

Center for Academic Medicine
453 Quarry Road, Palo Alto CA, 94304
Agenda

9:30 – 10:00 am	Check in
10:00 – 10:05 am	Welcome. Mark Stone, FSHD Society
10:05 – 10:30 am	FSHD Disease and Research Overview John Day, MD PhD, Stanford University
10:30 – 11:00 am	The MOVE and MOVE-Plus study Veronica Stevens, Stanford University
11:00 - 11:30 am	Exercise makes a difference Tina Duong, PhD, Stanford University
11:30 – 12:00 pm	Taking care of mental health Kent Drescher, PhD, Bay Area chapter co-director
12:00 pm – 12:45 pm	Lunch break and networking
12:45 – 1:30 pm	Genetics and the family Jacinda Sampson, MD, PhD, Stanford University
	New genetic testing technology Rojan Kavosh, MS CGC, PerkinElmer Genomics
	FSHD Society's genetic testing program Jamshid Arjomand, PhD
1:30 – 2:45 pm	Drug Development Roundtable <ul style="list-style-type: none">• The drug development ecosystem and a trial-ready community Jamshid Arjomand, PhD• Drug Development Panel Presentations<ul style="list-style-type: none">○ Kelly DiTripani, RN, VP Medical Affairs, Avidity Biosciences,○ Jennifer Webster, VP Program Lead, Fulcrum Therapeutics,○ Peter Jones, PhD, University of Nevada Reno
2:45 – 3:00 pm	Activating the Bay Area community – Beth Johnston & Leigh Reynolds, FSHD Society
	Overview of the Bay Area chapter – Kent and Sue Drescher
3:00 pm	Closing remarks Mark Stone, FSHD Society

**FSHD 360 Conference Bay Area
Speaker Bios**



Mark Stone, President & CEO, FSHD Society. Mark has served as an executive leader of research-focused patient advocacy nonprofit organizations for the past 18 years. Prior to joining the FSHD Society, he was the chief executive officer of NephCure Kidney International. From 2004-2011, he was executive vice president and COO of the Polycystic Kidney Disease (PKD) Foundation. Passionate about helping organizations work to accelerate treatments and cures in diseases that are both rare and of a genetic origin, he has successfully engaged patients, families and friends in raising up an “army of activists” while advocating with pharmaceuticals, the National Institutes of Health (NIH), and the FDA to increase funding levels and enlarge the pipeline of potential therapies.



John Day, MD, Professor, Neurology & Neurological Sciences Director, Stanford Neuromuscular Disorders Program. Dr. Day has over 25 years of experience in diagnosing, treating and supporting patients with neuromuscular diseases. He is involved in ongoing research defining causes, diagnosis and novel treatments of genetic neuromuscular disorders. Dr. Day serves as an advisor to many scientific committees researching neuromuscular diseases, including NIH’s Advisory Committees on Muscular Dystrophy and Muscular Dystrophy research.



Veronica Stevens, Clinical Research Coordinator, Day Lab, Stanford University. Veronica joined Dr. John Day’s research team as a clinical research coordinator in 2019. Prior to joining the Neuromuscular Division she worked for two years at Oregon Health & Science University in immunology and infectious disease research.



Tina Duong, MPT PhD, is a research physical therapist at Stanford University specializing in understanding and developing outcome measures used in examining the natural history of neuromuscular diseases as part of clinical trials readiness. Her doctoral studies focused on effects of contracture development on musculoskeletal and biomechanical changes associated with function. She hopes to build and continue her pursuit in understanding the benefits of rehabilitation and exercise as conjunctive therapies in neuromuscular disease.



Kent Drescher, PhD, is a California licensed clinical psychologist who provided clinical services, education, and research at the National Center for PTSD for more than 27 years before retiring in 2017. His primary areas of expertise include the intersection of trauma and spirituality, and moral injury. He has been an early advocate for the use of evidence-based Acceptance and Commitment Therapy (ACT) for veterans struggling with moral challenges following military service. Dr. Drescher was diagnosed with FSHD at age 28 in 1983, about 10 years after his first symptoms appeared. He and his wife currently volunteer as chapter directors for the FSHD Society chapter for the San Francisco Bay area.



Jacinda Sampson, MD PhD, is Clinical Professor of Neurology at the Stanford University School of Medicine. She is the attending neurologist in adult and pediatric Muscular Dystrophy Association clinics and co-investigator on multiple clinical observational and treatment trials of FSHD with the Stanford Neuromuscular research group. Member of the American Academy of Neurology and the American Society of Human Genetics.



Rojan Kavosh, MS CGC, PerkinElmer Genomics. Rojan is a genetic testing consultant and a licensed certified genetic counselor based in Los Angeles. Prior to joining PerkinElmer Genomics, she worked as a perinatal genetic counselor at Stanford Children's Hospital.



Jamshid Arjomand, PhD, chief science officer, 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.



Kelly DiTrapani, RN, BSN, BA, Vice President, Medical Affairs, Avidity Biosciences. Kelly brings extensive commercial and medical affairs leadership in the life sciences industry, focused on bringing innovative therapeutics to patients in the oncology and rare disease spaces including Gleevec, Soliris and Imbruvica. Throughout her career, Kelly has held positions in industry and academics across roles in research, commercial and medical affairs at Ortho Biotech (J&J), Novartis Oncology, Duke University, Alexion Pharmaceuticals, Pharmacyclics, Versartis and Iovance Biotherapeutics. Kelly received her Bachelor of Arts and Bachelor of Science in Nursing from Duke University.



Jennifer Webster, MBA, Vice-President Program Lead Fulcrum Therapeutics. Ms. Webster has contributed to and lead a multitude of programs including six first-in-class products across several therapeutic areas and rare diseases. Prior to Fulcrum Jennifer held various roles at Foundation Medicine, Takeda, Vertex and PAREXEL. Jennifer's proficiencies include strategic planning and execution, program and partner management, clinical and business operations and evidence generation for registrational and reimbursement use. Jennifer holds a BA in Psychology from the University of Rochester and an MBA from the University of Boston, Massachusetts.



Peter Jones, PhD. Peter and his wife Takako lead lab at the University of Nevada Reno focused on gene regulation and epigenetic processes that occur during development and disease. We are investigating the fundamental epigenetic dysregulation of the chromosome 4q35 D4Z4 locus that leads to the pathogenic gene expression causing FSHD. We are using what we learn about fundamental FSHD pathogenic mechanisms to identify new drug targets for therapy, design therapeutic CRISPR-based strategies, develop novel FSHD-like animal models, identify FSHD disease biomarkers, and improve FSHD diagnostics.



Beth Johnston, chief community development officer, 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. Prior to joining the Society, she was Founder & CEO of Social Bridges, a Denver-based social media marketing agency. She has also worked in information technology, project management, high-technology & telecommunications consulting, and real estate.



Leigh Reynolds, chief program strategist, FSHD Society. Leigh has worked in non-profit leadership and capacity building for more than 25 years, most often in the patient advocacy space. Immediately prior to joining the FSHD Society, Leigh was the founder and managing director of a private consulting firm that focused on "helping the people that help the world." Before launching her own consulting firm, Leigh served on the leadership and development teams for the Polycystic Kidney Disease (PKD) Foundation and the National Multiple Sclerosis (MS) Society.



Kent and Sue Drescher, Bay Area chapter directors. Kent and Sue are both recently retired. Kent spent 27 years as a clinical psychologist at the VA hospital and continues to be involved in some related research and writing. Sue retired from a tech company and has been enjoying having extra time to spend with family. See additional information about Kent above.



June Kinoshita, director of research and patient engagement, FSHD Society. Previously, June co-founded and served as Executive Editor of the [Alzheimer Research Forum](#), the pre-eminent Web community for researchers in neurodegenerative disorders. June has worked on initiatives for multiple sclerosis, schizophrenia, amyotrophic lateral sclerosis, Parkinson's disease, and other disorders. She co-founded [N-of-One, Inc.](#), a pioneering targeted oncology company. June began her career as a science journalist, working as a writer and editor for *Scientific American*, *Science*, *The New York Times Magazine*, and many other national publications.