

*Hosted by Dr. Jeffrey Statland, the University of Kansas Medical Center, & FSHD Clinical Trial Research Network. Sponsored by the FSHD Society.*

### **Preliminary Agenda**

9:00 – 10:00 am	<b>Check in, social time</b>
10:00 – 10:05 am	<b>Welcome! A new era for the FSHD community</b> Mark Stone, CEO, FSHD Society,
10:05 – 10:35 am	<b>FSHD overview of research at the CTRN</b> Jeffrey Statland, MD, KUMC, director of the CTRN
10:35 – 10:55 am	<b>The risk of shoulder injury in FSHD</b> William Liu, MD candidate, KUMC
10:55 – 11:15	<b>What are we learning from whole-body MRI?</b> Doris Leung, MD PhD, Kennedy Krieger Institute
11:15 – 12:15	<b>Care team panel QA&amp;</b> Physical therapy and exercise, genetic testing and counseling, orthotics and assistive devices, nutrition, mental health, accessing services
12:15 – 1:15 pm	<b>Lunch &amp; breakout session on pain and exercise</b>
1:15 – 1:35 pm	<b>Clinical trials and therapeutic approaches overview</b> Speaker TBD
1:35 – 1:55 pm	<b>MOVE+ study overview</b> Michaela Walker, KUMC & CTRN
1:55 – 2:15 pm	<b>TARGET FSHD – A study of clenbuterol</b> Rebecca Clay, KUMC
2:15 – 2:45 pm	<b>Break / Breakout session on managing fatigue</b>
2:45 – 3:30 pm	<b>Clinical trial overview and industry Q&amp;A</b>
3:30 – 3:45 pm	<b>BetterLife FSHD</b> Amanda Hiil, FSHD Society
3:45 – 4:00 pm	<b>Getting involved with Kansas chapter</b>
	<b>Closing remarks</b>

*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.*



**Merriam, Kansas  
October 5, 2024**

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