



MND Á ÍSLANDI

MND ICELAND CONFERENCE 2024 | June 21, 2024

BIOGRAPHIES: SPEAKERS AND FACILITATOR

SPEAKERS:



María Lovisa Guðjónsdóttir (Welcome from MND Iceland)

María Lovísa Guðjónsdóttir is the Executive Director of MND Iceland since 2021. Her passion for this cause stems from her personal experience — her father was diagnosed with ALS/MND 20 years ago, and she has been involved in the fight against ALS/MND ever since.

María believes in using humour and compassion to navigate through difficult times, and she also finds solace in singing, which brings her joy and peace. She is dedicated to raising awareness and support for those affected by ALS/MND.



Helga Rakefrafnsdóttir (PALS Address – Facing Challenges and Keeping the Hope Alive)

Helga Rakefrafnsdóttir was diagnosed with ALS/MND in 2021. She is a filmmaker and a mother of two.

Helga is a board member of MND Iceland. Her father, who also had ALS/MND, was one of the founding members of MND Iceland and the first chair of it. He passed away in 2004.



Dr. Angela Genge (Clinical Trials Update)

Dr. Angela Genge has been the Director of the Clinical Research Unit 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, Dr. Genge is the Director of the Neuro ALS clinical program and multidisciplinary clinic, and a neuromuscular neurologist. Throughout her career, she has received numerous awards, including the 2018 Forbes Norris Award, the DIVA of Distinction Award and the Governor General Diamond Jubilee Award.



Dr. Karen Halldorsdottir (Importance of Genetic Testing and Research Focus)

Dr. Karen Halldorsdottir is a neurologist at Landspítali–The National University Hospital of Iceland. She earned her medical degree from the University of Iceland and completed neurology residency training at the University of Vermont Medical Center. She further specialized in neuromuscular disorders through a fellowship at the University of California, Irvine, where she gained expertise in ALS/MND among other neuromuscular conditions.

Dr. Halldorsdottir joined as faculty at Landspítali–The National University Hospital of Iceland, following her training in 2024 where she works as a neurologist and performs electrodiagnostic testing.



Dr. Sara Feldman (Assistive Technologies)

Sara Feldman, PT, DPT, ATP, is the Physical Therapist and Assistive Technology Professional at the MDA/ALS Center of Hope at Temple University Lewis Katz School of Medicine, where she has been serving people with ALS/MND for more than 25 years. In addition to clinical care, she is involved in clinical trials, education, and the use of assistive technology.

Sara is the Clinical Liaison for the ALS Hope Foundation in Philadelphia. She served on the Board of Directors of the International Alliance of ALS/MND Associations from 2013-2019; chairs the PALS and CALS Advisory Council; and co-chairs the Allied Professionals Forum. She received the inaugural Allied Health Professional Award in December of 2018. She is a co-founder of the Northeast ALS Consortium (NEALS) Physical Therapy Committee and served as the Clinical Evaluator representative on the NEALS Executive Committee from 2013 to 2018. She looks forward to the day there is a cure for ALS/MND, but until that time, will continue to be an avid advocate for better care.



Dr. Richard Bedlack (Hope in ALS: Things I've Learned)

Richard Bedlack, MD, PhD, is the Stewart, Hughes and Wendt Distinguished Professor of ALS and leader of the ALS Program at Duke University. He received his MD and PhD in Neuroscience from the University of Connecticut, then went to Duke for his Medicine Internship, Neurology Residency and Neuromuscular Fellowship.

Since 2001, Dr. Bedlack has been working in partnership with patients to create new options for living a better and longer life with ALS/MND, empower people living with ALS/MND to be more effective research partners via the ALS Clinical Research Learning Institute, help patients and families make more informed decisions about alternative and off label treatments via the ALSUntangled program, and better understand ALS/MND reversals and try to make them happen more often. He has published over 160 papers and has received numerous awards for his patient care, research, teaching and advocacy.

Dr. Bedlack lives in NC with his wife Shelly, a closet-full of eye-catching blazers, and two mischievous cats.



Dr. Orla Hardiman (Women in ALS/MND)

Dr. Orla Hardiman is Professor of Neurology and 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. She is a Science (BSc, Human Physiology 1979) and Medical (MB BCh BAO 1983) (Doctor of Medicine 1992) graduate of University College Dublin. She undertook a Residency and Fellowship in Neurology at the Harvard Partners Programme Boston (1986-1991), prior to returning to Ireland.

A practicing clinical neurologist for over 30 years, Dr. Hardiman 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. In 2016, she was one of only three practicing physicians to ever have been elected as members of the prestigious Royal Irish Academy (Science Division).

Dr. Hardiman leads a research group of over 50 individuals in Neurodegeneration, with a 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 Principal Investigator of the European PRECISION ALS Consortium. She is the Editor-in-Chief of the journal, *Amyotrophic Lateral Sclerosis and the Frontotemporal Degenerations*.

Dr. Hardiman is the recipient of a number of international awards including the AAN Sheila Essey Award in ALS Research, and the International ALS Alliance Forbes Norris Award, and received the Science Foundation Ireland Research of the Year award, and the Trinity College Dublin Provost's Award in 2022. She has published over 450 peer-reviewed articles.



Cathy Cummings (Breaking the News)

Cathy Cummings has an eclectic mix of work experiences in the Canadian not-for-profit sector including the National Payroll Institute, the Canadian Bar Association, the Canadian Corporate Counsel Association, and now as the Executive Director of the International Alliance of ALS/MND Associations. She has also volunteered extensively with United Way, the Canadian Society of Association Executives and many charities, including ALS Ontario, ALS Canada and Ceridian Cares. She holds an MBA from Athabasca University and is a Certified Association Executive (CAE) designation.

On a personal note, Cathy is married to her wonderful husband Marty, has three awesome children, and has a mission nicknamed the “Bouquet Project,” where she is trying to reverse the statistic that people are 10 times more likely to complain than praise.



Fridgerdur Gudmundsdottir (Caregivers Address)

Fridgerdur Gudmundsdottir is a Sagittarius. Her milestones after the age of 20 include being a mother, a wife, a special education teacher, a carer, a burnt-out nervous wreck, a widow, a student, a grandmother, product designer, a partner and, most of all, a recovering survivor.



David Ali (Advocacy at the Local, National, and International Levels)

David Ali is an experienced CEO and Board member across several different environments. He also has an extensive background in social policy, communications, strategy development and implementation, relationship building and engagement, advocacy, organizational performance, industry reviews and investigations.

When asked around 23 years ago to join the MND Victoria Board, David had never heard of ALS/MND, let alone understood the cruel disease it is. Since then, he has volunteered in many ways including raising awareness, fundraising, and being on the Board of Directors of MND Victoria, MND Australia, and the International Alliance of ALS/MND Associations. David was until March 2024 the Chief Executive Officer of MND Australia.

David lives in Melbourne, Australia, which is year after year rated one of the world's most livable cities. Time away from work is spent with family, enjoying running and exploring his home city.



Dr. Melinda Kavanaugh (Youth Caregiving)

Dr. Melinda Kavanaugh is a professor of social work and licensed clinical social worker with expertise in multidisciplinary health/mental health settings addressing neurological disorders including Alzheimer's disease, ALS/MND and Huntington's disease. Funded by federal and non-profit organizations her research is informed by her clinical experience as a medical social worker. She is an international leader in translational and applied research and program development for children and youth caregivers "young carers", in families with ALS/MND.

Dr. Kavanaugh has created evidence-based interventions for young carers targeting caregiving education and skill, sleep, and mental well-being and quality of life across diverse care populations.

Dr. Kavanaugh is also the president of Global Neuro YCare, an international non-profit, focused on developing programs and supports for children, youth and families in neurological disorders in underserved areas. Using her research and clinical expertise, Dr. Kavanaugh has written several books for parents, children, and schools, translated into 8 languages, and created the multidisciplinary YCare program, youth caregiving, support and education program implemented across the United States and South Africa.



Dr. Colleen O'Connell (Emergency Preparedness)

Dr. Colleen O'Connell is a professor of Physical Medicine & Rehabilitation at Dalhousie University and a member of the Canadian ALS Research Network. She is Medical Director and Research Chief of New Brunswick's Stan Cassidy Centre for Rehabilitation, where she is lead of the provincial ALS/MND clinic.

Believing in strength of collaboration — or having difficulty saying no — she joins many networks and guidelines committees, including the Canadian ALS/MND best practice recommendations and faculty of the Breaking the News in ALS/MND education program.

As Co-Chair of the World Health Organization World Rehabilitation Alliance Emergencies workstream, Dr. O'Connell collaborates with an international team to advocate for the strengthening of rehabilitation in health systems. Her research interests are broad, tending to early adoption of technology (FOMO) in mobility and function. She has authored and provided technical guidance on rehabilitation in challenging regions, with infield emergencies humanitarian work including Haiti, Nepal and Ukraine.



Sascha Groen (LUKi and the Lights & Q&A)

Sascha Groen is a teacher, author and illustrator from the Netherlands. She has worked with children all her professional life and is specialized in explaining difficult issues visually. This proved particularly valuable when her husband and father of their children, Anjo, turned out to have ALS/MND at the age of 35.

Sascha wrote and illustrated the book, *Daddy Dragon Can't Be Cured* (for now only available in Dutch) This loving picture book, suitable for young children, tells about illness, death and grief in an honest way.

To better explain ALS/MND to children, Sascha and Anjo created the story LUKi & the lights. An animated short film that will help families all over the world.

Besides writing and illustrating, Sascha is an ambassador of young caregivers and children who live with a sick family member. Since she herself has MS, she speaks from experience as a caregiver, mother and sick parent. She is a proud member of Global Neuro YCare and works together with Dr. Melinda Kavanaugh to create more educational materials to support families.

Gudjon Sigurdsson (Final Words)



Gudjon Sigurdsson began as a plumber, but in 2004, when he was diagnosed with ALS/MND, he soon after dedicated his time and efforts to be of service to people living with ALS/MND.

Since 2005, Gudjon has served as Chair for MND Iceland, tirelessly advocating for those affected by ALS/MND. He has also held roles as the chair of the International Alliance of ALS/MND Associations and remains a board member. Additionally, he is a founding member and board member for EuPALS, furthering his commitment to supporting individuals with ALS/MND across Europe.

Gudjon's life's motto is "Enjoy every moment," reflecting his resilient spirit and positive outlook.

MODERATOR:



Eva Thengilsdottir

Executive Director, ÖBÍ, The Icelandic Disability Alliance

Eva Thengilsdottir holds a Cand.Oecon. degree from the University of Iceland and an MPA from the same university, as well as an AMP from IESE Business School, University of Navarra in Spain.

Since her teenage years, Eva has been actively engaged in the non-profit sector focusing on human rights, social needs and supporting positive change, both as a volunteer and as a professional.

Alongside her professional life, Eva has written and illustrated books, series of short plays for kids, material for kindergartens and scripts for television.