

MDCRN Investigator Meeting – FSHD CTRN Agenda

FSHD CTRN Sites: University of Rochester Medical Center | University of Kansas Medical Center | Virginia Commonwealth University | University of Calgary | University of Colorado | University College London | Duke University | Kennedy Krieger Institute | Montreal Neurological Institute-Hospital | Royal Children’s Hospital Melbourne | Nationwide Children’s Hospital | NeMO | CHU de Nice | Institute of Myology | University of Munich | The Ohio State University | University of Ottawa | Radboud University Medical Center | University of Sao Paulo | Seattle Children’s Hospital | Sheffield Teaching Hospitals | Stanford | University of California Los Angeles | University of California San Diego | University of Florida | University of Iowa | University of Nevada Reno | University of Utah | University of Texas Southwestern | University of Washington |

November 9th				
7:15am	Meet in Omni or Quirk Lobby to Shuttle to Greater Richmond Convention Center			
7:45am	ReSolve Didactic Session: QMA, MFM, and IOPI	Kate Eichinger	Evaluators	Large CE Room - E11AB
8:00am	Breakfast and Check-In at Greater Richmond Convention Center			
9:00am	Keynote Speaker	Scott Harper	All	Main - E10ABCD
9:45am	FSHD CE Didactic Training (Adults & Peds)	Kate Eichinger, Katy deValle	Evaluators	Large CE Room - E11AB
11:30am	Lunch			
12:30pm	FSHD CE Hands-On Adults Training (FSHD-COM, TFTs, MMT, PFTs)	Kate Eichinger	Evaluators	Large CE Room - E11AB
2:30pm	Session 3: Strength and Function Across the Dystrophies		All	Main - E10ABCD
4:00pm	Session 4: Trial Design Considerations		All	Main - E10ABCD

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November 10th				
7:30am	Meet in Omni or Quirk Lobby to Shuttle to Greater Richmond Convention Center			
8:00am	Breakfast and Check-In at Greater Richmond Convention Center			
8:30am	FSHD CE Hands-On Pediatric Training (Peds-COM, MMT, PFTs)	Kate Eichinger, Katy deValle	Evaluators	Large CE Room - E11AB
8:30am	Opening Remarks	Jeff Statland, Rabi Tawil	Investigators / Coordinators	Main - E10ABCD
8:45am	Biorepository Updates	Don Henderson	Investigators / Coordinators	Main - E10ABCD
9:00am	Data Management and Quality Assurance	Bill Martens	Investigators / Coordinators	Main - E10ABCD
9:15am	Coordinator Breakout	Leann Lewis, Rebecca Clay	Coordinators	Small CE Room – E11C
9:15am	PI Breakout	Jeff Statland, Rabi Tawil	Investigators	Main - E10ABCD
10:15am	Break/Sponsor and Collaborator Arrivals			
10:30am	ReResolve Dyne EU Baseline Data	Enrico Buigiardini	All	Main - E10ABCD
10:50am	ReResolve Late Onset Cohort	Sabrina Sacconi	All	Main - E10ABCD
11:10am	Revised RWS Analysis	Maya Hatch	All	Main - E10ABCD
11:30am	Pediatric Outcomes for FSHD	Katy deValle	All	Main - E10ABCD
11:50am	Open Session		All	Main - E10ABCD
12:15pm	Group Photo and Lunch			
12:45pm	MOVE Baseline Data	Channa Hewamadduma	All	Main - E10ABCD
1:05pm	MOVE Methylation Data	Peter Jones	All	Main - E10ABCD
1:25pm	MOVE Remote Pilot & Actigraph Data	Katy Eichinger, Johanna Hamel	All	Main - E10ABCD
1:45pm	MOVE+ Preliminary MRI Analysis	Seth Friedman, Doris Leung	All	Main - E10ABCD
2:05pm	Open Discussion		All	Main - E10ABCD
2:45pm	Closing Remarks	Jeff Statland, Rabi Tawil	All	Main - E10ABCD

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