



The Latest in Health & Research

Presented by the FSHD Society & UT San Antonio Medical Center
Allen R. Baca Center 301 W. Bagdad Ave. Building 2, Round Rock, TX

Round Rock, Texas

April 27, 2024

Agenda

- 9:00 – 10:00 a.m. **Doors open, social time. Massage warm-up with Steve Kowalik**
- 10:00 – 10:05 a.m. **Welcome! What is a 360? CTRNs in Texas**
Beth Johnston, FSHD Society
- 10:05 – 10:25 a.m. **FSHD 101 and overview of FSHD centers in Texas**
Matthew Wicklund, MD, UT San Antonio Medical Center
- 10:25 – 10:45 a.m. **Caring for your breath**
Michael Shapiro, MD, pulmonologist
- 10:45 – 11:05 a.m. **Caring for your mental health**
David Younger, PhD, clinical psychologist
- 11:05 – 12:00 p.m. **Q&A with FSHD Care Panel**, moderated by Matt Wicklund, MD
Kaitlin Batley, MD, UTSW Children’s Health
Adam Horvit, MD, director, MDA clinic for Central Texas
Steve Kowalik, massage therapist
Leslie Nelson, physical therapist
Martinna Raineri Tapies, genetic counselor
David Younger, PhD, psychologist
- 12:00 – 1:00 p.m. **Lunch Break**
- 1:00 – 2:00 p.m. **Drug development and trial overview**
Amanda Hill, FSHD Society
- Industry panel Q&A moderated by Amanda Hill**
Mel Hayes, Fulcrum Therapeutics, & Amy Halseth, Avidity Biosciences
- 2:00 – 2:15 p.m. **Clinical trial patients’ perspectives, moderated by Ashley Ferreira**
Rebecca Anderson & David Younger
- 2:15 – 3:00 p.m. **Independent living**
Antoinette Verdone, assistive technologies;
Michelle Szumski, financial & workforce issues
- 3:00 – 3:15 pm **Activating our Texas communities**
Ashley Ferreira & Beth Johnston, FSHD Society
Rachel Sartin & Ashley Bryan, Central Texas Chapter
Glen Denehie & Tara Hall, North Texas Chapter
- 3:15-4:30 pm **Physical therapy and massage demonstrations**
Accessible van demo – Toni Diaz

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.



Texas FSHD 360 Conference Speaker Bios



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.



Matthew Wicklund, MD, is Professor of Neurology and Vice Chair for Research within the Department of Neurology at UT Health San Antonio (UTHSCSA), where he directs the neuromuscular multidisciplinary care center. Prior to his transition to academic medicine in 2011, he served as a neurologist and in leadership positions for 22 years in the United States Air Force. He has served as the site director for the FSHD Clinical Trial Research Network, as well as for research networks in Limb Girdle Muscular Dystrophy and Myotonic Dystrophy. At UT Health San Antonio, he conducts his own clinical research and leads the research program in a neurology department with 60+ clinical trials and more than a dozen clinical research personnel.



Michael Shapiro, MD, is with Ascension Medical Group where he specializes in treating patients with pulmonary complications of neuromuscular disease. He is also a faculty affiliate of the Dell Medical School at the University of Texas of Austin. He received his medical education at UTMB Galveston; did his internship and residency at the Kansas University Medical Center in Kansas City; and had a pulmonary fellowship at Baylor College of Medicine Houston.



David Younger, PhD, is a licensed psychologist in Texas and New York with a 100% online private practice. He sees individuals and couples in different parts of the world, some of whom live with chronic illnesses, and runs a therapy group and teaches mindfulness and meditation as well. David has been married to his amazing wife, Debbie, who is also a therapist in private practice, for 21 years. They have a 19 year-old son who's a sophomore at Rice and a 10 year-old daughter who wants to train dolphins. David was diagnosed with FSHD when he was 4. His late mother, grandmother and great grandfather all had FSHD.



Martinna Raineri Tapies is a Certified Genetic Counselor specializing in Neurology. She is originally from Chile and received her undergraduate degree in Biology at the University of Maryland. After graduation, Martinna dedicated herself to neuronal signaling and calcium signaling research in Chicago. She then moved her career to genetics and pursued a Masters in Genetic Counseling at the University of Utah. Fueled by her passion for Neurogenetics, she now serves as a Neurology Genetic Counselor at UT Health San Antonio, blending her expertise in genetics with her earlier work in neurology research.



Leslie Nelson, PT PhD, is a physical therapist at the University of Texas Southwestern Medical Center in Dallas, where she serves as Assistant Faculty in the Department of Physical Therapy. She specializes in clinical management including evaluation and treatment of pediatric and adult patients with various neuromuscular disorders. She is also an investigator and evaluator for independent and industry sponsored clinical trials in diseased including FSHD, SMA, DMD, myotubular myopathy, CMT, myotonic dystrophy, and others. Leslie's practice and research focus has been focused on neuromuscular disorders since 2004, with special interest in clinical outcomes for neuromuscular populations.



Steven Kowalik is a licensed massage therapist specializing in recovery from injury and chronic conditions. My focus is helping people regain and maintain function of the body in order to live the best life possible. Over the last 15 years, I have worked with professional and college athletes, Olympians, Wounded Warriors, and countless others, and worked with diagnoses including FSHD, muscular dystrophy, spina bifida, and cerebral palsy as well as a host of sports and chronic injuries.



Adam Horvit, MD, is from Houston, TX. He attended medical school at Baylor College of Medicine where he also completed his neurology residency and neuromuscular fellowship. He has been practicing neurology in Central Texas since 1997 as a member of Central Texas Neurology Consultants. His practice focuses on neuromuscular diseases. He has been the director of the Muscular Dystrophy Association (MDA) clinic in central Texas for over 20 years. He has also run the MDA ALS clinic for more than 15 years. He is also an adjunct assistant professor at Texas A&M College of Medicine.



Kaitlin Batley, MD, is a Pediatric Neuromuscular Neurologist and the Director of the Pediatric Neuromuscular Program at UT Southwestern (UTSW) and Children's Health in Dallas, TX. After completing Child Neurology residency and Pediatric Neuromuscular Fellowship at UTSW, Dr. Batley then joined faculty as an Assistant Professor of Pediatrics and Neurology, also serving as the Pediatric Neuromuscular Fellowship Director. She oversees clinical operations and manages a multidisciplinary team to provide care to children affected by neuromuscular disorders and their families. Dr. Batley is also involved in research, participating in over 20 clinical trials and natural history studies.



Amanda Hill, Director of Clinical Research at the FSHD Society, brings expertise in biomedical sciences, clinical research, scientific communication, and project management. Amanda's husband was diagnosed with FSHD in 2016, spurring her personal and professional drive to serve the FSHD community. Amanda earned her BA in Molecular Biology from Scripps College in Claremont, CA and her MBA in Bioinnovation and Entrepreneurship from the University of Colorado Denver. She lives in Highlands Ranch, CO with her husband and two dogs and enjoys exploring food and wine, running, knitting, and gardening.



Mel Hayes joined Fulcrum in September 2021 and currently serves as Executive Vice President, Patient Experience. Mel is responsible for developing an external facing integrated enterprise model that leverages the intersection of Patient Affairs, Advocacy, Access, Policy, and Communication to support the pipeline in both Sickle Cell Disease and FSHD. Prior to Fulcrum, Mel served as Global Head Commercial, Vice President, Rare Blood Disorders at Sanofi-Genzyme



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.



Amy Halseth, PhD, is the FSHD Development Lead at Avidity Biosciences, based in San Diego, CA. She is relatively new to the FSHD world but has worked on drug development for more than 20 years. Her favorite part of her job is knowing that what she is working on has a real opportunity to make an impact to people living with FSHD and their families. In her spare time, Amy enjoys spending time with her dog Bondi, running, gardening, and reading. Amy holds a Ph.D. from Vanderbilt University.



Rebecca Anderson is from Baytown, Texas. She is a pediatric nurse practitioner and has worked for Texas Children's Hospital for 25 years. She and her husband of 25 years, Jeff, have two children, Jaylee, 17, and Carter, 15. Becca was diagnosed with FSHD at the end of 2020, at the age of 46, when her very perceptive neurologist identified signs that she had not recognized as significant. She attended the FSHD Connect international conference in Florida in June 2022 and began to pursue opportunities to participate in research at that time.



Antoinette Verdone has been in the assistive technology industry for over 20 years. She has a bachelor's degree in mechanical engineering and a master's degree in biomedical engineering, with a focus on rehabilitation engineering. Antoinette has worked in government, non-profit, and private settings providing a wide range of assistive technologies for people with a wide range of disabilities. Antoinette is the founder and lead consultant for ImproveAbility, an assistive technology sales and consulting firm in Austin. She serves clients throughout Texas as well as the Gulf Coast.



Michelle Szumski is the program specialist for assistive and rehabilitation technology for Texas Workforce Commission. She provided program support, planning of services, and education across the state to vocation rehabilitation counselors, assistive technology specialists, and rehabilitation assistants, business partners, and customers in assistive technology, vehicle modification, durable medical equipment and home and office modification. Michelle has a masters of education from the University of Texas at Austin, 15 years of experience as a human resource manager and 12 years as a licensed professional counselor (LPC) and certified rehabilitation counselor (CRC).



Frank & Toni Diaz live just south of Houston in League City. Frank was diagnosed with FSHD in 2005. Toni is his full-time care partner. They have been married almost 28 years and have two daughters, Briana 26 and McKenzie 23. Frank owns Salsas Mexican Restaurant on Galveston Island. He work from home handling the business/financial side while his business partners handle things at the restaurant. Toni is a member in the Care Partners Zoom group, and the family is also active in the CenTex Walk & Roll. They are looking forward to treatments and a cure for others in our family who may become affected in the future.



Rachel Sartin had been involved with the FSHD Society for several years when the chapter program started. She volunteered to be the first leader of the CenTex group and has enjoyed working with Ashley Bryan on building awareness, support, and fundraising. Rachel grew up in Iowa and earned a masters in computer science from the University of Iowa. In Austin, she worked at a software start-up which went public and was acquired by IBM. At IBM, she rose into executive management managing software teams across the world until she retired several years ago. Rachel and her husband Rob live in far Northwest Austin where they had their wheelchair accessible home built from the ground up. They have two sons, Spencer, who graduated from the University of Chicago in 2022, and Jacob, who is a sophomore at Bradley University in Peoria Illinois.



Glen Denehie is co-director of the North Texas Chapter of the FSHD Society. He calls Dallas home now, but grew up in South Mississippi and Louisiana. He completed his undergraduate studies at the University of Louisiana- Lafayette and graduate studies at the University of Dallas. He has been married to his wife, Beth, for 27 years. They have two teenage sons. "We believe there is power in these cornerstones," he says, "and these cornerstones will provide a safe and solid place for impacted individuals to get help as well as have the opportunity to help others as we take this journey together."



Tara Hill is co-director of the North Texas Chapter of the FSHD Society. A transplant from Missouri, Tara has been in Texas for 13 years. She contacted FSHD Society in 2022 and began helping Glen Denehie launch the North Texas Chapter. "When I was diagnosed in 2000, there was virtually nothing for patients and their families. Now I have a chance to reach out to others who are on their own journey with FSHD and offer them community and hope." Tara lives in North Texas with her spouse and enjoys gardening, music and reading.



Ashley Bryan - FSHD warrior – was diagnosed at 21, symptomatic since age 10. "Been a member of the FSHD Society since almost the beginning! I live out on Lake Travis with my rockstar husband, Steve. Our one and only, Audrey was genetically confirmed 3 years ago and lives in Pittsburgh, working for the Pittsburgh Penguins. I roll in a Whill Ci and use a disability van with a fold out ramp. Making "art" (using that term very liberally...Sticks and Stones might be more accurate !) and making people laugh is my jam! I am sick and tired of this disease and obsessed with getting a treatment for Audrey asap! My immediate goal is to get Texas FSHers to band together and truly make a difference.



Ashley Ferreira is Regional Director of Volunteer Leaders for the FSHD Society. Previously, she she worked at PicnicHealth to drive patient and care partner engagement from 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.