



2026
FSHD
CONNECT



Speaker Booklet



Chelsea Moeller

FSHD Society

Chelsea Moeller serves as the director of development at the FSHD Society, where she leads fundraising and partnership efforts to support research, education, and community programs for individuals living with FSHD. She is passionate about building meaningful relationships with donors, partners, and families to advance the Society's mission and drive progress toward treatments. Chelsea brings a collaborative and community-centered approach to her work, helping ensure that every initiative is grounded in impact and connection.



Raymond Huml, DVM

Rare Disease Strategy

Raymond A. Huml, MS, DVM, RAC-US, is an executive leader in the healthcare and biopharmaceutical industries and serves as Vice President of Rare Disease Strategy at Sciensus, a European life sciences company focused on improving patient access, engagement and insights. With more than three decades of leadership experience in the CRO sector, he has held global roles spanning rare disease, biosimilars and due diligence, and his strategic work has helped secure nearly \$3.0B in capital commitments for transformative partnerships. A prolific author and thought leader, Dr. Huml has published 150+ articles, contributed to numerous book chapters and authored four books, and has been recognized with awards from the North

Carolina Veterinary Medical Association, Triangle Business Journal, the Regulatory Affairs Professionals Society and industry leadership honors at Quintiles Transnational Corp (now IQIVA).

A Returned Peace Corps Volunteer (Ghana) and former member of North Carolina State University's Board of Visitors, he holds an MS in Biology (East Stroudsburg University) and a DVM (North Carolina State University).

Russell Butterfield, MD, PhD **University of Utah**

Dr. Russell Butterfield is a clinician scientist focused on translational research in neuromuscular disorders. He received his PhD in genetics, and medical degree from the University of Illinois. He completed his residency training in pediatric neurology and fellowship in neuromuscular disorders at the University of Utah. He is currently a Professor in the Departments of Pediatrics and Neurology at the University of Utah where he directs the Muscular Dystrophy Clinic at the University of Utah and Neuromuscular Clinic at Primary Children's Hospital. Dr Butterfield leads a translational research program that includes clinical and basic research studies, and he leads the newly formed Utah Center for Gene Therapy. Dr. Butterfield's research is focused on implementation of genetic therapies and understanding genetic modifiers of severity in various types of muscular dystrophy including FSHD, Duchenne muscular dystrophy, and collagen VI-related muscular dystrophies.



Ian Woodcock, PhD

Royal Children's Hospital Melbourne

Ian Woodcock is a paediatric neurologist at the Royal Children's Hospital and the Murdoch Children's Research Institute. He completed his PhD in 2024 and was involved in the translational change to prepare the Melbourne Children's Campus to be an approved gene therapy centre culminating in the first patient being treated with gene therapy at RCH in July 2021. He has been an investigator in almost thirty clinical trials in neuromuscular disease. He was the principal investigator in the first clinical trial specifically aimed at children with FSHD. He was also co-PI in the Australian Natural History Study of childhood onset FSHD which has led to the International MOVE Peds study currently enrolling.



Katy de Valle, PhD

Royal Children's Hospital Melbourne

Dr. Katy de Valle is a Senior Physiotherapist at The Royal Children's Hospital and a Postdoctoral Researcher at the Murdoch Children's Research Institute in Melbourne, Australia, with a 20-year career dedicated to improving the lives of children with neuromuscular diseases, particularly childhood-onset facioscapulohumeral muscular dystrophy (FSHD), through optimising clinical care and developing and validating clinical outcome measures. She has led and contributed to FSHD studies (including iFSHD-LOS, FSHD MOVE Peds and MINDS-FSHD), co-chairs the CTRN paediatric FSHD Special Interest Group, and led the 279th ENMC workshop on childhood-onset FSHD, aiming to enhance clinical management and support the design and readiness of paediatric FSHD clinical trials as emerging therapies become available.



Jennifer Egert, PhD

Private Practice

Jennifer Egert, Ph.D., is a clinical psychologist based in New York City, integrating Mindfulness Based Cognitive Therapy (MBCT), ACT, and mindfulness training in private practice. She trained as a health psychologist at Duke University worked with individuals with medical issues, disability, and at end of life for over 25 years. Dr. Egert has FSHD as do several family members. It is very meaningful and important to her to bring her personal and professional experience to the FSHD community.



Charu Nagar, MD **Northwestern Medical Group**

Charu Nagar MD is a neuromuscular neurologist at Northwestern University Feinberg school of medicine, practicing at Lake Forest Hospital. Her interest in neuromuscular disorders took her to training for her fellowship Washington University school of medicine Barnes Jewish Hospital in St. Louis, Missouri. She completed her neurology residency at Loyola University school of medicine. Her philosophy to care is patient centric care. She strongly believes in adaptation of care to individual needs and individualizing their care plan. She has a strong interest in muscular dystrophy, particularly FSHD, myasthenia gravis, inflammatory, and immune mediated neuropathies. Patient education and medical literacy improvement amongst patients are key drivers in her philosophy of care.



Marvella Bowen, MSGH **Northwestern Medical Group**

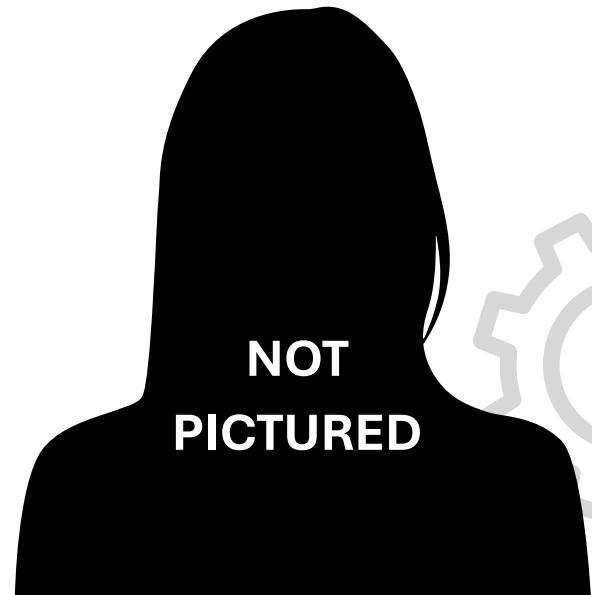
Marvella Bowen is a Registered Nurse with a Bachelor of Science in Nursing (BSN) and a Master of Science in Global Health (MSGH). For the past four years, she has worked as a Nurse Clinician at NMG Neurology. In her role as a neurology triage nurse, she assesses, prioritizes, and manages patients with neurological conditions, including neuromuscular disorders (e.g., Myasthenia Gravis, FSHD, ALS, Peripheral Neuropathy, etc.), multiple sclerosis, epilepsy, Alzheimer's disease and dementia, movement disorders, and migraines primarily through phone calls and an electronic portal.



She enjoys using her critical thinking and communication skills to triage calls effectively. This involves listening carefully to the caller's concerns, quickly assessing their individual needs, and coordinating care with the neurologist and the interdisciplinary team to determine the level of care. Additionally, she provides follow-up to guide patients diagnosed with neurological disorders. Over the past five years, she has earned her MSGH, maintained RN licensure, and held BLS and ACLS certifications.

Janet Robinson, MSN
Northwestern Medical Group

Janet Robinson is a master-prepared nurse currently with Northwestern Medicine, specializing as a neurology nurse clinician.



John Moynihan, DPT
Northwestern Medical Group

John Moynihan, PT, DPT, OCS, earned his Bachelor of Science in Kinesiology with a minor in Psychology from the University of Wisconsin–Milwaukee before completing his Doctor of Physical Therapy degree at Carroll University. He subsequently completed an Orthopedic Physical Therapy Residency through UW Health and is a Board-Certified Orthopaedic Clinical Specialist (OCS). John currently practices with Northwestern Medicine, where he specializes in orthopaedic rehabilitation, sports rehabilitation, and the treatment of neuromuscular deficits. His clinical interests include optimizing movement performance, restoring functional mobility, and providing evidence-based care to active individuals and athletes across all levels of performance.

June Kinoshita **The Waltham Times**

June Kinoshita is co-founder and president of The Waltham Times, a nonprofit newspaper serving Waltham, Massachusetts. She also co-founded and is executive director of New Harmony Line, a nonprofit transforming music education through technology. From 2012 to 2025, she held senior leadership roles at the FSHD Society, a research-driven patient advocacy organization advancing therapies for facioscapulohumeral muscular dystrophy and improving patient care. Previously, she co-founded and led the Alzheimer Research Forum and co-founded N-of-One, an early innovator in precision oncology decision support. A longtime science journalist, Kinoshita has been an editor at Scientific American and a contributor to leading national publications, as well as a consultant and producer for major science television documentaries. She is a Harvard College graduate and the recipient of multiple awards and fellowships recognizing her excellence in science and medical writing.



Amanda Hill, MBA **FSHD Society**



Amanda Hill, Research & Care Programs Officer at the FSHD Society, leads initiatives to accelerate therapy development and elevate the patient voice in research and clinical care. She works with patients, clinicians, researchers, industry, and decision-makers to turn scientific findings into meaningful actions for the FSHD community worldwide. Amanda also directs the Society's patient registry, BetterLife FSHD, ensuring rigorous research standards and driving insights to advance the field. Before joining the Society, she worked at the University of Colorado in cancer and Down syndrome research and volunteered as an FSHD Society Chapter Director, writer, and fundraiser. Her husband's FSHD diagnosis in 2016 inspired her personal and professional commitment to the community. Amanda holds a BA in Molecular Biology from Scripps College and an MBA in Bioinnovation from the University of Colorado Denver.

Lucienne Ronco, PhD

FSHD Society

Lucienne is a scientific leader with extensive experience in translational science, clinical trial design and implementation, drug discovery, and pharmaceuticals. Dr. Ronco earned a Ph.D. in Biological Chemistry from UCLA and returned to Boston for post-Doctoral training at Harvard Medical School. She worked in both pharma and biotech as she advanced to become a Vice President and a global scientific leader of basic research and clinical trial design. She has global project management and collaboration experience. While at Fulcrum Therapeutics, Lucienne participated in FSHD molecular and imaging characterization as she discovered, designed, and developed methods to assess how well new therapeutics work in human clinical trials of FSHD.



Amanda Rickard

FSHD Global Innovation Hub

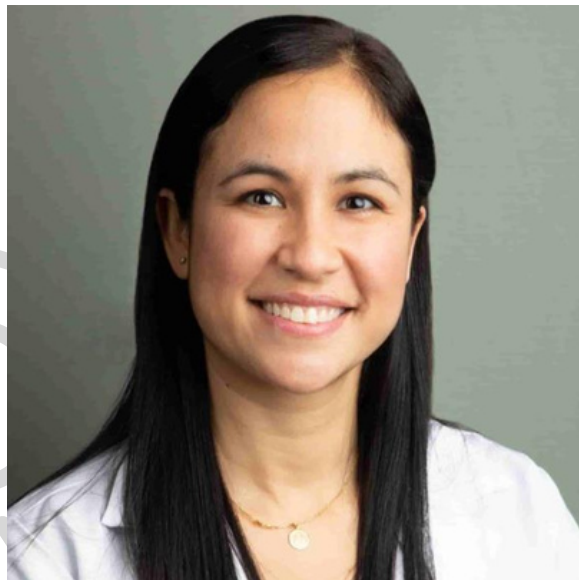
Amanda is a passionate scientist and business leader who has spent 16 years in the FSHD field spanning academic, biotech, pharma, and non-profit roles. She has co-authored seven publications on FSHD, including the first to describe the genetic cause of FSHD Type 2. Amanda began her career at the University of Washington's Institute for Stem Cell and Regenerative Medicine where she studied FSHD molecular pathophysiology in Dr. Dan Miller's lab. She has held drug development and leadership roles at Genea Biocells as lead of the FSHD therapeutics discovery team, Pfizer Oncology R&D where she also served as FSHD advisor to the Rare Disease Research Unit, and Notch Therapeutics leading external innovation and partnerships. She



is currently Managing Director of the Global FSHD Innovation Hub, a subsidiary of the FSHD Society, and serves in advisory roles for Friends of FSH Research, FSHD Canada Foundation, Nucleate Global Activator, and Histone Therapeutics.

Kayleigh Worek, MS **FSHD Society**

Kayleigh Worek is the Program Manager for BetterLife FSHD at the FSHD Society. She holds a master's degree in medical Speech Language Pathology and has five years of experience as a speech therapist, where she supported families with a wide range of medical conditions from premature infants in NICUs to older adults in nursing homes. In 2020, she transitioned to clinical research. She has since worked on a variety of research projects including biobanks, patient registries, investigator-initiated trials, as well as global pharmaceutical-sponsored clinical trials across a variety of therapeutic areas.



Alejandra Lastra, MD **University of Chicago Medicine**

Dr. Lastra directs the Sleep Medicine Fellowship and the Advanced Respiratory Care (ARC) Program at the University of Chicago. She is Associate Medical Director of the UChicago Sleep Center, Chair of the AASM Education Committee and immediate past president of the Illinois Sleep Society. Her expertise spans hypercapnic COPD-morbid obesity overlaps, home invasive and non-invasive ventilation, and complex sleep-disordered breathing, including neurostimulation. Recognized for her contributions to education, diversity, and research, Dr. Lastra has authored peer-reviewed publications, presented at national and international conferences, and mentored numerous trainees. She holds fellowships with the American College of Chest Physicians and the American Academy of Sleep Medicine.

Marisa Spain

Disability Rights Michigan

Marisa is a disability justice advocate and power wheelchair user living with early onset FSHD. She works for Disability Rights Michigan - her state's protection and advocacy organization for people with disabilities - as a Client Assistance Program advocate. In this role, Marisa helps people experiencing difficulties accessing services from Michigan's Vocational Rehabilitation agency. She has personal experience navigating this system through her (difficult!) journey to obtain support for a wheelchair accessible van, and works to help make systemic change so that other Disabled individuals can more easily access the services they need to obtain, maintain, and advance in the employment of their choice.



Andrea Kosten, PsyD

The Sacred Vessel Therapy and Wellness



Andrea M. Kosten, Psy.D. is a Licensed Clinical Psychologist and founder of The Sacred Vessel Therapy and Wellness. She holds her doctorate from The Illinois School of Professional Psychology and works from a trauma-informed, Emotion-Focused Therapy (EFT) lens with individuals and couples. Her clinical focus centers on early emotional patterns, inner child work, and helping clients reconnect with their emotional wisdom — particularly those who learned early on that their feelings would be dismissed, minimized, or ignored. Through individual therapy, couples therapy, groups, workshops, and retreats, Dr. Kosten creates spaces where clients feel emotionally held, empowered, and supported in expressing their needs with confidence and authenticity.

Michelle Mellion, MD

FSHD Society

Dr. Michelle Mellion is a neurologist with subspecialty training in clinical neurophysiology and neuromuscular disease, bringing over 20 years of experience guiding patient care, clinical research and drug development. After earning her undergraduate degree in molecular biology at Colgate University, Dr. Mellion attended Wake Forest University Medical School for her MD and completed her internship in medicine, residency in neurology, and fellowship in clinical neurophysiology/neuromuscular disease at Brown University. At Brown, she spent more than a decade teaching, conducting her own grant funded research, and seeing patients. After transitioning to industry, Mellion held roles at Biogen and Vertex before leading the development of the FSHD program at Fulcrum Therapeutics through Phase 2 and planning for Phase 3 clinical trials. She has expertise in developing small and large molecule therapeutics as well as gene modulating therapies. In her current role as chief medical officer at AstronauTx, Dr. Mellion oversees the development and execution of clinical trials, ensuring regulatory compliance and scientific integrity, while advancing innovative therapies to enhance sleep quality and improve cognitive function. She continues to remain highly engaged with the FSHD community as the medical advisor for the FSHD Society.



Anna Sylvester

FSHD Society

Anna Sylvester joined the FSHD Society in March 2018, after working in community engagement for Northeastern University. Previously, she had also advocated for the community as a constituent liaison for Boston City Council. Over the past 8 years, she has had the honor of working with and getting to know many FSHD families. She has held a variety of roles for the organization, but at all times hopes to uphold the power of the patient voice in the drug development process. Currently, Anna leads the Society's efforts in legislative and regulatory advocacy, where she is excited to build momentum toward awareness, increased funding, and more effective access decisions. Anna believes that a rising tide lifts all ships.



Mark Stone

FSHD Society

Mark Stone, CEO of the FSHD Society, is a mission-driven executive leader who has been dedicated to helping organizations create meaningful change in the lives of those they serve. Throughout his career, Mark has helped organizations expand their reach and capacity, launching major initiatives, cultivating sustainable growth, and developing partnerships across North America, Europe, Asia, and Australia. His leadership has contributed to the evolution of national organizations into global movements, creating opportunities for greater collaboration, innovation, and collective impact. A trusted advisor, speaker, and capacity-builder who has worked in more than 40 countries, Mark is passionate about developing leaders, fostering healthy organizational cultures, and helping mission-driven organizations realize their fullest potential. Whether leading strategic transformation, building teams, or advancing advocacy efforts, his work is guided by a simple belief: when people unite around a common purpose, extraordinary things become possible.

