



Hilton Denver City Center, June 15-16, 2024

Preliminary agenda

Day One

8:00 AM	Doors open. Warm-up activities
9:00 AM	Welcome
9:05 AM	Keynote: Retired Army Command Sgt. Major Gretchen Evans, <i>Team Unbroken</i>
10:00 AM	The Big Picture, Nicholas Johnson, MD
10:20 AM	Research call – A new biomarker for FSHD? Suja Jagannathan, PhD
10:25 AM	A new standard of care for FSHD. Nicol Voermans, MD PhD
10:45 AM	Morning break
11:00 AM	Care to enhance quality of life, Molly Morrill, NP
11:20 AM	TBD
11:40 AM	Morning session Q&A
12:10 PM	Lunch break
1:05-5:30 PM	<p>Breakout sessions (choose four topics)</p> <ul style="list-style-type: none"> • Meet the doctors • Meet the scientists / science table • Pediatric and early-onset panel • Pain management, CBD, and medical marijuana • Energy self-management technique • Physical therapy for FSHD • All about orthotics • Assistive technology clinic • Nutrition and anti-inflammatory diet • Meet the FSHD Navigators • Test drive BetterLife FSHD • Wheelchair accessible vehicles
7:00 PM	Banquet, awards, dancing, kids' movie night
9:00 PM	Young adults group outing

FSHD Connect Conference Day Two

8:00 AM	Doors open. Morning warm-up activities
9:00 AM	Welcome to Day 2
9:05 AM	FSHD drug development 101, Amanda Hill Industry panel Q&A
10:05 AM	Enrolling and participating in clinical trials, with the University of Colorado clinical trial team
10:35 AM	Break
10:50 AM	How the FSHD Society serves the FSHD Community <ul style="list-style-type: none">• BetterLife FSHD integrated health platform• FSHD Navigator• Hill Day and advocacy• Volunteer leaders
12:00 PM	Adjourn