

ALS/MND CONNECT 2021

Agenda &
Program Book





ALS/MND Connect Agenda

December 3, 2021 @11:00 AM – 1:00 PM

all times are shown in Eastern Standard Time (New York)

December 3		
11:00 AM – 1:00 PM (EST)		
11:00 – 11:10 AM	Welcome	Moderator: Dr Nortina Shahrizaila
	Welcoming Address	Felipe Ocampo
11:10 AM – 12:10 PM	ALS Research: Time for optimism	Prof. Orla Hardiman
	Genetics: Providing Insights into ALS Disease Mechanisms and Targeted Treatments	Dr. Terri Heiman Patterson
	Outcome measures in clinical trials in ALS- How to interpret recent results	Dr. Angela Genge
12:10 – 12:55 PM	Live Q&A	
12:55 – 1:00 PM	Closing Remarks	



Moderator: Dr Nortina Shahrizaila

Dr Nortina Shahrizaila graduated from University of Nottingham Medical School, UK in 1997. She went on to complete her general medical training, specialist neurology training and doctorate degree in the UK before returning to Malaysia in 2009. As part of her specialist neurology and neurophysiology training, she worked at tertiary neurology centres including Queens Medical Centre, Nottingham and the National Hospital for Neurology and Neurosurgery, Queen Square, London. She is currently employed as Consultant Neurologist at University Malaya Medical Centre as well as Professor of Neurology at University of Malaya. She has subspecialty clinical and research interests in the field of neuromuscular disorders and motor neurone disease/amyotrophic lateral sclerosis.



Speaker: Felipe Ocampo

Born and raised in Colombia, Felipe is a medical surgeon whom currently resides in California with his loving husband and five dogs.

Felipe's life changed drastically when he was diagnosed with ALS/MND in February 2021. Unfortunately, he realized that many of his colleagues, friends, family, and himself didn't know the depths of this disease. He became a member of ACELA, the Colombian ALS/MND Association and it has become his mentor throughout this journey. He feels lucky because his family and friends are his main line of support, all the while dedicating his time on increasing ALS/MND awareness around his community and colleagues. In addition, he enjoys traveling and spending time with his loved ones.



Presenter & Panelist: Professor Orla Hardiman

Orla Hardiman is Professor of Neurology and is Head of the Academic Unit of Neurology at Trinity College Dublin and Consultant Neurologist at Beaumont Hospital, where she is Director of the National Amyotrophic Lateral Sclerosis (ALS) service.

A practicing clinical neurologist for over 30 years, she joined the academic faculty of Trinity College Dublin in 2013 as the first Professor of Neurology in modern times and was elected a Fellow of TCD in 2014. She also leads a research group of over 50 individuals in Neurodegeneration, with particular focus on ALS/MND. She is Co- Chair of the European Network for Cure of ALS (ENCALS) and the European Treatment Initiative to Cure ALS (TRICALS) and is Editor in Chief of the journal Amyotrophic Lateral Sclerosis and the Frontotemporal Degenerations.

ALS Research: Time for optimism

By: Professor Orla Hardiman

This presentation will describe the current “state of the art” in our understanding of ALS/MND with respect to the development of new treatments. Professor Hardiman will discuss why previous trials have been disappointing, and why our improved understanding of the disease, coupled with our recognition of the limitations of animal models, provide grounds for optimism. She will explain that enrolment in previous clinical trials has been restricted, and will outline ways that might improve these restrictions.



Presenter & Panelist: Dr Terry Heiman Patterson

Dr. Heiman-Patterson is Professor of Neurology at the Lewis Katz School of Medicine at Temple University where she is Director of the Center for Neurodegenerative Diseases and for the MDA/ALS Center of Hope.

She is board certified in neurology, with subspecialty certification in neuromuscular diseases. Her research has focused on ALS and includes both clinical and laboratory interests. She is president and co-founder of the ALS Hope Foundation a nonprofit committed to making a difference to people living with ALS. She is committed to patient care and education actively participating in the Clinical Research Learning Institute to train PALS to be Research Advocates.

Genetics: Providing Insights into ALS Disease Mechanisms and Targeted Treatments

By: Dr. Terry Heiman Patterson

This talk will provide a review of the genes that are implicated in familial ALS and how they provide a window into the mechanisms underlying motor neuron degeneration in ALS and provide treatment opportunities. It will include information regarding the occurrence of genetic changes in “sporadic” ALS and a discussion regarding genetic influences on disease. As an extension of the importance of genetics, she will briefly discuss the development of cell and animal based models that leverage our knowledge of genetics.



Presenter & Panelist: Dr Angela Genge

Dr. Angela Genge has been the Executive Director of the Clinical Research Unit at the Montreal at the Montreal Neurological Institute since 2004. Since 2020, she has also served as Chief Medical Officer for QurAlis and Scientific Director of CATALIS. Her expertise and ground-breaking work in the introduction of innovative therapies in the rare disease space has led her to be a sought-after member of numerous advisory boards for companies developing therapies for these diseases. Clinically, she is the Director of the Neuro ALS clinical program and multidisciplinary clinic, and a neuromuscular neurologist. Throughout her career she has received numerous awards, most recently the 2018 Forbes Norris Award, the DIVA of Distinction Award, and the Governor General Diamond Jubilee Award.

Outcome measures in clinical trials in ALS-How to interpret recent results

By: Dr. Angela Genge

Dr. Genge will describe briefly the major Outcome measures and evolving lead Biomarkers and the importance of making them better, improving them in order to be able to determine which new therapies are actually effective. She will be concluding with the need for the patient community to engage in these non treatment programs aimed at improving and validating our biomarkers and outcome measures.