



2023 Annual Leadership Summit, Milan, Italy

Day 1 – June 17, 2023

9:00 AM	Welcome. Goals of the meeting	June Kinoshita, FSHD Society Zoom host: Leigh Reynolds
9:05 AM	Ice breaker - getting to know one another	Sheila Hawkins, FSHD EU
10:00 AM	Medical care standards for FSHD	Nicol Voermans, MD PhD, Radboud Medical Center
10:30 AM	Q&A	
10:45 AM	Break	
11:00 AM	Research highlights from the International Research Congress on FSHD	Alexandra Belayew, PhD, University of Mons
11:30 AM	Drug development & clinical trial overview	Jamshid Arjomand, PhD, FSHD Society
12:00 PM	Q&A	
12:30 PM	Lunch	
1:30 PM	Project Mercury overview:	Mark Stone, FSHD Society
2:00 PM	Q&A	Moderator:
2:30 PM	TREAT-NMD and international registries	David Allison, PhD, TREAT-NMD
2:50 PM	Q&A	
3:00 PM	Break	
3:15 PM	Challenges of access to future therapies	Josie Godfrey, Project HERCULES
3:45 PM	Q&A	
4:00 PM	Break	
4:15 PM	Patients and Industry dialog on clinical trials	Moderator: Josie Godfrey
5:15 PM	Summary of day / prepping for Day 2	Moderator: Ricardo Gerpe, FSHD Spain
5:30 PM	Adjourn and Break	
7:00 PM	Dinner	

Day 2 – June 18, 2023

9:00 AM	Welcome. Recap Day 1. Day 2 goals	Sheila Hawkins; Zoom host: Leigh Reynolds
9:15 AM	World Alliance areas of focus Each organization to define outcomes that best fit its local conditions and organizational interests and capacity.	Moderator: Sheila Hawkins
10:15 AM	Break	
10:45 AM	Breakout groups by areas of focus: - Patient education and engagement - Clinical resources and clinician engagement - Registries and research - Advocacy, access to treatments - Sustainability	There will be parallel Zoom breakout rooms per topic.
11:45 AM	Task forces present their goals and plans	Moderator:
12:15 PM	Looking forward	Mark Stone
12:25 PM	Adjourn.	

Thank you to our sponsors!



UNIONE ITALIANA LOTTA
ALLA DISTROFIA MUSCOLARE

