



INTERNATIONAL ALLIANCE
OF ALS/MND ASSOCIATIONS

INTRODUCTION TO ALS/MND GENETICS

October 14, 2021, 7:00 – 8:00 AM ET (New York)

Recent discoveries are adding significant knowledge to the understanding of genetics in ALS/MND and potential treatments. This webinar will provide you with an overview of the current ALS/MND landscape and an understanding of genetics, so that people impacted by ALS/MND and their families have the basic tools to understand what this means and their options.

Moderators:



Kristiana Salmon joined the Clinical Research Unit (CRU) of the Montreal Neurological Institute-Hospital (The Neuro) as a National Programs Manager Genetic ALS in 2011. She holds a Bachelor of Science in Microbiology & Immunology from McGill University, and an Executive MBA from Concordia University.



Bruce Virgo is a maritime lawyer qualified in Australia, England/Wales & Scotland. Australian, he has lived in Edinburgh for over 20 years. Following symptoms in 2013, Bruce was diagnosed with MND in late 2014. Since 2014 Bruce has been participating in various MND research projects; raising awareness of MND; and fundraising. He has attended International ALS/MND Symposia as a Patient Fellow and Plenary Speaker. He is on the PALS/CALS Advisory Council of the International Alliance of ALS/MND Associations.



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Presenters:



Dr. Kelly Williams is a Senior Research Fellow and Group Leader of the Genomics & Bioinformatics Research Team within the multidisciplinary Centre for MND Research at Macquarie University, Sydney, Australia. For the past 15 years, she has focused on determining the genetic basis of ALS/MND. Dr Williams has written 55 original research papers and a bioinformatics encyclopaedia chapter, with 45 of her publications specifically on ALS/MND genetics and genomics. She has played a central role in critical breakthroughs in ALS/MND through the identification of causal mutations in several genes and published in high-impact journals including Science and Nature Genetics. These seminal discoveries have opened new chapters in ALS/MND and frontotemporal dementia (FTD) research and have directly led to key insights into the pathology of these diseases. Dr Williams's research has translated into improving clinical practice with these disease genes now added to diagnostic tests worldwide, including preimplantation genetic diagnosis (PGD) and pre-symptomatic testing.

As one of Australia's leading ALS/MND geneticists, Dr Williams was recruited in 2013 as a founding member of the Macquarie University Centre for MND Research. This is now Australia's largest dedicated ALS/MND research centre with over 90 staff and students. She established Australia's first ALS/MND gene discovery bioinformatics pipeline and led the setup, establishment and governance of the largest Neurodegenerative Diseases patient sample Biobank in Australia, held onsite at Macquarie University currently comprising >50,000 biological samples. Dr Williams was awarded her PhD on ALS/MND genetics in 2013 from the University of Sydney, Australia during which she spent time studying at the Centre hospitalier de l'Université de Montréal, Canada. She has since received two research fellowships to continue her genetics and genomics research into ALS/MND. Dr Williams's Genomics & Bioinformatics research team's current research themes include bioinformatic pipeline development to uncover



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ancestral cryptic relatedness in global ALS/MND and biostatistical analysis of Australian ALS/MND genomics datasets.

Dr Williams currently lives on the Northern Beaches of Sydney, Australia with her young family.

<https://researchers.mq.edu.au/en/persons/kelly-williams>



Ammar Al-Chalabi is a Consultant Neurologist at King's College Hospital, NIHR Senior Investigator and Professor of Neurology and Complex Disease Genetics at the Maurice Wohl Clinical Neuroscience Institute at King's College London, and Director of the King's Motor Neuron Disease Care and Research Centre. His research focuses on amyotrophic lateral sclerosis, also known as ALS, MND or motor neuron disease. His research team works on finding the causes of ALS, potential treatments, and what might influence the way the disease manifests and progresses, particularly where this involves genes, environmental exposures, or lifestyle, or involves changes in thinking and coping. He runs a large clinical research programme along with clinical trials. He leads or co-leads multinational consortia, such as the JPND STRENGTH, BRAIN-MEND, and Project MinE initiatives. He is the recipient of several international awards including the Sheila Essey Award for ALS Research from the American Academy of Neurology and ALS Association, the Forbes Norris Award from the International Alliance of ALS/MND Associations, and the AMG Healey Innovation Prize for ALS Research. He has held honorary positions abroad at Massachusetts General Hospital, Harvard University and Cold Spring Harbor Laboratory.