

2026



The Future in Motion
Empowerment, Connection, and Care
for Life with FSHD

PROGRAM OUTLINE

Friday, June 26, 2026

6:00 – 8:00 PM | IRC & Connect Joint Reception

Saturday, June 27, 2026

8:00 – 9:00 AM | Registration & Breakfast

9:00 – 9:10 AM | Welcome & Opening Remarks

9:10 – 9:50 AM | The Future in Motion: Preparing as a Community for
What Comes Next

9:50 – 10:20 AM | The FSHD Journey: Past, Present, and Future of
Research and Care

10:20 – 10:40 AM | Break

10:40 – 11:10 AM | Advancing Early On-Set FSHD: Insights from
Natural History Studies & MRI Findings

11:10 – 11:40 AM | Exploring Emotional Well-Being: Meaning, Practice,
and the Human Experience

11:40 – 12:00 PM | On-Site Research Opportunity

12:00 – 1:00 PM | Lunch

1:00 – 5:00 PM | Breakout Sessions

5:00 – 6:00 PM | The Gathering Place (Peer Support Groups)

5:00 – 7:00 PM | Break

7:00 – 9:00 PM | Connect Dinner Banquet



FSHD SOCIETY



Sunday, June 28, 2026

8:00 – 9:00 AM | Breakfast

9:00 – 9:15 AM | Welcome & Opening Remarks

9:15 – 10:00 AM | The State of FSHD Research: From Discovery to Therapies

10:00 – 11:00 AM | Industry Panel & Research Announcements

11:00 – 11:20 AM | Break

11:20 – 11:50 AM | Becoming a Treatment-Ready Community

11:50 – 12:10 PM | The Power of Community: Shaping Research, Care, and Policy

12:10 – 12:20 PM | The Future in Motion: Empowerment, Connection, and Care for Life with FSHD

12:20 – 12:30 PM | Closing Remarks

12:30 PM | Program End

Breakout Sessions for Saturday, June 27th

General FSHD Care

FSHD 101: Understanding the Basics

Building Your Care Team:
Navigating Specialists, Clinics,
and Support Resources

Physical Therapy and Adaptive
Exercise for FSHD

Living Well with FSHD: Whole-
Person Health and Quality of
Life

Research in FSHD

The Road to Treatments:
Understanding the FSHD Drug
Development Pipeline

Different Roads to Treatment:
Understanding Research
Approaches in FSHD

Biomarkers and Imaging: How
They Are Changing the Future
of FSHD Research

The Voice of the Patient: How
Your Data and Experiences
Drive Research Forward

Whole-Person Care in FSHD

Breathing with FSHD:
Pulmonary and Sleep Medicine

FSHD in the Workforce:
Vocational Rehabilitation
Services

Caring for the Caregiver:
Managing Stress and Avoiding
Burnout

Our Personal Experience &
Practice of Emotional Well-
Being

Disclaimer: Program sessions and content are current as of April 1, 2026, and are subject to change. Participants will be notified in advance of any updates or modifications.

