Presented by the FSHD Society, The Ohio State University, and Nationwide Children’s Hospital

Preliminary Agenda

9:00 – 10:00 a.m.  
Check in, social time

10:00 – 10:05 a.m.  
Welcome! What is a 360? What is the CTRN?  
Anna Gilmore, FSHD Society

10:05 – 10:25 a.m.  
FSHD 101 and overview of research in Columbus  
Bakri Elsheikh, MD, OSU FSHD Center

10:25 – 10:35 a.m.  
FSHD genetics and genetic counseling  
Jennifer Roggenbuck, LGC, OSU

10:35 – 11:20 a.m.  
Q&A with the OSU Care Panel  
Jennifer Roggenbuck, LGC; Marco Tellez, Sr. CRC; Andrea Jaworek, PT; Mike Isfort, MD; Laura Domrose, RD; and Kinsey Ludt, LSW

11:20 – 11:30 a.m.  
Break

11:30 – 11:45 a.m.  
FSHD history and the Center for Gene Therapy  
Kevin Flanigan, MD, Nationwide Children’s Hospital

11:45 – noon  
Pediatric FSHD studies and future trials  
Linda Lowes, PT, PhD

noon – 1:00 p.m.  
Q&A followed by Lunch  
Share your favorite tips and tricks

1:00 – 1:20 p.m.  
Clinical trial overview and trial readiness for FSHD  
Jamshid Arjomand, PhD, FSHD Society

1:20 – 2:05 p.m.  
Drug development Q&A panel  
Amy Halseth (Avidity) and Mihaela Levitchi Benea (Fulcrum)

2:05 – 2:15 p.m.  
Break

2:15 – 3:00 p.m.  
Future directions for therapy and trials  
Scott Harper, PhD, Nizar Saad, PhD

3:00 – 3:25 pm  
MOVE and MOVE + natural history studies.  
How to enroll in current studies and trials  
Mike Isfort, MD, Andrea Jaworek, PT, & Marco Tellez

3:25 – 3:35 pm  
Activating the local community  
Sue Aumiller, Anna Gilmore, and Heidi Roy, FSHD Society

Disclaimer: This is an educational conference. The inclusion of information about therapies and products does not imply an endorsement by the FSHD Society or by any participating research or medical institutions. Always consult your personal medical provider before trying out a novel treatment.