

MODERATORS

Michael Benatar
MD, PhD



USA

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Martin Turner
MD, PhD

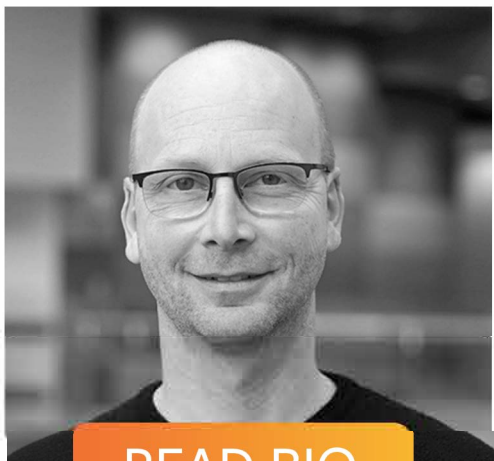


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SPEAKERS

Pietro Fratta, MD, PhD



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Eric Green, MD, PhD



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Cathleen Lutz, PhD, MBA



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Piera Pasinelli, PhD



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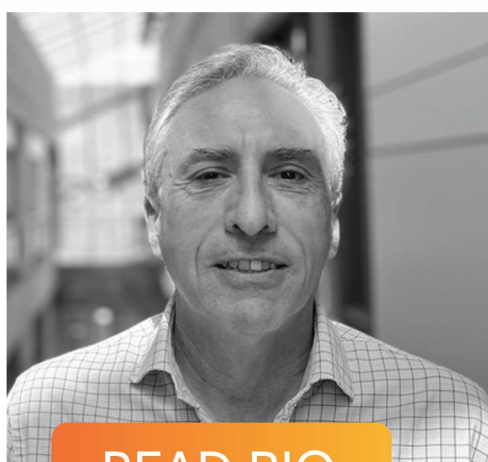
Ludo Van Den Bosch, PhD



BELGIUM

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Richard Robitaille, PhD



CANADA

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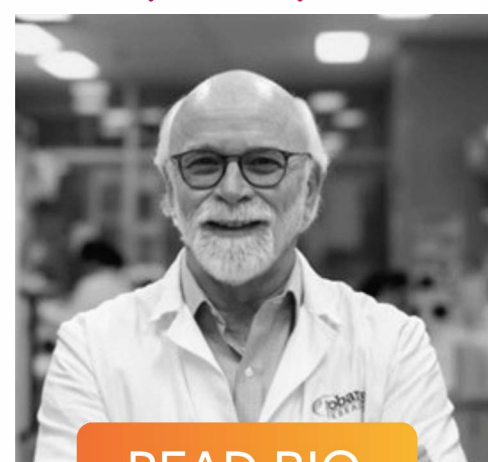
Chantelle Sephton, PhD



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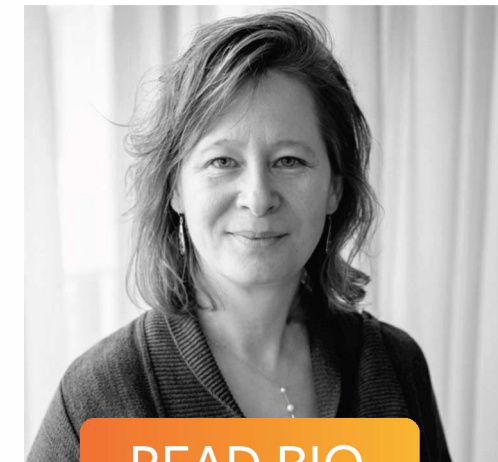
Michael Strong, MD,
FRCPC, FCAHS, FAAN



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Christine Vande Velde, PhD



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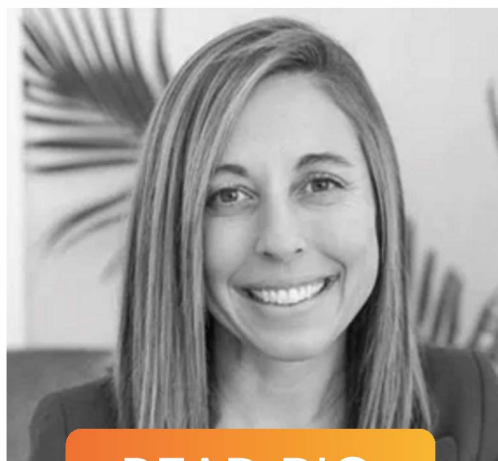
Lucie Bruijn, PhD



SWITZERLAND

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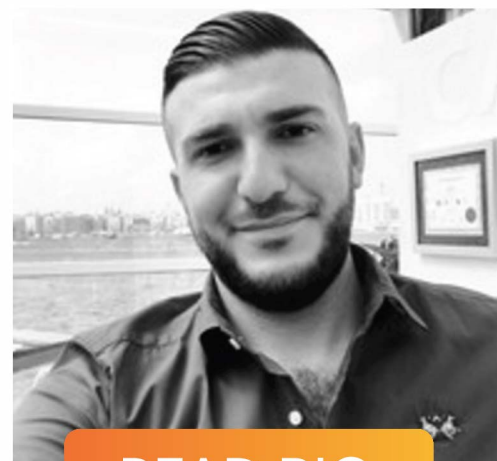
Stephanie Fradette, PharmD



USA

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Keith Mayl, MD, PhD



UK

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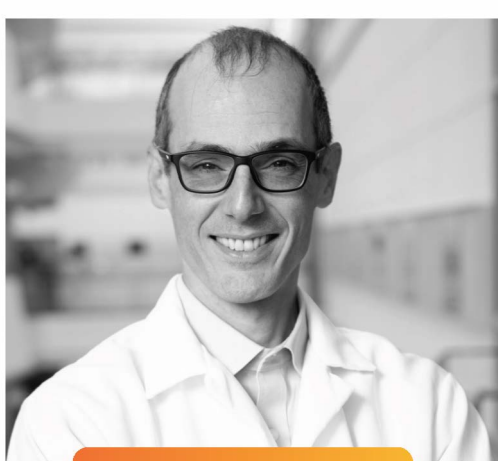
Ruben van Eijk, PhD



NETHERLANDS

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Sami Barmada MD, PhD



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Jenna Gregory, PhD



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Evangelos Kiskinis, PhD



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Rita Sattler, PhD



USA

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SESSIONS
1 & 3

USA

**Michael Benatar MD, PhD**

Michael Benatar, MBChB, MS, DPhil, is a professor of neurology and the Walter Bradley Chair in ALS Research at the University of Miami. He obtained his medical degree at the University of Cape Town (South Africa), and his doctorate in neuroscience while a Rhodes Scholar (University of Oxford). He runs an active clinical/translational research program focused on ALS biomarker and therapy development, with a particular focus on pre-symptomatic disease, biomarker development, and the intersection between ALS, FTD and related neurodegenerative disorders. Dr. Benatar has been a thought-leader in challenging existing paradigms and dogma.

**Walter Bradley Chair
in ALS Research,
Professor of Neurology,
Chief, Neuromuscular Division**

Vice Chair

Clinical and Translational Research
Department of Neurology
Miller School of Medicine
University of Miami

Executive Director

The ALS Center

SESSIONS
2 & 4

UK

**Martin Turner, MD, PhD****Professor of Clinical
Neurology &
Neuroscience**

Nuffield Department of Clinical
Neurosciences
Oxford University

Consultant Neurologist

John Radcliffe Hospital
Oxford University

Martin Turner is Professor of Clinical Neurology & Neuroscience within Oxford University's Nuffield Department of Clinical Neurosciences, and Honorary Consultant Neurologist to the John Radcliffe Hospital in Oxford, UK. He is Co-Director of the Oxford MND Care & Research Centre, one of the UK's largest tertiary referral clinics for MND. His research focus is the development of biomarkers across a range of techniques to accelerate therapy discovery. He co-leads the 'EXPERimental Route To Success in ALS' (EXPERTS-ALS), now recruiting to an innovative multi-centre, open label drug screening platform using a biomarker-based outcome measure of change in serum neurofilament light chain.

PLENARY
LECTURE
&
SESSION 1

USA

**Pietro Fratta, MD, PhD****Professor**

UCL Queen Square Institute of Neurology & Francis Crick Institute in London

Consultant Neurologist

The National Hospital for Neurology and Neurosurgery

Scientific Founder

Trace Neuroscience

Dr. Fratta Pietro is Professor of Cellular and Molecular Neuroscience and a Consultant Neurologist, and his clinical and research interests center on motor neuron diseases (MND) and RNA biology. He has been leading an independent research team since 2015 in University College London, and since 2023 at the Francis Crick Institute. He is a Consultant Neurologist at the National Hospital for Neurology and Neurosurgery, where he established in 2015 the only Kennedy's Disease-dedicated clinic in the UK and an MND Genetics clinic. He previously trained at UCL, King's College London, San Raffaele Scientific Institute in Milan, and the University of Southern California. His laboratory uses patient derived tissue, iPS cells and mouse models to understand disease mechanisms. They are developing gene therapy approaches to target the sporadic ALS population, and they harness the longitudinal sample collections in their cohorts to develop biomarkers using patient tissue and biofluids. Over the last five years his laboratory has 1) discovered novel molecular consequences of TDP-43 dysfunction leading to the development of novel biomarkers; 2) identified TDP-43 targets that impact disease progression and devised therapeutic strategies to correct these, currently entering clinical trials; 3) developed precision medicine gene therapy technologies to specifically target the diseased cells in ALS.

PLENARY
LECTURE

USA

Chief Executive Officer,
Trace Neuroscience**Eric Green, MD, PhD**

Dr. Eric Green serves as Chief Executive Officer at Trace Neuroscience. To this role, he brings over a decade of experience as a physician-scientist and entrepreneur building and leading companies to translate insights from the human genome into new medicines. Throughout his career, Eric has launched and grown numerous leading biotechnology companies.

As Co-Founder and Chief Scientific Officer at Maze Therapeutics, Eric built and led the scientific organization responsible for target discovery, validation, drug discovery, and translational science with an emphasis on applying insights from human genetics. While at Maze, he and his team led the generation of five development candidates across multiple modalities and therapeutic areas. Earlier in his career, Eric served as Head of Translational Research at MyoKardia, a company developing targeted therapies for the treatment of serious cardiovascular diseases which was acquired by Bristol-Myers Squibb.

SESSION

1

USA

**Cathleen Lutz, PhD, MBA****Professor
Vice President**

JAX Rare Disease Translational Center

As the Vice President of the Rare Disease Translational Center at The Jackson Laboratory (JAX), I work with patient-based foundations, researchers and industry partners to engineer preclinical mouse models for rare diseases and to accelerate the discovery and treatments for this important class of diseases. Previously, I held the position of the Senior Director of the In Vivo Pharmacology at JAX in our Bar Harbor campus for seven years. I was responsible for establishing the preclinical drug efficacy testing service for neurological disorders and continue to work closely with this department in scientific oversight and new platform development. As a neuroscientist by training, I have over 30 years of experience in the field of mouse genetics and have extensive experience in developing phenotypically relevant disease platforms for neurological disorders, in particular ALS. My lab has generated multiple genetic mouse models of ALS, with the goal to make the models broadly accessible to the scientific community. In addition to the generation of mouse models, my lab has worked to establish pre-clinical drug testing platforms for ALS based on the models we generated and adopted by others, including the *Stmn2*, *Unc13a*, and other genetic models. The central mission of my lab and my work is to facilitate and accelerate the discovery of therapeutics for ALS and other rare neurological diseases.

SESSION

1

USA

**Professor**

Thomas Jefferson University

Director

Jefferson Weinberg ALS Center

Piera Pasinelli, PhD

Piera Pasinelli is the Frances & Joseph Weinberg Professor in Neuroscience at Jefferson University and the founder and Director of the Jefferson Weinberg ALS Center. For 12 years (2008-2020) she has been the Science Director of the Robert Packard Center for ALS Research at Johns Hopkins, where she is now a member of the Scientific Executive Committee.

Pasinelli graduated with a dual Bachelor and Master in Science from the University of Milan, Italy, where she studied Chemistry and Technology in Pharmaceutical Industry. She then obtained her PhD in Neuro-biochemistry for the University of Utrecht, The Netherlands (Rudolf Magnus Institute for Neuroscience). After graduating, she moved to the United States where she started her career working on understanding the molecular mechanisms underlying ALS pathogenesis, first as a post-doctoral fellow in Dr. Bob Brown's laboratory at Massachusetts General Hospital-Harvard Medical School and, then, as an Instructor in Neurology at Harvard Medical School. In 2006, after 11 years in Boston, Dr. Pasinelli joined Thomas Jefferson University as the co-director of the Frances & Joseph Weinberg Unit for ALS Research, the area's first and only research unit solely dedicated to the basic and translational study of ALS. In 2016, under Dr. Pasinelli's leadership Jefferson expanded its ALS program adding a multidisciplinary clinic and a clinical-research program to complement its basic science laboratories and launching the Weinberg ALS Center. The Weinberg Center is structured around a new academic healthcare model at Jefferson, called Clinical and Research Integrated Strategic Programs (CRISPs), in which programs are developed based on disease focus, rather than medical or research specialty, creating a collaborative environment in which members from multiple disciplines work together around the patients' needs, with a 360-degree approach that also includes research and innovative technology. Basic research is present in clinic, educating and involving the patients every step along the way.

Acknowledged as an expert in the cell death processes that overtake the central nervous system in ALS, Pasinelli has been working on understanding the pathogenic mechanisms that trigger ALS for the past twenty-five years. She received several awards for her commitment to science in ALS, including the Wings Over Wall Street Award from the Muscular Dystrophy Foundation and the Flame of Hope award from the ALS Association. Pasinelli's background in neuro-biochemistry and her familiarity with the pharmaceutical industry and drug design, allow her to oversee the 360 bench-to-bedside approach taken to accelerate the pace to drug discovery for effective therapies for ALS.

SESSION
1

BELGIUM

**Ludo Van Den Bosch, PhD****Professor**
KU Leuven**Group Leader**
Center for Neuroscience, VIB

Ludo Van Den Bosch is a professor at KU Leuven and a group leader at VIB, where his work focuses on the molecular mechanisms underlying neurodegenerative and neuromuscular disorders. His research has made important contributions to understanding the role of histone deacetylase 6 (HDAC6) in axonal transport, cytoskeletal dynamics, and neuronal homeostasis. In particular, his group has been at the forefront of exploring HDAC6 as a therapeutic target across neurodegenerative diseases, including motor neuron disease and inherited peripheral neuropathies. Through this work, Van Den Bosch has helped to bridge fundamental neurobiology with translational strategies aimed at developing new approaches for the treatment of ALS and related neurodegenerative conditions.

SESSION
2

CANADA



Professeur

Département de neurosciences,
Université de Montréal

Richard Robitaille, PhD

Dr. Richard Robitaille's current research explores the roles of glial cells in the regulation of function of neurons and the neuronal contacts. His work focuses particularly on the contribution of glial cells in the demise of neuromuscular synapse in ALS, using neuromuscular preparations from rodent models of ALS and samples from patients. His work led to an ongoing Phase 2a clinical trial testing a strategy that help stabilize neuromuscular synapses. The current goals are to develop novel neuromuscular-based biomarkers, understand the mechanisms underlying neuromuscular demise and identify new therapeutic targets with potential clinical applications.



Professor

Department of Psychiatry and
Neurosciences,
Université Laval/CERVO Brain
Research Centre

Chantelle Sephton, PhD

Dr. Chantelle F. Sephton received her Bachelor's of Science in Biochemistry from the University of Saskatchewan in Saskatoon (2002) and her PhD in Psychiatry from the University of Saskatchewan (2007). She did her postdoctoral studies at the University of Texas (UT) Southwestern Medical Center at Dallas under the mentorship of Dr. Gang Yu in the Department of Neuroscience (2007-2014). She started her lab at Université Laval in the CERVO Brain Research Centre in 2014 and is currently an Associate Professor in the department of psychiatry and neuroscience.

Dr. Sephton's research interests are focused on the mechanism of action of post-transcriptional regulation of RNA by RNA-binding proteins. Several RNA-binding proteins including TDP-43 and FUS are mutated in some patients with familial amyotrophic lateral sclerosis (ALS). Mutations in these proteins result in their cytoplasmic mislocalization and aggregation, which are thought to contribute to neurodegeneration in these diseases. Stemming from her post-doctoral work and the discovery of the biological functions of disease-linked RNA-binding proteins, her current work now focuses on understanding the mechanisms by which disease-associated mutations of TDP-43 and FUS influence RNA metabolism and how this may lead to neurodegeneration.

SESSION
2

CANADA



Distinguished University
Professor,
Arthur J Hudson Chair in
ALS Research

Department of Clinical Neurological
Sciences/Department of Pathology and
Laboratory Medicine
Western University

Michael Strong, MD, FRCPC, FCAHS, FAAN

Dr Michael J. Strong is a Distinguished University Professor in the Department of Clinical Neurological Sciences at Western University. He served as the President of the Canadian Institutes of Health Research from 2018 to 2023 and prior to this, as the Dean of the Schulich School of Medicine & Dentistry at Western University. From 2000 to 2010, he was Chief of Neurology and Co-Chair of the Department of Clinical Neurological Sciences. As a clinician-scientist with a specific research focus on amyotrophic lateral sclerosis (ALS; Lou Gehrig's Disease), he has published over 240 peer-reviewed articles and 29 chapters, edited 4 textbooks and has given over 200 invited lectures related to his research in ALS. He was awarded the Sheila Essay Award in 2005 and the Forbes Norris Award in 2008 and is the only Canadian to have received both international awards for ALS research. He was elected as a fellow of the American Academy of Neurology in 2008 and of the Canadian Academy of Health Sciences in 2009. In 2025, he was awarded the King Charles III Coronation medal. His research has focused on understanding the pathogenesis of ALS, including the role of altered RNA metabolism in its genesis in addition to defining a role for altered tau metabolism in the frontotemporal spectrum disorder of ALS.

SESSION
2

CANADA

**Professor**

Department of Neuroscience,
Université de Montréal/CRCHUM

Scientific Director

Robert Packard Center for ALS
Research at Johns Hopkins

Christine Vande Velde, PhD

Dr. Christine Vande Velde is Full Professor in the Department of Neurosciences at the Université de Montréal and Université de Montréal Hospital Research Center (CRCHUM). Her research is centered on understanding the underlying pathological mechanisms that lead to the fatal neurodegenerative diseases amyotrophic lateral sclerosis (ALS) and frontotemporal dementia (FTD) and the exploitation of that knowledge for biomarker and therapeutic development. Dr. Vande Velde is the current Scientific Director of the Robert Packard Center for ALS Research at Johns Hopkins and a member of the Scientific and Medical Advisory Council of ALS Canada.

SESSION
3

SWITZERLAND

**Therapeutic Area Lead,
Neuroscience**

Novartis

Lucie Bruijn, PhD

I have worked in the neurodegenerative field for the past 30 years with a specific interest in developing therapies for these devastating disorders. I currently lead biomarker development for clinical studies in ALS, AD, PD and Huntington's disease at Novartis. Combining my pharmacology background and prior academic research efforts in disease mechanisms and modelling, I continue my passion for academic and industry collaborations to further therapeutic developments.

In my prior position at The ALS Association, I established the first translational research program for ALS, Translational Research Advancing Therapies for ALS (TREAT ALS). Through partnerships between academia, government and industry and soliciting donor contributions for strategic programs, I established initiatives for drug development, clinical trials, biomarkers, assistive technology, precision medicine, large scale sequencing and analytics. This set the stage for many global resources to support new therapeutic approaches, including the development of antisense therapies for neurodegenerative disorders. These are now the first successful disease modifying treatments for SMA and ALS (those families carrying the SOD1 and FUS gene mutations).

At Novartis, we have an active ALS portfolio with assets entering the clinic and at various stages in pre-clinical development.

I received a Pharmacology degree at Rhodes University; South Africa; MSc in biochemistry and PhD in Molecular Biology; Kings College, London; MBA Imperial College, London. My post-doctoral studies at John's Hopkins, Baltimore and UCSD, San Diego focused on developing models of ALS and understanding disease mechanisms.

SESSION
3

USA

**Vice President**Head of Neuromuscular
Development Unit,
Biogen**Stephanie Fradette, PharmD**

Dr. Stephanie Fradette is the Head of the Neuromuscular Development Unit at Biogen. In her role, she oversees development of therapies for Amyotrophic Lateral Sclerosis (ALS), Spinal Muscular Atrophy (SMA), Friedreich's Ataxia (FA), and other neuromuscular diseases. Stephanie has spent the last 15 years in various roles across Research and Development, including Safety, Regulatory, and Clinical Development helping to bring meaningful therapies to patients around the world. Recently, she led the development of the first approved therapy for a genetic form of ALS (SOD1-ALS), which supported significant advancement of neurofilament as a biomarker and optimization of clinical trial design in ALS. Stephanie co-chairs the Accelerating Medicines Partnership (AMP) for ALS, a public-private initiative involving the NIH, FDA, academia, and industry, aimed at accelerating the development of ALS treatments. Dr. Fradette continues to advocate for patient-centered research and has actively engaged with policymakers and regulatory bodies to raise awareness of the challenges and opportunities in rare disease drug development.

UK



Senior Medical Director,
Clinical Development,
Global ALS Indication
Lead

argenx

Keith Mayl, MD, PhD

Keith Mayl MD PhD is a physician-scientist in neurology with expertise in neurodegeneration, neurogenetics, genomic medicines and drug development. He currently serves as a Senior Medical Director in Clinical Development at Argenx where he leads development of their ALS program. Prior to Argenx, Keith served as a Senior Clinical Lead at Servier where he led the translation of antisense oligonucleotide therapeutics from late research into early phase clinical trials for rare neurological diseases. Prior to joining industry, Keith completed a clinical research fellowship in neurodegeneration at King's College London with a focus on ALS and FTD under the mentorship of Prof Chris Shaw. In this role he gained broad experience as an Investigator and led multiple first-in-human clinical trials involving antisense oligonucleotides targeting different genetic subtypes ALS-FTD, including the pivotal trial of Tofersen; the first approved therapy for SOD1-ALS. He also completed doctoral research in molecular biology and genetics with a focus on developing viral-vector based gene therapy strategies targeting C9orf72-ALS-FTD. Keith earned his MD from the University of Malta and a PhD in Clinical Neuroscience from King's College London. His interest is in accelerating the development of novel therapeutics for neurological diseases with high unmet medical needs.

SESSION
3

NETHERLANDS



Associate Professor,
Medical Statistician
University Medical Center Utrecht

Ruben van Eijk, PhD

Ruben van Eijk is an associate professor and biostatistician at UMC Utrecht, The Netherlands. He previously served as a Visiting Scholar at Stanford University's Center for Innovative Study Design. His research focuses on integrating real-world data into clinical trials and developing new endpoints that address both multidimensionality and patient preferences.

**Sami Barmada MD, PhD****Associate Professor**

Department of Neurology, University of Michigan Medical School

Director

Michigan Brain Bank

Dr. Barmada received his Ph.D. in the Medical Scientist Training Program at Washington University in St. Louis, and completed his neurology residency and postdoctoral fellowship at the University of California, San Francisco (UCSF). Dr. Barmada moved to the University of Michigan as an Assistant Professor of Neurology in 2013, was promoted to Associate Professor in 2020, became Director of the University of Michigan Brain Bank in 2021, and an Associate Director of the Medical Scientist Training Program at UM in 2024. Combining basic biology with translational research and technology development, his research centers on critical abnormalities in RNA and protein metabolism in neurodegenerative diseases such as amyotrophic lateral sclerosis (ALS) and frontotemporal dementia (FTD).

Dr. Barmada was awarded the Young Physician Scientist Award from the American Society for Clinical Investigation in 2014, was named the distinguished Angela Dobson and Lyndon Welch Research Professorship at the University of Michigan in 2015, received the prestigious Derek Denny Brown Award from the American Neurological Society in 2022, and the Javits Neuroscience Award from the NINDS in 2025. Dr. Barmada serves on the scientific advisory board of the Robert Packard Center for ALS Research, the NEALS consortium, the Live Like Lou Foundation, Eikonizo Therapeutics, Synapticure, and Ninesquare Therapeutics. He has taken an active role in raising awareness of ALS and FTD in the community, participates in several local and national fundraising efforts, and helps guide priorities for national research funding through NIH-sponsored panels.

UK

**Clinical Professor,
Consultant Pathologist**

Institute of Medical Sciences, University of
Aberdeen/NHS Grampian

Clinical Lead

NHS Grampian Biorepository and Tissue
Bank

Jenna Gregory, PhD

Professor of Pathology and Consultant Pathologist at the Institute of Medical Sciences, University of Aberdeen / NHS Grampian. Clinical Lead for the NHS Grampian Biorepository and Tissue Bank, and Co-Lead of the Aberdeen Clinical Academic Track (ACAT) programme, supporting and overseeing clinical academics across all specialties in Aberdeen, from trainees to senior researchers.

Research focuses on the prevention and early diagnosis of amyotrophic lateral sclerosis and related dementias, using innovative technologies and well-curated biosamples to define the earliest molecular and pathological changes in disease.

SESSION
4

USA



Associate Professor

Department of Neurology,
Northwestern University Feinberg
School of Medicine

Evangelos Kiskinis, PhD

Evangelos Kiskinis PhD is a tenured Associate Professor of Neurology and Neuroscience at Northwestern University Feinberg School of Medicine in Chicago and a New York Stem Cell Foundation Robertson Investigator. Dr. Kiskinis earned a PhD from Imperial College London and carried out postdoctoral training at Harvard University where he pioneered some of the first models of ALS using personalized stem cell-based approaches. His laboratory utilizes patient-specific iPSCs and reprogramming approaches to develop models of neurological diseases such as ALS and pediatric forms of severe neurodevelopmental epilepsy syndromes. The overarching goal of his research is to provide novel insights into neuronal development and identify points of targeted and effective therapeutic intervention for epilepsy and ALS. Dr. Kiskinis also serves as the Scientific Director of the Stem Cell Core Facility at Northwestern University and the Scientific Director of the LiveLikeLou ALS Foundation. He also serves as an advisor to several biotech companies and non-profit disease foundations including ResQ Bio, Synapticure, NuCyRNA Therapeutics, Packard ALS Center, LiveLikeLou ALS Foundation, ALS Find A Cure and NeuronGrow.

SESSION
4

USA

**Professor**

Barrow Neurological Institute

Rita Sattler, PhD

Dr. Rita Sattler is Professor of Translational Neuroscience and the David and Weezie Reese Chair for Neurodegeneration Research at the Barrow Neurological Institute (BNI) in Phoenix, Arizona. She serves as Director of the Barrow Research Education Programs and Co-Director of the Interdisciplinary Graduate Program in Neuroscience (IGPN) at BNI–Arizona State University.

Dr. Sattler received her MSc and PhD degrees from the University of Toronto and completed postdoctoral training in the Department of Neuroscience at Johns Hopkins University. She subsequently served as lead scientist at a biotechnology startup, where she oversaw assay development and drug screening efforts for amyotrophic lateral sclerosis (ALS). She later joined the Johns Hopkins University Drug Discovery Center, further strengthening her expertise in preclinical drug development. With this strong translational background, Dr. Sattler joined the Department of Neurology at Johns Hopkins University as an Assistant Professor before relocating to Barrow Neurological Institute in 2015.

Dr. Sattler's research focuses on the molecular and cellular mechanisms of synaptic dysfunction in neurodegenerative diseases, including frontotemporal dementia (FTD), FTD with motor neuron disease (FTD/ALS), Alzheimer's disease, and Lewy body dementia. Her work integrates human disease-relevant models, including postmortem brain tissue and patient-derived induced pluripotent stem cells differentiated into neuronal and glial cell types.

Her research is supported by federal funding from the National Institutes of Health (NIH) and the Department of Defense (DoD), as well as awards from disease foundations and the Barrow Neurological Foundation. Dr. Sattler is an active member of the Society for Neuroscience and the American Society for Neurochemistry and serves as a grant reviewer for the NIH, DoD, and national and international disease foundations. She co-chaired the 2022–2023 NIH/NINDS ALS Strategic Planning Effort and served on the 2023–2024 National Academies of Sciences, Engineering, and Medicine committee on Amyotrophic Lateral Sclerosis: Accelerating Treatments and Improving Quality of Life.