UK 2023



Our presenters

Professor Ammar Al-Chalabi, King's College London

Ammar Al-Chalabi is a Clinician Scientist at King's College London, neurologist at King's College Hospital and Director of the King's MND Care and Research Centre. His team researches genetics, epidemiology and clinical trials in ALS. He co-leads the Project MinE international whole genome sequencing consortium having previously led the BRAIN-MEND and STRENGTH consortia on risk and modifying factors in ALS. He sits on the Executive Board of ENCALS where he chairs the Young Investigator Award Committee, chairs the International Symposium on ALS/MND, and is a National Institute for Health Research Senior Investigator. He is a senior editor for the journal Brain. His work has been recognized by multiple prizes, including the Forbes Norris Award from the International Alliance of ALS/MND Associations, the Healey Center International Prize for Innovation in ALS, the Sheila Essey Award from the American Academy of Neurology, a Gold National Clinical Excellence Award, and (many years ago!) the Charcot Young Investigator Award from the MND Association.

Dr Scott Allen, University of Sheffield

Dr Scott Allen is a Lecturer in Neuroscience at SITraN at the University of Sheffield. Having obtained a PhD from the University of Manchester in 2003, there followed two post-doctoral placements in Manchester and AstraZenca. He then joined the University of Sheffield as a post-doctoral researcher working on mitochondrial dysfunction in MND. In 2015 he was awarded an MND Association Non-Clinical Senior Fellowship focusing on bioenergetic dysfunction in MND. He then took up a lecturer position in 2019. The main research focus of Dr Allen's group is identifying the role of dysfunctional energy generation in neurodegenerative conditions, with particular interest in Motor Neurone Disease (MND). The group's primary aim is to develop therapeutic strategies by using phenotypic metabolic screening to identify novel targets for therapeutic intervention using patient-derived fibroblasts and induced neural progenitor cell derived human astrocytes and neurones; and to develop nutritional supplementation regimes for people with MND.

Dallas Campbell

Dallas is an Honorary Fellow of the British Science Association. In 2014 he gave the Stoneley Lecture for the Petroleum Exploration Society of Great Britain, and this year he won the Space Achievement Media Award at the Arthur Clarke Centenary Awards. Dallas is one of the most versatile and well-travelled factual presenters working in the industry. He has filmed in some of the most extraordinary and challenging locations all over the world as has presented shows ranging from Bang Goes the Theory to The Gadget Show, Britain Beneath Your Feet to Tutankhamun: The Truth Uncovered and Voyager: Beyond the Final Frontier to The Sky at Night. Experienced working in a live environment, Dallas has hosted countless roadshows and worked on many other science events. Including the monthly Science Museum Lates. When not risking life and limb investigating life, the universe and everything, he enjoys cooking and is an accomplished amateur magician.

Professor Joanne Kirby, University of Sheffield

Prof Kirby's research interests encompass the genetics of neurodegenerative diseases, particularly ALS/MND, and how gene expression profiling (GEP) can be used to investigate the pathogenic mechanisms of neurodegeneration and identify diagnostic and prognostic biomarkers. Technologies have evolved significantly since Janine began by screening patient samples for mutations in SOD1 and using differential display to identify changes in gene expression. Subsequent research using GEP of human biosamples, as well as animal and cellular models, has elucidated pathogenic mechanisms of ALS, such as detecting the dysregulation of NRF2, a cell survival transcription factor, which is now a therapeutic target in ALS. More recently, GEP of patient's blood samples enrolled in the IMODALS clinical trial have established the effect of low-dose interleukin-2 and demonstrated the personalized nature of the response. Finally, the value of routine genetic screening of all ALS-related genes in all ALS patients has been demonstrated, identifying C9orf72 and SOD1 variants in patients with no family history, thereby making them eligible to participate in clinical trials for patients with specific gene. As well as an active researcher, Janine is an advocate for learning and teaching (L&T), having led the development and initial delivery of the MSc Translational Neuroscience in Sheffield. She now co-leads the MSc Advanced Cell & Gene Therapies and delivers teaching across all of the Department's postgraduate courses. She balances these academic duties with leadership roles, including Departmental Director of Education for Neuroscience, Faculty Director of Postgraduate Education and member of University Senate and University Council.

Professor Chris McDermott, University of Sheffield

Prof McDermott studied for his medical degree at the University in Leeds graduating in 1994. He then continued is general medical and specialist neurology training in Leeds before taking up a clinical research training fellowship at the University of Newcastle upon Tyne. He moved to the University of Sheffield with Professor Dame Pamela Shaw in 2000 to undertake his Wellcome Trust Research Training PhD Fellowship and to complete his Specialist Training in Neurology to become a Consultant Neurologist in 2006. Prof McDermott is now the Professor of Translational Neurology at SITraN and a Consultant Neurologist at the Sheffield Teaching Hospitals Foundation NHS Trust regularly undertaking specialist MND and neuromuscular clinics in Sheffield. In 2022 he was awarded an NIHR Research Professorship. The main drive of Prof McDermott's research programme is developing the evidence base for delivering effective treatments and symptomatic care for patients living with motor neuron disease. He leads several research programmes aimed at improving care that is available for those living with MND. The programme has influenced national and international care practice. An important part of conducting research is ensuring the findings get to those that they affect. His group take research findings and support people living with MND and their carers to create interactive resources integrating their lived experience with the evidence so that individuals in the future can make the best decisions about options available to them. This approach has been recognised, with several awards for the myMND platform, https://mymnd.org.uk. Prof McDermott is an investigator on a number of clinical trials and chairs the UK MND Clinical Studies Group.

Dr Jacqueline Mitchell, King's College London

Dr Mitchell studied for a BSc in Neuroscience at the University of Nottingham, and then moved to King's College London where she obtained her PhD exploring the neurological mechanisms underpinning the impact of stress on female reproduction. She then moved into the field of neurodegeneration, taking up a post-doctoral role exploring in vivo models of Alzheimer's disease with Profs Chris Miller and Declan McLoughlin at the Institute of Psychiatry. In 2009 she side-stepped into the field of ALS research, taking up a post with Prof Chris Shaw to characterise mouse models of FUS and TDP-43 linked ALS. She obtained MNDA funding to establish and develop an organotypic slice culture model of disease, and is currently using this model, as well as cell and in vivo models to try to understand how environmental factors play into the disease process, as well as exploring differential disease vulnerability in different neuronal populations, with a focus on exploring cerebellar differences in TDP-43 linked-disease.

Suzanne Ostler, MND Association

Suzanne Ostler heads up the communications and marketing team at the MND Association. With a passion for storytelling from a young age, Suzanne began her career as a journalist on regional newspapers before moving into the national media, writing for a sizeable portion of the newspapers and magazines found on newsagents' racks. After a stint learning the ropes at a full-service public relations and marketing agency, Suzanne set out to use her skills for good, landing her first charity job 10 years ago. Since then, she's led the full range of communication and marketing functions at three national charities.

Freya Robb, Science Media Centre

Freya Robb is a Senior Press Officer at the Science Media Centre (SMC). The Science Media Centre is an independent press office and charity that helps to ensure that the public have access to the best scientific evidence and expertise through the news media when science hits the headlines. Our work relies heavily on working with top experts in their field to help journalists cover contentious and complex scientific topics accurately and in a measured way.

Kristiana Salmon, QurAlis

Kristiana Salmon is a Clinical Scientist and Director of Clinical Development at QurAlis, a clinical-stage biotechnology company developing precision therapeutics for ALS. Prior to joining QurAlis, she was the National Programs Manager for Genetic ALS at the Montreal Neurological Institute-Hospital, where she developed and executed a Canadian strategy to improve access to genetic counselling and testing for people living with ALS. During this time, she expanded this movement to the international level, leading a clinician working group and delivering educational and strategic programs on ALS genetics for the International Alliance of ALS/MND Associations. She has co-authored numerous articles on this topic in journals such as Brain, European Journal of Human Genetics, and Amyotrophic Lateral Sclerosis & Frontotemporal Degeneration. Kristiana spent over a decade of her career at the ALS Clinic and Clinical Research Unit of the Montreal Neurological Institute-Hospital, from which she has extensive experience in ALS clinical trial operations, trial design, and as an advocate for people living with ALS as research partners.

Dr David Taylor, ALS Society of Canada

Dr David Taylor is the Vice President, Research & Strategic Partnerships at the ALS Society of Canada. He completed his PhD in ALS research at McGill in 2001, followed by two postdoctoral fellowships at the EPFL in Lausanne, Switzerland and University of Toronto before joining ALS Canada in 2012. For the past decade, Dave has been responsible for the National ALS Research Program by managing grant delivery, driving the strategic direction of ALS Canada's research portfolio, and acting as a key facilitator between members of the Canadian ALS research community, the international research community, and other stakeholders of the organization. He is also the Chair of the Scientific Advisory Council of the International Alliance of ALS/MND and consults for other national ALS associations on research. In his role, he has been privileged to give more than 100 presentations across Canada and internationally, meet over 100 Members of Parliament through federal advocacy work and participate in dozens of TV and radio interviews. Maintaining a comprehensive knowledge of the current state of ALS clinical and preclinical research is Dave's passion and opportunities to share and learn from others are truly the highlight of his professional work.

Dr Caroline Vance, King's College London

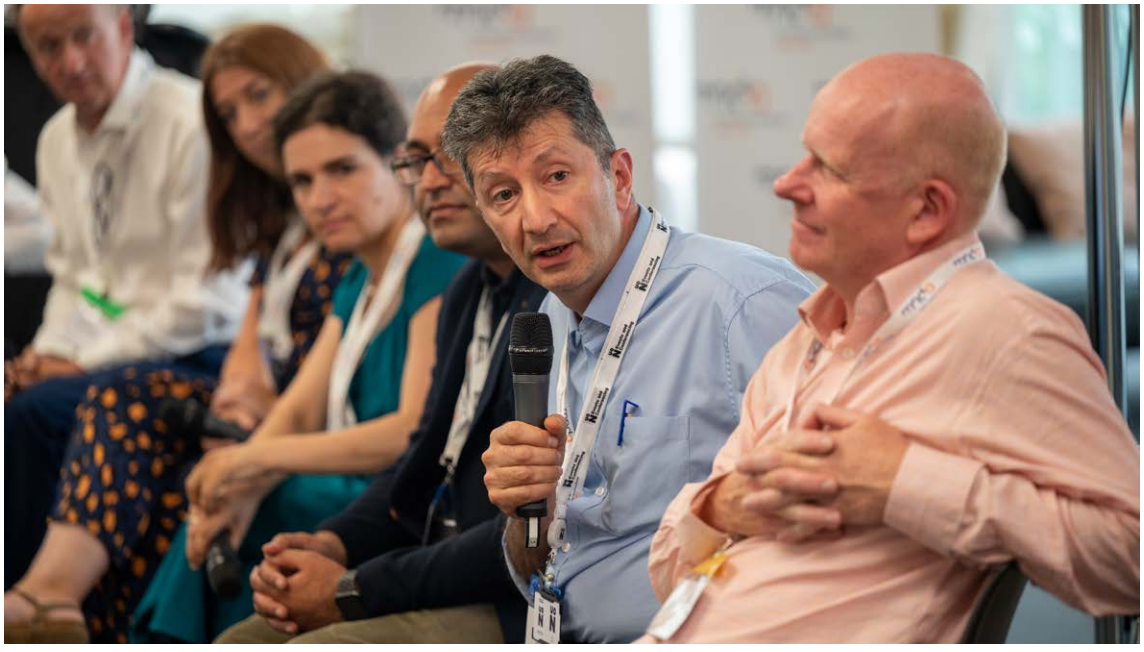
Dr Caroline Vance is a Senior Lecturer at King's College London investigating the roles of RNA binding proteins in the pathogenesis of amyotrophic lateral sclerosis (ALS) and frontotemporal dementia (FTD), with a focus on the three FET proteins (FUS, EWS, and TAF15). Mutations in FUS cause the most aggressive form of ALS whilst all three FET proteins are found in aggregates in FTD, and Caroline and her team study how these contribute to disease using a combination of biochemical techniques and super-resolution microscopy in cell, zebrafish and mouse models. Caroline has focused on this research since her PhD but before that she undertook an undergraduate degree in Biochemistry and an MSc in Molecular Medicine. Away from research, Caroline chairs the PhD Neuroscience subcommittee which oversees all of the PhD students ensuring their progression through their programme and monitoring their well-being. In addition, she also participates in education across Neuroscience at King's with a focus on leading modules on the MSc in Clinical Neuroscience and the BSc in Psychology and Neuroscience.

Dr Paul Wright, LifeArc

Dr Paul Wright is the Motor Neuron Disease Translational Challenge Leader. He joined the team in 2011 and leads the development of our Challenge strategy, with overall responsibility for the delivery of our MND portfolio across drugs, devices, diagnostics and digital. Paul works with LifeArc's science and funding groups to help deliver benefit to MND patients. Paul was part of LifeArc Therapeutics Discovery group where he led multiple projects focused on Neuroscience. During this time, he collaborated with international pharmaceutical companies, academics and CROs. Paul has 20 years' experience working within the neuroscience field (or we could just say life sciences), previously he worked at the Institute of Psychiatry, Psychology and Neuroscience, King's College London, as well as Harvard Medical School and University of Massachusetts Medical School where he focused on MND research. Paul has a PhD in Neuroscience and was awarded a place on the prestigious Academy of Medical Sciences Future Leaders in Innovation, Enterprise and Research (FLIER) program.

"THANK YOU, A WONDERFUL EVENT"

ECR, EnCouRage 2022



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MND EnCouRage UK 2024

Provisional dates:

Event: Tuesday 16 and Wednesday 17 July
Summary submission opens: March 2024
Registration opens: April 2024

Venue: TBC

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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 2023, 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 802 6262
Email: mndconnect@mndassociation.org

www.mndassociation.org/support-and-information/our-services/mnd-connect