

**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

- 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, Shirley Ryan Abilitylab
- 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, RN, President & Founder, 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
- The path to clinical trials in FSHD**, 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 Chicagoland? Vision and strategy**  
Dave Lukas, chapter director
- 5:30-6:00 pm **Social Time**

## Chicagoland FSHD Family Day Conference Speaker Bios

**Leah Hanson** graduated from St. Ambrose University with a BA in Psychology and MS in Occupational Therapy. Leah has worked at the Pain Management Center at Shirley Ryan Abilitylab for the past four years. She has a background and special interest in community mental health occupational therapy rehabilitation. Leah is currently leading a program re-design project at the Pain Management Center and enjoys participating in student education and community education regarding chronic pain management.

**Don McGovern, CPO, FAAOP**, is a certified and licensed orthotist/prosthetist at the Shirley Ryan Abilitylab. A Fellow of the American Academy of Orthotists and Prosthetists, he has practiced for forty years in several Chicago settings including medical centers and private practice.

**Charulatha Nagar, MD**, is a neurologist at the Northwestern Feinberg School of Medicine, with a specific focus on neuropathies, muscle disorders, myasthenia gravis, neurotoxins in medical therapeutics, clinical trials, and medical education. She received her MD from JSS Medical College in India, did her neurology residency at Loyola University Medical Center, and was a Fellow in neuromuscular disorders and clinical electromyography at Washington University in St. Louis, Barnes Jewish Hospital.

**Alejandro Rojas, PhD**, is a principal scientist at Fulcrum Therapeutics. Dr. Rojas has been an instrumental member of the Fulcrum team that screened and validated drug candidates for treating FSHD, resulting in the identification of losmapimod as a promising therapeutic which is now in a phase 2b clinical trial. Dr. Rojas earned his doctorate in the renowned laboratory of Danny Reinberg at the New York University Langone Medical Center.

**Joy Wagner, BSN**, founder and president, NeuroBalance Center. Wagner received a Bachelor of Science in Nursing (BSN) from the University of Iowa. She was diagnosed with MS in 2001, which led her to concentrate her energies on quality of life for those living with neuromuscular and autoimmune conditions. Joy saw the isolation and depression in the individuals she was working with, and launched an adaptive fitness and rehabilitation program. The program quickly attracted people with many other chronic conditions that threaten independence, including Parkinson's, stroke, epilepsy, ALS, muscular dystrophy, and myasthenia gravis. By 2010, fitMS had evolved into the NeuroBalance Center, a 501(c)3 charity providing chiropractic, functional medicine, physical/occupational therapy, acupuncture, adaptive personal training, massage, infusion services, and educational programs. NeuroBalance Center is headquartered in Barrington, IL in a state-of-the-art fitness and rehabilitation center.

**Lindsay Wallace, PhD**, is currently a Research Scientist with the Harper Lab, in the Center for Gene Therapy at the Abigail Wexner Research Institute at Nationwide Children's Hospital, in Columbus, Ohio. She received a bachelor's degree in microbiology from Miami University in 2005 and her PhD in molecular, cellular and developmental biology from The Ohio State University in 2012. Since joining Dr. Scott Harper in 2009, she has been dedicated to understanding the disease mechanisms of FSHD and developing gene therapy approaches for treatment.