Families for the Treatment of Hereditary MND (FaTHoM)

Thursday, 30th April 2026 Milton Hill House Hotel

UNIVERSITY OF OXFORD

A meeting for people from families affected by inherited forms of MND, with the aim of sharing the latest developments in research, treatment and trials.

9:30 – 10:00	**Tea & Coffee**
10.00 – 10.10	**WELCOME & OVERVIEW** MARTIN TURNER
10:10 – 10:30	**GENE TARGETING UPDATE** KEVIN TALBOT
10:30 – 11:00	**ACORN+** ALEX THOMPSON
11:00 – 11:30	**TOFERSEN: THE LONGER-TERM DATA** LAUREN ELMAN (PRE-RECORDED)
11:30 – 12:00	**Refreshments**
12:00 - 12:30	**DECISION-MAKING TOOLS FOR GENETIC TESTING** ALISDAIR MCNEILL
12:30 – 13:00	**CAN A ROBOT BE A GENETIC COUNSELLOR?** AMMAR AL-CHALABI
13:00 – 14:00	**Lunch**
14:00 – 14:20	**INSIGHTS FROM UK-BIOBANK** JIALI GAO
14:20 – 14:40	**TOWARDS PERSONALISED GENETIC RISK CALCULATION** ANDREW DOUGLAS
14:40 – 15:00	**RESEARCH PARTICIPANT PERSPECTIVE** EMMA BOUCHÉ
15:00 – 15:30	**Refreshments**
15:30 – 16:00	**GENFI UPDATE** RHIAN CONVERY
16:00 – 17:00	**Q&A SESSION**

SPEAKERS

Martin TURNER is Professor of Clinical Neurology & Neuroscience in the University of Oxford's Nuffield Department of Clinical Neurosciences, and Consultant Neurologist to the John Radcliffe Hospital. His research focus is on biomarker discovery and development in MND, currently focused on brain networks and rapid drug screening using blood neurofilament light chain.

Kevin TALBOT is Professor of Motor Neuron Biology and Head of the Nuffield Department of Clinical Neurosciences at the University of Oxford. The focus of his laboratory research is to improve pre-clinical models of MND, with the aim of accelerating translation of promising drugs into therapies for patients.

Alex THOMPSON is Associate Professor in the University of Oxford's Nuffield Department of Clinical Neurosciences, and Consultant Neurologist to the John Radcliffe Hospital. His research centres around identifying biomarkers and risk factors through the study of carriers of MND-causing genetic variants and in large population-based studies, with the aim of developing earlier interventions.

Lauren ELMAN is Professor of Neurology at the University of Pennsylvania, Director of the Penn Comprehensive ALS Center and Director of the Muscular Dystrophy Association Center at Penn. Her research has focused on phenotype-genotype correlations in ALS and in early phase clinical trials for ALS and disorders of inherited muscle and the motor nerve.

Alisdair McNEILL is senior clinical lecturer in neurogenetics at the University of Sheffield and honorary consultant in clinical genetics at the Sheffield Children's Hospital NHS Foundation trust. His research focus is on meeting patient priorities for genomic testing and rational application of genome sequencing in common and rare disease.

Ammar AL-CHALABI is Professor of Neurology and Complex Disease Genetics at King's College London, and Director of the Motor Nerve Clinic at King's College Hospital. His research focus is on understanding the causes and modifiers of MND, and the pathway to bringing new treatments to clinic.

Jiali GAO is an Academic Clinical Research Fellow in Neurology within the Oxford Deanery. She will be commencing a DPhil later this year studying genetic factors in MND.

Andrew DOUGLAS is a Consultant in Clinical Genetics at the Oxford Centre for Genomic Medicine, specialising in neurogenetic disorders. He also carries out research into the genetics of MND at the University of Oxford's Nuffield Department of Clinical Neurosciences, with a particular focus on genetic factors that modify the risk of the condition.

Emma BOUCHÉ is a healthcare leader and patient advocate with over 20 years' experience across MedTech, digital health and patient engagement. She participates in the GENFI research study, motivated by the opportunity to contribute to the development of future therapies for genetic FTD and ALS — conditions that have affected her own family. Emma is also a board member of End the Legacy, where she supports awareness, community building and research engagement for families impacted by inherited FTD and ALS.

Rhian CONVERY is a Postdoctoral Research Fellow at the Dementia Research Centre, University College London. Her work focuses on the development and validation of cognitive digital biomarkers for clinical trials as part of the Early detection of Frontotemporal dementia (EDoF) study.

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