

**University of Rochester Saunders Research Building**  
**265 Crittenden Blvd., Rochester, NY**

**Preliminary Agenda**

9:00 – 10:00 am	<b>Check in, social time</b>
10:00 – 10:10 am	<b>Welcome! What is a 360? What is the CTRN?</b> Beth Johnston, FSHD Society
10:10 – 10:30 am	<b>FSHD Today</b> Rabi Tawil, MD, University of Rochester
10:30 – 10:50 am	<b>FSHD in children</b> Natalie Katz, MD, University of Rochester
10:50 – 11:05 am	<b>FSHD Research: Insights from MD StarNet</b> Shannon Kilburn, MPH, NY State Dept of Public Health
11:05 – 11:35 am	<b>Current Clinical Trials</b> Johanna Hamel, MD, University of Rochester
11:35 – 11:50 am	<b>Break</b>
11:50 am – 12:35 pm	<b>Care Team panel / Q&amp;A</b> <ul style="list-style-type: none"><li>• Kate Eichinger PT DPT</li><li>• Nicole White, PT DPT</li><li>• Jordan Bontrager MS CGC</li><li>• Cindy Gibson, ANP-BC, CRRN</li><li>• Rabi Tawil MD</li></ul>
12:35 – 1:20 pm	<b>Lunch and Ice Breaker</b>
1:20 – 1:50 pm	<b>Trial readiness for FSHD</b> Jamshid Arjomand, PhD, FSHD Society
1:50 – 2:20 pm	<b>Clinical Trials: Enrolling, FAQs, future trials</b> Rabi Tawil, MD; Leann Lewis; Jordan Bontrager MS CGC
2:20 – 2:35 pm	<b>Break</b>
2:35 – 2:50 pm	<b>FSHD Research: The MOVE and MOVE+ studies</b> Michaela Walker, University of Kansas
2:50 – 3:20 pm	<b>Living with FSHD – Panel with patients and families</b>
3:20 – 3:30 pm	<b>Igniting the Community - Beth Johnston, FSHD Society</b>
3:30 pm	<b>Adjourn and social time</b>



**University of Rochester**  
**May 6, 2023**