

Chicagoland FSHD Family Day Conference

Shirley Ryan Abilitylab, 355 E. Erie St, Chicago, IL 60611

Sunday, October 20, 2019, 12:00 to 6:00 pm

Preliminary Agenda (September 26, 2019)

- 12:00 pm—12:30 pm **Lunch and Welcome**
- 12:30—12:45 pm **Vision for Chicagoland FSHD Community**
Mark Stone, CEO of the FSHD Society
- 12:45—2:00 pm **Best practices in caring for FSHD (45 mins + 30 mins Q&A)**
- FSHD 101 – What every patient needs to know**
Charu Nagar, MD, Northwestern Feinberg School of Medicine
- Managing pain and navigating daily activities**
Leah Hanson, Occupational Therapist
- Brace Yourself - Orthotics for FSHD**
Donald McGovern, CPO, FAAOP, Shirley Ryan Abilitylab
- 2:00-3:15 pm **Refreshment Break / Tour of the Shirley Ryan Abilitylab**
During this break, enjoy socializing. Three tour guides will take groups of up to 15 people for 30-minute tours of the lab.
- 3:15-4:00 pm **Resources for Living Your Best Life (20 min + 25 min Q&A)**
Joy Wagner, Neurobalance Center
- 4:00-5:00 pm **Advances in FSHD treatments (20 mins each + 20 min Q&A)**
- Gene therapies for FSHD, Lindsay Wallace, PhD, Nationwide Children's Hospital, The Ohio State University**
- ReDUX₄ clinical trial, Alejandro Rojas, PhD, Fulcrum Therapeutics**
- 5:00-5:15 pm **An engaged and empowered community**
June Kinoshita, Chief Strategic Programs Officer, FSHD Society
- 5:15-5:30 pm **What's next for the Chicagoland community? Vision and strategy**
Dave Lukas, chapter director
- 5:30-6:00 pm **Reception**