



INTERNATIONAL ALLIANCE
OF ALS/MND ASSOCIATIONS

GENETICS – COUNSELLING & TESTING

October 28, 2021, 1:00 – 2:00 PM ET (New York)

The Alliance’s Fundamental Rights were updated this year to include the right to have access upon diagnosis to genetic counselling and testing. There are numerous therapies in development for the genetic forms of ALS/MND. For people living with ALS/MND to be able to access clinical trials, and future potentially approved therapies, access to both genetic counselling and testing will be necessary.

This webinar will touch on: What is genetic counselling and role of a genetic counsellor, what is involved in genetics counselling & testing, availability, awareness of ethical issues surrounding genetic testing, psychological effects of genetic testing, and tackling difficult concepts in ALS/MND clinical genetics.

Moderators:



Kristiana Salmon joined the Clinical Research Unit (CRU) of the Montreal Neurological Institute-Hospital (The Neuro) as National Programs Manager Genetics 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.

Presenters:



Dr. Adriano Chiò is a neurologist currently working in Torino, Italy. He is Professor of Neurology and Director of the ALS Center at the University of Torino and the Città della Salute e della Scienza Hospital, Torino, Italy. He is director of the ALS Expert Center in Torino, that aims for optimal diagnostic work-up, care and treatment for patients with ALS and other motor neuron diseases in Piedmont. He leads the Italian ALS Genetic (ITALSGEN) Consortium. Adriano Chiò, whose main areas of research are epidemiology, cognition, neuroimaging, and genetics of ALS, is best known for his research on risk of ALS in soccer players, the phenotypic heterogeneity of ALS and has contributed to the discovering of several ALS genes, including C9ORF72, VCP, MATR3 and KIF5A. He has published over 330 papers in peer-reviewed journals. He was awarded the 2015 Sheila Essay Award, presented by the American Academy of Neurology and ALS Association.



Dr Alisdair McNeill (FRCP Edin PhD DCH FHEA) is a Senior Clinical Lecturer in Neurogenetics at the University of Sheffield and Consultant Clinical Geneticist at Sheffield Children's Hospital NHS Foundation Trust. He graduated MBChB (Hons.) from the University Of Edinburgh Medical School in 2004. He undertook postgraduate medical training in Newcastle-upon-Tyne and Edinburgh, and Clinical Genetics training in Birmingham with an MRC Clinical Research Training Fellowship at UCL. He obtained a certificate of

completion of training in Clinical Genetics in 2015. He became a Fellow of the Royal College of Physicians of Edinburgh in 2017. He is both an active Clinical Geneticist and university researcher. Research interests focus upon identifying novel disease genes and improving clinical utilisation of genetic testing.



Jennifer Roggenbuck, MS, CGC, is a genetic counselor and Associate Professor at The Ohio State University Wexner Medical Center. She studies the clinical applications of ALS genetics and co-directs the NEALS ALS GAP program. She is currently leading a project to develop evidence-based guidelines for ALS genetic testing funded by the ALS Association.