FSHD 360 Conference
The Latest in Health & Research

University of Utah
October 22, 2022

University of Utah Guest House & Conference Center
110 Fort Douglas Blvd, Salt Lake City, Utah

Preliminary Agenda

9:30 – 10:00 am	**Check in**
10:00 – 10:05 am	**Welcome. Why are we here? What is the CTRN?** FSHD Society
10:05 – 10:30 am	**FSHD Disease and Research Overview** Russell Butterfield, MD, PhD, University of Utah
10:30 – 11:30 am	**Your questions answered: Exercise, Diet and More** Amelia Wilson & Melissa McIntyre, PT, DPT, physical therapy Summer Gibson, MD, neurology Becky Hurst-Davis, MS, RDN, CD, CNSC, diet and nutrition
11:30-11:45	**Break**
11:45 - 12:30 pm	**Genetic testing – what's best for me and my family?** Genetics of FSHD – Kristen Wong, CGC Advances in genetic testing – Rojan Kavosh, CGC, PerkinElmer Genomics FSHD Society's genetic testing program – Jamshid Arjomand, PhD
12:30 pm – 1:15 pm	**Lunch break and networking**
1:15– 1:45 pm	**Research at the University of Utah** The MOVE Study – Sarah Moldt, senior clinical research coordinator Utah Family Study – Robert Weiss, PhD
1:45– 2:45 pm	**The latest on drug development** • The drug development ecosystem and a trial-ready community – Jamshid Arjomand, PhD • Industry presentations – Olga Mitelman, MD, Fulcrum Therapeutics – Amy Halseth, PhD, Avidity Biosciences • PACT (Patients Accelerating Clinical Trials) – Beth Johnston
2:45 – 3:15 pm	**Activating the Utah and Idaho communities** Allison Calder, Utah chapter Minette Hale, Idaho chapter Beth Johnston, FSHD Society
3:15 pm	**Closing remarks and social time**

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Speaker Bios

Russell Butterfield, MD PhD. Russell Butterfield is an associate professor in the Pediatrics and Neurology departments at the University of Utah. He directs the Muscular Dystrophy Clinic at the University of Utah and Neuromuscular Clinic at Primary Children's Hospital. He is principal investigator for the FSHD Clinical Trial Research Network (CTRN) site at the University of Utah. His research involves studying hundreds of members of an extended FSHD family in Utah to search for genetic factors that influence the disease.

Amelia Wilson, physical therapist**,** was born in raised in Wisconsin but has lived in Utah for over 10 years. She has practiced physical therapy in several different settings and has experience working with adults and children with a variety of medical diagnoses including neurologic, orthopedic, and developmental conditions. Amelia has specialized in neuromuscular diseases as a physical therapist and clinical evaluator since 2018. In her free time Amelia enjoys cooking, rock climbing and taking her dog on hikes and trail runs.

Melissa McIntyre is a physical therapist and clinical evaluator with the Utah Program for Inherited Neuromuscular Disorders (UPIN) at the University of Utah. Through UPIN, her work focuses on research and clinical care of neuromuscular disorders affecting both adult and pediatric populations. In addition to her work on multiple clinical trials. Melissa aims to minimize barriers patients face when engaging in independent recreation and physical activity regardless of their physical limitations. Melissa received her Doctor of Physical Therapy (DPT) from the University of Utah and is currently pursuing a PhD in Rehabilitation Sciences at the University of Utah.

Summer Gibson, MD, is an associate professor of neurology and chief of the Neuromuscular Medicine Division at the University of Utah. She received her medical degree from the University of Texas Health Science Center San Antonio before completing her neurology residency training and a fellowship in clinical neurophysiology and neuromuscular diseases at the University of Utah. Her clinical interests are in neuromuscular disorders and electrodiagnosis (EMG). Within neuromuscular disorders her focus is on amyotrophic lateral sclerosis (ALS), muscular dystrophies, peripheral neuropathies, and myasthenia gravis. She co-directs the motor neuron disease/ALS clinic at the University of Utah.

Becky Hurst Davis MS, RD, CSP, CD, CNSC, is a registered dietitian at Primary Children's Hospital in Salt Lake City, UT. She is a certified specialist in pediatric nutrition and in nutrition support for all ages. Her primary focus is nutrition and nutrition-related research for individuals with neuromuscular conditions.

Kirsten Wong, CGC, is a board certified and licensed genetic counselor in the Department of Pediatrics at the University of Utah, where she helps patients and providers to coordinate appropriate genetic testing, help families understand the implications of their genetic results, and provide support. Her main clinical interests include neuromuscular (NM) disorders, leukodystrophies, and general neurogenetic indications. In addition to her outpatient clinical work, Kristen also participates in follow up for the state of Utah newborn screening programs for SMA and X-linked adrenoleukodystrophy. She enjoys working at a variety of institutions in the Salt Lake Valley including Primary Children's Hospital, Shriners Hospital for Children-Salt Lake City, and the University of Utah MDA Clinic.

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.

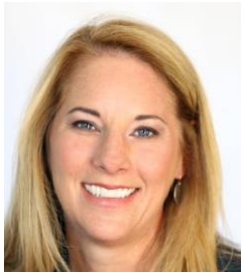
Jamshid Arjomand, PhD, is chief science officer at the FSHD Society. A neuroscientist with more than 15 years of pharmaceutical and biotechnology experience in chronic pain, neurodegeneration, neuromuscular disorders and human stem cell disease modeling, Jamshid came to the FSHD Society from Genea Biocells, 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.

Sarah Moldt is a senior clinical research coordinator with the Utah Program for Inherited Neuromuscular Disorders (UPIN) at the University of Utah with Pediatric Neurology. Sarah first started her career in research during her undergraduate years at the University of California San Diego (Go Tritons!), developing a clinical trial education program for Asian American and Pacific Islanders. Now she is focusing on genetic modifier studies and gene therapies in several neuromuscular dystrophies such as FSHD, SMA, and Duchenne, while pursuing her MBA at the University of Utah.

Robert Weiss, PhD, is a Professor in the Department of Human Genetics. He received his BS in Biology from the Massachusetts Institute of Technology and his PhD in Genetics from the University of Washington, studying the fidelity of protein synthesis. His research efforts have involved studying the genetics and genomics of various human disorders, including hereditary cancers, nicotine dependence and numerous types of neuromuscular disorders. Through a collaborative effort, the United Dystrophinopathy Project, his laboratory developed and offers DNA diagnostics to patients afflicted with Duchenne muscular dystrophy (DMD). His current research efforts include discovering genetic modifiers of disease progression in patients with neuromuscular diseases using genome-wide association strategies.

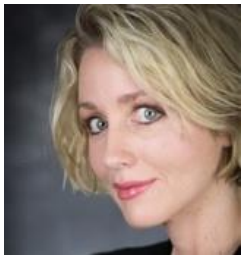
Olga Mitelman, MD, is Senior Vice President, Head of Medical Affairs, at Fulcrum Therapeutics. She has twenty years of experience in medical affairs at such companies as Johnson & Johnson, Merck, Biogen, and Sarepta, leading both global and US functions. She has worked in the therapeutic areas of neurology, psychiatry, and hemophilia with exposure to rare disease and orphan indications. She received her MD from the University of Pennsylvania.

Amy Halseth, PhD, is Executive Director, Clinical Development, Avidity Biosciences. Amy joined Avidity in March 2022 as Executive Director of Clinical Development and serves as the Program Lead for the company's FSHD program. Amy 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.



Beth Johnston, 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. 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.

Allison Calder, director of the Utah Chapter, FSHD Society. FSHD became part of Allison's life in 2013 when her husband, Curtis, was diagnosed at age 29. "As a nurse, I immediately dove in, learning about the mechanisms of the disease and how it would affect our little family," she says. "The FSHD Society was an incredible resource and becoming part of this great community has helped our family immensely. Curt and I live in Salt Lake City with our 5 children. We started our business, Anson Calder, shortly after Curt was diagnosed and use our business to support the FSHD Society's mission."



Minette Hale, director of the FSHD Society's Idaho Chapter, comes from a strong family line of FSH Muscular Dystrophy. She and 6 of her 8 siblings have inherited the condition from her father and grandmother. It has been a huge part of not only her life, but her immediate and extended family as well. Having people in her life who can relate to her struggles has been a strength. She hopes, as a chapter director, to help others feel support from their FSHD family as we are all brothers and sisters in this disease.