

Tamkin Auditorium, Ronald Reagan Hospital
757 Westwood Plaza, Los Angeles, CA 90095

Noon– 12:25 pm	FSHD 360 luncheon (incl. w registration) and icebreaker
12:25 – 12:30 pm	Welcome. Mark Stone, CEO, FSHD Society
12:30 – 12:45 pm	Symptoms, Variability, and introduction to genetics Tahseen Mozaffar, MD, UC Irvine
12:45 – 1:05 pm	Clinical research and FSHD, Perry Shieh, MD PhD, UCLA
1:05 – 1:15 pm	The MOVE Study, Jennifer Hyunh, UCLA
1:15 – 1:30 pm	Q&A with speakers
1:30 – 1:45 pm	Genetic testing for FSHD: advances in technology Rojan Kavosh, MS CGC, PerkinElmer Genomics
1:45 – 2:00 pm	Physical therapy and exercise for FSHD Julie Hershberg PT, DPT, NCS, USC
2:00 – 2:15 pm	Resources for independent living Cosette Case, LCSW, CALIF Independent Living Center
2:15 – 2:30 pm	Q&A with the panel
2:30 – 3:00 pm	Break
3:00 – 3:30 pm	FSHD research at UC Irvine Jay Han, MD, and Maya Hatch, PhD, UC Irvine
3:30 – 4:30 pm	Therapy development panel followed by Q&A Mark Stahl, MD PhD, Avidity Bioscience James Hamilton, MD MBA, Arrowhead Pharmaceuticals Alex Kiselyov, PhD, Myocera Jenny Shoskes, PharmD, Fulcrum Therapeutics.
4:30 – 4:45 pm	Activating the community, from research to advocacy Colette Wheeler, Amy Bekier, and Beth Johnston
4:45 – 4:50 pm	Concluding remarks, Mark Stone, CEO, FSHD Society
4:50 – 5:30 pm	Social Time

**FSHD 360 Conference Los Angeles
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. He has also served as the deputy director of an international relief and development organization and as a pastor within the Nazarene Church. 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.



Perry Shieh, MD, PhD, is Professor of Neurology and Pediatrics at the David Geffen School of Medicine at UCLA. He received his MD and his PhD in Neuroscience from Johns Hopkins University in Baltimore, Maryland. He completed residency training in neurology at Stanford University Hospital and fellowship training in clinical neurophysiology/EMG at Brigham and Women’s Hospital/Harvard Medical School. Dr. Shieh’s principal clinical interests include muscular dystrophy including FSHD, myasthenia gravis, inflammatory myopathy, and spinal muscular atrophy. He has served as an investigator in numerous clinical trials for neuromuscular conditions and has a particular interest in gene therapy.



Tahseen Mozaffar, MD, FAAN, is a Professor of Neurology and Pathology and Laboratory Medicine and the Vice Chair for Research in the Department of Neurology at University of California, Irvine. He is the Director of the UC Irvine-MDA ALS and Neuromuscular Center and the Director of the UC Irvine Neuromuscular Program. Dr. Mozaffar serves as chair of one of the biomedical committees and the institutional liaison for Trials Innovation Hub for the Center for Translational Sciences Award (CTSA) at University of California, Irvine. He is the Principal Investigator for UCI-NEXT, the NeuroNEXT award to the University of California, Irvine, one of 25 such NeuroNEXT sites funded by the NINDS/NIH.



Jennifer Hyunh, Clinical research coordinator at UCLA Department of Neurology. Jennifer was born and raised in Los Angeles, California. A graduate from California State University, Northridge with a B.S. in Biology-Microbiology, she always knew she would follow a career path that was in healthcare and patient services. After college, she volunteered at Seattle Childrens where she discovered that a career in clinical trials combined her interest in patient services and fulfilled her curiosity in learning about the effects of drugs on the body. Since joining Dr. Shieh’s team, Jennifer is excited about the future of research and is constantly inspired by the selflessness of patients and their community.



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.



Julie Hershberg PT, DPT, NCS, University of Southern California. Julie is a neurologic physical therapist and founder of re+active therapy & wellness in Los Angeles and professor at University of Southern California Division of Biokinesiology and Physical Therapy. She founded the Schmidt Movement Disorders Fellowship with UCLA and re+active to train physical therapists in movement disorders. She is passionate about therapy and exercise for degenerative neurologic diagnoses.



Cosette Case, LCSW, CALIF Independent Living Center. As a Licensed Clinical Social Worker providing services in the Los Angeles Community for over 25 years, I've worn many professional hats. I have a deep passion for equity care. I've focused on working with those experiencing any type of disability. Providing case management to those living with development disabilities, psychotherapy to individuals living with mental health disabilities, designing programs for those living with physical and learning disabilities. Currently, I'm working at the Aging and Disability Resource Connection in the City of Los Angeles supporting those over 60 and those of any age living with any type of disability.



Jay J. Han, MD is a Professor and Vice Chair of the Department of Physical Medicine & Rehabilitation at the University of California at Irvine. Dr. Han has clinical interests in neuromuscular diseases affecting both adult and pediatric populations. His research interests focus on the development of innovative technology-based physical function outcome measures in various neuromuscular conditions. Dr. Han's team has developed sensor-acquired 'reachable workspace' measure that tracks individual's upper extremity reachability function.



Maya N. Hatch, PhD is a Research Project Scientist in the Department of Physical Medicine & Rehabilitation and the Reeve-Irvine Research Center at the University of California at Irvine. Dr. Hatch's current research is in rehabilitation outcomes development/improvement, with a primary focus on upper extremity & balance/postural trunk control measures for neuromuscular and neurological disorders. During these studies she tries to incorporate the use of new and innovative technologies for improved sensitivity and accuracy.



Mark Stahl, MD, PhD, Senior Medical Director, Clinical Development, Avidity Biosciences. Prior to joining Avidity in March of 2021, he served as Medical Director in Early Clinical Development at Neurocrine Biosciences, where he worked on multiple preclinical and clinical stage programs including the initiation of new gene therapy programs in rare diseases. Previously, Mark was an Assistant Professor at Penn State University, where he founded a research laboratory focused on modeling neurodegenerative diseases, was associate director of the university's Medical Scientist Training Program and maintained an active clinical practice in neurology.



James Hamilton, MD MBA, is Senior Vice President, Discovery & Translational Medicine at Arrowhead Pharmaceuticals and is responsible for target discovery as well as non-clinical and early clinical development. Dr. Hamilton led the clinical development of ARO-HBV (now JNJ-3989) which was licensed to Janssen Pharmaceuticals and ARO-AAT, recently licensed to Takeda. In parallel, Dr. Hamilton served as Head of Corporate Development and led Arrowhead's in-licensing transaction of Novartis' RNAi assets, as well as the out-licensing of ARO-LPA (now AMG890) to Amgen. He holds both MD and MBA degrees from The Ohio State University. He is a licensed physician and completed residency training with board certification in emergency medicine.



Alex Kiselyov, PhD. Myoceia. Alex has spent over two decades in pharmaceutical and biotechnology companies doing all aspects of target identification and validation, drug discovery and early clinical development. He started his career at Amgen and held multiple positions of increasing responsibility at Imclone/Lilly, deCODE, Huntington's Disease Foundation (CHDI) and Genex Biocells. Alex's expertise includes rational design and development of diverse modalities to treat life threatening conditions, molecular and cell biology including regenerative aspects of embryonic and pluripotent stem cells. Alex is a founder and CEO of Myoceia that develops therapeutics to treat muscular dystrophies including facioscapulohumeral dystrophy.



Jennifer Shoskes, PharmD, is a Clinical Scientist at Fulcrum Therapeutics. Her work is focused on supporting and advancing Fulcrum's FSHD programs. Jennifer received her PharmD from Northeastern University, where she founded a student chapter for the National Organization for Rare Disorders (NORD) which began her passion for working with rare diseases. She brings extensive experience in rare disease drug development from Alnylam Pharmaceuticals and Apellis Pharmaceuticals, most recently having worked on advancing therapies for ALS and Paroxysmal Nocturnal Hemoglobinuria (PNH).



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. There he designed and managed a complex portfolio of projects for Huntington disease.



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.



Amy Bekier, San Diego chapter and Walk & Roll leader, FSHD Society Board member. Amy obtained a Master's degree in Education from Queens College, NY, and led a successful career as an insurance agent and Chartered Life Underwriter. Her mission is to expand the Society's role in the public awareness of FSHD, which in turn will assist in patient identification, fundraising and clinical trial readiness. Her personal motto, "We cannot sit and cope. We must get active and hope," is her mantra and hopefully serves to inspire others.



Colette Wheeler supports the FSHD Society by providing digital marketing and partnership counsel and by volunteering with the local Los Angeles chapter. She brings more than a decade of marketing and PR experience working with fortune 500 brands and non-profits. Recently, Colette has been busy falling in love with her new role as mom to her 4 month old son. Colette is a graduate from UC Berkeley and enjoys spending time outdoors with her family and cooking.



June Kinoshita, director of research and patient engagement, FSHD Society. June joined the FSHD Society in 2012 and served as its Executive Director until September of 2017. Previously, June co-founded and served as Executive Editor of the [Alzheimer Research Forum](#), the pre-eminent Web community for researchers in neurodegenerative 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.