

**New York City FSHD Family Day Conference**  
New York Athletic Club, Presidents Room  
180 Central Park South, New York, NY 10019  
**Saturday, November 16, 2019, 10:00 am to 3:30 pm**

- 10:00—10:30 am      **Welcome**
- Self-introductions**
- 10:30—10:45 am      **Vision for the New York City FSHD Community**  
Mark Stone, CEO of the FSHD Society
- 10:45—11:45 am      **FSHD 101** (15 mins each + 15 mins Q&A)
- In the beginning...what is FSHD? Genetic cause and characteristics**  
Matthew Harms, MD, Columbia University Medical Center
- Best practices - What every patient needs to know**  
Michio Hirano, MD, Columbia University Medical Center
- Physical therapy and exercise**  
Fondre Goulbourne, DPT, Columbia University Medical Center
- 11:45—12:30 pm      **Lunch break hosted by FSHD Society**
- 12:30—1:30 pm      **Moving Through FSHD – biopsychosocial aspects**  
Jennifer Egert, PhD, and Jennifer Jo Brout, PsyD
- 1:30– 2:30 pm      **The age of clinical trials is here** (15 mins each + 15 min Q&A)
- Clinical trials 101**  
Jinsy Andrews, MD, Columbia University Medical Center
- ReDUX4 clinical trial**, Michelle Mellion, MD, Fulcrum Therapeutics
- Applying Genome-wide CRISPR Screening for Therapeutic  
Discovery in FSHD**, Justin Cohen, PhD, Yale University
- 2:30-2:45 pm      **It's time to activate!**  
June Kinoshita, Chief Strategic Programs Officer, FSH Society
- 2:45-3:00 pm      **What's next for the Greater NYC community? Vision and strategy**  
Jennifer Jo Brout, PsyD, chapter director
- 3:00-3:30 pm      **Social time**