

*Burnhamthorpe Community Centre, 1500 Gulleden Dr. , Mississauga, ON L4X 2T7
Hosted by FSHD Canada Foundation and the FSHD Society*

Agenda

9:00 – 10:00 am	Check in, social time
10:00 – 10:05 am	Welcome! A new era for the FSHD community Neil Camarta, FSHD Canada Foundation Beth Johnston, Chief Community Engagement Officer, FSHD Society,
10:10 – 10:25 am	FSHD 101 and research overview Hanns Lochmuller, MD PhD, University of Ottawa
10:25 – 10:45 am	The neuromuscular care landscape in the Toronto region Charles Kassardjian, MD, University of Toronto
10:45 – 11:05 am	Care for pediatric patients with neuromuscular disease Hernan Gonorazky, MD, Hospital for Sick Children
11:05 – 11:25 am	Exercise and physical therapy Marija Radenovic, PT
11:25 – 11:45 pm	Services and resources provided by MD Canada Victoria Larocca, PhD
11:45 – 12:25 pm	Panel: Tips and tricks for navigating life with FSHD Jennifer Wells, Lori Brand & Danika Painter, mod. by Carrie Wilkinson
12:25 – 1:25 pm	Lunch break
1:25 – 1:40 pm	Canadian Neuromuscular Disease Registry , Lawrence Korngut, MD
1:40 – 1:55 pm	BetterLife FSHD , Amanda Hill, FSHD Society
1:55 – 2:15 pm	Muscle regeneration research , Ryan Mitchell, Satellos
2:15 – 3:15 pm	Drug development, clinical trials and trial readiness , Hanns Lochmuller FORTITUDE clinical trial , Henry Nchienzia, Avidity Biosciences Drug development Q&A , moderated by Amanda Hill
3:15 – 3:25 pm	Project Mercury in Canada , Neil Camarta, FSHD Canada Foundation
3:25 – 3:35 pm	Activating the local community , Carrie Wilkinson, Sam Johnston

Disclaimer: This is an educational conference. The inclusion of information about therapies and products does not imply an endorsement by the FSHD Society or by any participating research or medical institutions. Always consult your personal medical provider before trying out a novel treatment.

FSHD 360 Ontario Conference Speaker Bios



Neil Camarta is a chemical engineer and a member of the Canadian Academy of Engineering. Neil has led the development and delivery of world-class energy projects in Canada and abroad for various companies including Shell, Petro-Canada and Suncor Energy Inc. Neil is currently a director of Western Hydrogen and Enlighten Innovations, two cleantech start-ups he founded which are focused on commercializing green fuel technologies and grid-scale battery systems. Neil is dedicated to finding a cure for FSHD, a rare form of muscular dystrophy which afflicts Neil and his family. He co-founded the FSHD Canada Foundation, SOLVE FSHD and Project Mercury - a global initiative to speed-up access to FSHD therapies.



Beth Johnston is Chief Community Engagement Officer with the FSHD Society. Beth joined the FSHD Society staff in August of 2016. Her long history with the Society began as a volunteer shortly after her husband was diagnosed with FSHD. She continues her commitment to raising awareness of the disease and building an "army of activists" that will help us achieve our mission of treatments and a cure. Beth has also worked in information technology, project management, high-technology & telecommunications consulting, and real estate.



Hanns Lochmuller, M.D., Ph.D. Principal investigator, FSHD Clinical Trial Research Network. He is Senior Scientist at the Children's Hospital of Eastern Ontario (CHEO) Research Institute. He also holds appointments as Professor of Neurology in the University of Ottawa Faculty of Medicine and the Department of Medicine, Division of Neurology at The Ottawa Hospital. His research interests include molecular therapies of neuromuscular disorders; molecular pathogenesis of muscle and neuromuscular junction disorders; neurogenetics and translational research; data sharing and -omics in neuromuscular and rare diseases; and genomics and systems medicine.



Charles Kassardjian, MD, is a neurologist with a clinical focus in the area of peripheral neurological diseases and neurophysiology, with a special interest in genetic myopathies such as FSHD. He is an Assistant Professor at the University of Toronto in the Department of Medicine. His research and educational interests are in the area of quality improvement and patient safety.



Hernan Gonorazky, MD, co-leads the NMD4C's work in developing a clinical research curriculum for neuromuscular fellowship programs. He graduated from medical school at University of Buenos Aires. He completed his residency in adult neurology and afterward he did his specialization in adult neuromuscular disorders. He continued his studies in paediatric neuromuscular disorders at Sick Kids in 2014 and joined the permanent staff in 2019. Since then, he has been working on translational and clinical research with special interest in SMA and congenital myopathy.



Marija Radenovic, PT, is a Registered Physiotherapist at One Step Ahead *Mobility* in Toronto. She specializes in working with individuals with complex neurological conditions, especially those with progressive conditions. She has also worked with individuals with muscular dystrophies, including those with FSHD. Marija employs an active based approach that aims to allow individuals more freedom and confidence in their mobility. This often includes a developed personalized treatment program and the use of supportive assistive devices. She is passionate about integrating exercise into daily routines to enhance both physical and psychological well-being.



Victoria Larocca, PhD, of Muscular Dystrophy Canada, is a dedicated knowledge mobilization specialist with a passion for advancing health research and education. She earned her Ph.D. and M.Sc. in Kinesiology and Health Science from York University in 2022 and 2018, respectively, following her Bachelor of Education from Brock University in 2016. Throughout her academic journey, Victoria has immersed herself in health psychology and clinical research. With her experience and education in health research, Victoria is committed to advancing the research conducted at Muscular Dystrophy Canada, and the education and curriculum for neuromuscular trainees at the Neuromuscular Disease Network for Canada (NMD4C).



Lori Brant is a Master Spirit Life Coach, Speaker, Life Coach Trainer and Mentor, with the Rhema Group of Coach Training schools and is also an Ordained Metaphysical Minister. Her life coaching is informed by her experience living with FSHD. She is a Bachelor of Psychology, Bachelor of Education, Master of Metaphysics, is the Author of "The Happiness Toolbox," and "The Alignment Strategy." Lori has received the 2019 Coaching Professional Halo Award, the 2020 Coaching Professional Halo Award, the 2020 Women of Wisdom Award, the 2021 Coaching Professional, Writer/Composer and Spiritual Excellence Certificate.



Carrie Wilkinson serves as leader of the Ontario chapter of the FSHD Society. She lives on a hobby farm north of Toronto with her husband, John, and two children. Her daughter was diagnosed with FSHD at the age of six and John was diagnosed shortly after. Professionally, Carrie works as an occupational therapist in neuro rehabilitation. "I pour my heart and soul into helping my patients achieve their goals," she says. "I am equally dedicated to build a collective voice for FSHD in our province. Although Ontario encompasses a large geographical area, I know we will come together to support one another, share resources, and actively engage in finding a cure for FSHD."



Danika Painter was born and raised in Seattle and received her FSHD diagnosis as a teen when she and her extended family participated in a clinical study at the University of Washington. Now a Canadian citizen, she has lived and raised her family in Ottawa for the last 23 years. Danika holds a PhD in physiology and works at Health Canada. She loves being outdoors, backcountry canoe camping with her two kids and her dog, and playing jazz piano.



Lawrence Korngut, MD, is a neuromuscular neurologist at the Calgary Neuromuscular Program where he diagnoses and treats neuromuscular conditions including FSHD. He is a member of the Scientific Advisory Board at SOLVE-FSHD. He is an Associate Professor at the University of Calgary Cumming School of Medicine and has led the University of Calgary Neuromuscular Clinical Trial Program since 2009 having conducted over 80 clinical trials of new therapies. He led the formation of the Canadian Neuromuscular Disease Registry (CNDP), which has resulted in over 230 data releases supporting clinical trial recruitment and advocacy for improved access to emerging therapies.



Amanda Hill is the Senior Director of Research at the FSHD Society, where she leads BetterLife FSHD and global collaborations that use patient data to speed therapy development and access. 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.



Ryan Mitchell, PhD, has 15 years of combined scientific and biotech experience, from stem cell research to business and corporate development. Previous to Satellos, he was a Scientific Consultant at Bloom Burton & Company, where he contributed to the financial and corporate strategies for pre-seed start-ups to large multinational pharmaceutical companies. Prior to that Dr. Mitchell was a Group Leader at the Stem Cell and Cancer Research Institute at McMaster University, where he led a cellular reprogramming work group to develop personalized disease models. Dr. Mitchell has authored scientific publications in high impact journals, including Nature and Cell. He received his Ph.D. and B.S. in biochemistry and biomedical science from McMaster University.



Henry Nchienzia, PhD, joined Avidity Biosciences in April 2024 as a senior Medical Science Liaison. Henry is responsible for building KOL networking, establishing Avidity Biosciences' medical affairs presence in the medical community through long term and valued scientific relationships with thought leaders and represents Avidity Biosciences at patient, scientifically and medically relevant events.



Samantha Johnston has been the leader of the Ontario Walk and roll for three years. Her father was diagnosed with FSHD when she was a child which has sparked her desire for involvement with the FSHD Society. Prior to being the Walk and Roll leader, she volunteered for both the Ontario chapter and the Colorado Chapter of the FSHD Society.

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