FSHD 360 Conference
The Latest in Health & Research

Pacific Northwest
October 14, 2023

The Museum of Flight
9404 East Marginal Way S, Seattle, WA 98108
Presented by the FSHD Society, Friends of FSH Research, Univ. of Washington
Wellstone Muscular Dystrophy Specialized Research Center: Seattle

Preliminary Agenda

9:00 – 9:30 am	**Check in, social time**
9:30 – 10:00 am	**Warm-up exercises with Coach Alex Walker**
10:00 – 10:05 am	**Welcome! What is a 360? What is the CTRN?** June Kinoshita, FSHD Society
10:05 – 10:20 am	**FSHD 101 and overview of research at UW** Leo Wang, MD PhD
10:20 – 11:35 am	**UW science mini-symposium** Stephen Tapscott, MD PhD; Joel Chamberlain, PhD, & Dennis Shaw, MD
11:35 am – 12:15 pm	**Photo scavenger hunt in the museum**
12:15 – 1:00 pm	**Lunch** Share your favorite tips and tricks
1:00 – 1:20 pm	**Rehabilitation medicine for managing your symptoms** Nassim Rad, MD, University of Washington
1:20 – 1:40 pm	**Physical therapy and exercise** Cat Kieu, PT DPT, University of Washington
1:40 – 2:00 pm	**Clinical trial overview and trial readiness for FSHD** Jamshid Arjomand, PhD, FSHD Society
2:00 – 2:40 pm	**Drug development Q&A panel** Leo Wang, MD, Casey Childers, MD (Epic Bio), Amy Halseth (Avidity), Mihaela Levitchi Benea (Fulcrum)
2:40 – 2:45 pm	**How to enroll in current studies and trials** Dani Dixon or Mike Willis, research coordinator, University of Washington
2:45 – 3:00 pm	**Activating the community** Anna Gilmore, Ashley Ferreira, Selina Lai
3:00 –3:30 pm	**Community sharing and open discussion** Selina Lai and Chris Haven
3:30 pm	**Adjourn and social time**

Disclaimer: This is an educational conference. The inclusion of information about therapies and products does not imply an endorsement by the FSHD Society, University of Washington, or Friends of FSH Research. Always consult your personal medical provider before trying out a novel treatment.

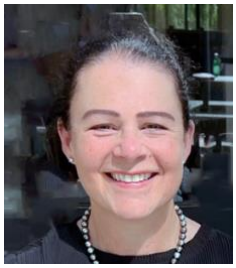
Pacific Northwest FSHD 360 Conference
Speaker Bios

Alex Walker is a personal trainer and strength coach. "I have been weightlifting most of my life and started my personal training business 11 years ago while also coaching football and lacrosse for several years. As a USAW certified performance coach, I can teach and refine weightlifting techniques, assess mobility, effectively communicate with my clients, and implement optimum training plans. This combined with being also a Bioforce certified conditioning coach, allows me to truly assess the needs of my clients. Over the past several years, I have become a rehabilitation specialist working with FSHD muscular dystrophy clients increasing their functional strength and improving their daily lives."

June Kinoshita, is Senior Director of Research and Education for the FSHD Society. June works at the intersection of research and the FSHD community. With the science team, she advises on strategies and programs to make sure the Society addresses the urgent needs and realities of those who are living with FSHD. With the community, she develops educational programs to support a highly engaged network of patients and family members who are empowered to advocate for their health and well-being and understand their vital role in advancing research. Previously, she has worked at Scientific American, Science, and co-founded the Alzheimer Research Forum and n-of-one.

Leo Wang, MD PhD, is Professor of Neurology at the University of Washington. He received his MD, PhD, and neuromuscular fellowship training at Washington University. He has led the successful recruitment and clinical evaluation efforts as a co-investigator in the Seattle Wellstone Center. He is grateful for funding through the MDA and Friends of FSH Research, and as a participating investigator in the U01 FSHD Clinical Trial Research Network which was partly funded by the FSHD Society.

Stephen Tapscott, MD PhD, is a professor in the Human Biology and Clinical Research Divisions of the Fred Hutchinson Cancer Center and a Professor of Neurology at the University of Washington. His research has focused on the regulation of gene expression in normal development and disease. His group helped identify the causative role of the DUX4 transcription factor in FSHD and defined the gene networks it regulates. Together with clinical studies on how muscle damage progresses in FSHD, this work has helped to establish the basis for therapeutic development and clinical trials in FSHD.



Joel Chamberlain, PhD, is a faculty member of the UW School of Medicine where she has developed a gene therapy research program aimed at treating dominantly inherited muscle disorders. Her approach is based on RNA interference methods using AAV-mediated muscle delivery for the most common adult muscular dystrophies, myotonic dystrophy (DM) and facioscapulohumeral dystrophy (FSHD). She is also studying FSHD in both patient muscle biopsies and a tunable mouse model developed in her laboratory. One of her current projects is studying the effects of DUX4 expression in muscle to facilitate FSHD blood-based biomarker development

Dennis Shaw, MD, is division chief of magnetic resonance imaging at Seattle Children's Hospital and professor of pediatric radiology at the University of Washington. "My work involves using imaging technology for diagnosis and in the guidance of minimally invasive interventions," he says. "It is very gratifying to employ these techniques to improve outcomes and decrease the discomfort of treatment for childhood diseases." He is a member of the FSHD Clinical Trial Research Network's imaging working group.

Nassim Rad, MD. Dr. Rad is an assistant professor with the Department of Rehabilitation Medicine. She serves as the Rehab Director of the Electrodiagnostic Laboratory and co-Director of the Muscular Dystrophy Association Care Center at UW Medical Center – Montlake. She is board certified in neuromuscular medicine.

Cat Kieu, PT. I have been a physical therapist for 9 years working at the University of Washington Medical Center in an outpatient rehabilitation clinic. I am mainly a clinical PT but work as a PT evaluator for the neurology department working on various research studies which include FSHD, Limb Girdle MD, Inclusion Body Myositis, and SMA. I am passionate about physical therapy at any stage of the disease process whether it be at the beginning of diagnosis where exercise can be more proactive or in later stages where equipment recommendations can be made.

Jamshid Arjomand, PhD, is chief science officer at the FSHD Society. A neuroscientist with more than 15 years of pharmaceutical and biotechnology experience in chronic pain, neurodegeneration, neuromuscular disorders and human stem cell disease modeling, Jamshid came to the FSHD Society from Genea Biocells, a San Diego-based biotechnology company where he served for five years as Vice President of Business Development. Genea's pipeline included FSHD for which their lead asset, GBC0905, received orphan drug designation by the FDA in May 2018. From 2005 to 2013, he served as Director of Basic Research at CHDI Foundation working on Huntington disease.

Amy Halseth, PhD, is Executive Director, Clinical Development, Avidity Biosciences. She joined Avidity in March 2022 and serves as the Program Lead for the company's FSHD program. She brings extensive experience in clinical development and medical affairs across a number of therapeutic areas, including diabetes, obesity, osteoarthritis, and pain. She has held leadership positions in industry at Amylin Pharmaceuticals, Genentech, Orexigen Therapeutics, and Biosplice. Amy holds a Ph.D in Molecular Physiology and Biophysics from Vanderbilt University.

Mihaela Levitchi Benea, MD, holds the position of Executive Director, Neuromuscular, Medical Affairs at Fulcrum Therapeutics. Her career spans over two decades in biotech and pharmaceutical industry focused primarily on neurology, including neurodegenerative and neuromuscular disorders. Mihaela graduated in Medicine and completed her residency in Neurology in Cluj-Napoca, Romania and completed a Master of Science in Pharmacology at University of Montreal, Canada.

Casey Childers, MD, currently serves as Chief Medical Advisor for Epic Bio, Inc., a biotherapeutics company in San Francisco, CA., developing therapies to dynamically control gene expression and to treat complex diseases such as FSHD. He previously served as Professor at the University of Washington, Seattle, Washington, School of Medicine where he co-directed the MDA Care Center and the Institute for Stem Cell and Regenerative Medicine. He led the collaborative research consortia to generate proof-of-concept and subsequent IND-enabling data to enable the first-in-human AAV gene therapy for X-linked myotubular myopathy in 2017 by Audentes Therapeutics, Inc.

Michael Willis BSHS (they/them), is Research Coordinator in Neurology at University of Washington. They studied physiology and biochemistry at the University of Arizona College of Medicine. Their previous research includes one of the largest CDC funded COVID follow up studies at UWMedicine for over two years. Mike joined the Neurology department in June of 2023 and is excited to continue and improve the great program at their new department as they pursue medical advancement in the fields of FSHD and beyond!

Anna Gilmore is Director of Patient Engagement for the FSHD Society. She joined the FSHD Society in March 2018. After spending a wonderful few years getting to know FSHD families as a part of the community engagement team, Anna is now working to open up even more avenues through which people can access information and make connections. She comes to the organization from Northeastern University, where she worked in the City & Community Affairs division for the last 7 years. Her projects there included implementing co-curricular volunteering programs and facilitating student leadership development and training with a focus on civic engagement and social justice. She lives in Wells, Maine with her awesome family.

Ashley Ferreira is Regional Director of Volunteer Leaders for the FSHD Society. Previously, she worked as a community partnerships manager with PicnicHealth where she worked to drive patient and care partner engagement from different rare disease communities to real world data research. Ashley brings over 8 years of experience in community and patient engagement, including having led Diversity, Equity, and Inclusion initiatives and the national Walk for PI program at the Immune Deficiency Foundation. As a caregiver to her mother and younger siblings, she is passionate about ensuring patients and caregivers have access to the resources they need to be their own best advocates, participate in research to accelerate treatments, and come together to raise awareness for their communities.

Chris Haven is a board members of Friends of FSH Research. “I was diagnosed with FSHD in 2017 with several years of mystery symptoms. It was then that I pivoted to see how I can help others like me in finding a cure,” she says. “I joined the Friends of FSH Research as a board member and am an active participant with the FSHD society, local meetups and any available studies and trials.” A seasoned software executive, Chris is currently exploring Artificial Intelligence techniques for assessing patterns for achieving lifestyle goals. She is also extremely interested in how AI will help with earlier diagnosis of FSH.

Selina Lai is director of the FSHD Society’s Pacific Northwest Chapter. For over 10 years Selina has been active in the FSHD community as a fundraiser and supporter both in the Los Angeles area and more recently, the Pacific Northwest. With numerous years of experience as a community leader, she hopes to grow the reach of the PNW Chapter to all those affected by FSHD in the area. Several members of her family have been diagnosed with FSHD and she believes that continued advocacy, education, and research will soon lead to a cure or treatment.