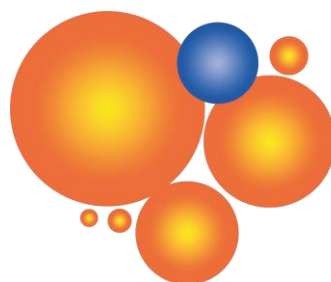




2025 FSHD CONNECT EUROPE



Program
June 13-15, 2025



FSHD
Europe

2025 FSHD Connect Europe

Friday, June 13 – Welcoming Reception

5:00 - 8:00 pm

Foyer 1e floor

REGISTRATION OPEN

7:00 - 9:00 pm

Foyer 1e floor

JOINT RECEPTION FOR THE INTERNATIONAL RESEARCH CONGRESS & FSHD CONNECT EUROPE

Saturday, June 14 – FSHD Connect Europe Day 1

9:00 - 9:10 am

WELCOME*Hicham Alaoui, Amis FSH France**Ria de Haas PhD, CEO FSDH Europe*

9:10 - 9:40 am

THE TRIGGER TO LIVE FULLY WITH FSHD*Marion Sellenet, Visual artist living with FSHD*

9:40 - 10:05 am

FSHD EUROPE & FSHD EUROPEAN TRIAL NETWORK*Sheila Hawkins, President FSHD Europe**Prof. dr. Nicol Voermans MD PhD, Neurologist Radboud university medical centre - Medical advisor**FSHD Europe & European Trial Network Chair*

10:05 - 10:15 am

Q&A

10:15 - 10:30 am

COMFORT BREAK

10:30 - 11:00 am

RESEARCH HIGHLIGHTS FROM THE INTERNATIONAL RESEARCH CONGRESS ON FSHD*Alexandra Belayew Ph.D., Professor emerita, v Research Institute for Health Sciences and Technology, University of Mons, Belgium*

11:00 - 11:25 am

PHYSIOTHERAPY AND EXERCISES IN FSHD – OPTIMISING FUNCTION AND MOBILITY*Ulrike Uta, Co-Lead Physiotherapist MDSC Coventry**Lynn Ward, Co-Lead Physiotherapist MDSC Coventry*

2025 FSHD Connect Europe

Saturday, June 14 – FSHD Connect Europe Day 1

11:25 - 11:40 am

Q&A

11:40 am - 12:10 pm

COFFEE BREAK**Workshops**

12:10 - 12:55 pm

BREAKOUT SESSION 1

Genetic testing | Use It or Lose It | Nutrition and FSHD | Physical exercise class (standing) | FSHD Café

1:00 - 2:15 pm

LUNCH

2:15 - 3:00 pm

BREAKOUT SESSION 2

Family-planning | Living Life to Fullest | Nutrition and FSHD | Energy self-management | FSHD Café

3:00 - 3:15 pm

BREAK/SWITCH ROOMS

3:15 - 4:00 pm

BREAKOUT SESSION 3

Parents of children with FSHD | Empowering Mobility | Living Life to Fullest | Physical exercise class (seated) | FSHD Café

4:00 - 4:15 pm

BREAK/SWITCH ROOMS

4:15 - 5:00 pm

BREAKOUT SESSION 4

Family-planning | Empowering Mobility | Use It or Lose It | Energy self-management | FSHD Café

5:00 - 5:30 pm

BREAK

5:30 - 6:30 pm

MOVIE MARION OR THE METAMORPHOSIS

6:30 - 7:00 pm

BREAK

7:00 - 9:00 pm

DINNER

2025 FSHD Connect Europe

Sunday, June 15 – FSHD Connect Europe Day 2

9:00 - 9:05 am

WELCOME

9:05 - 9:30 am

AN UPDATED INTERNATIONAL STANDARD OF CARE FOR FACIOSCAPULOHUMERAL MUSCULAR DYSTROPHY

Prof. dr. Nicol Voermans MD PhD, Neurologist Radboud University Medical Centre - Medical advisor FSHD Europe & European Trial Network Chair & Raj Badiani, Patient Representatives / Co-Authors 30+ FSHD Clinicians, Researchers - on FSHD International Standards of Care FSHD UK

9:30 - 9:55 am

CLINICAL TRIALS IN FSHD AND THERAPEUTIC DEVELOPMENT UPDATES

Lucienne Ronco Ph.D., CSO FSHD Society

9:55 - 10:15 am

HOW TO PREPARE FOR TRIAL PARTICIPATION

Umesh Badrising Md, PhD, neuromuscular neurologist Leiden University Medical Center (Dutch FSHD expertise center) & Esmee Tournaij, second year medical Leiden University

10:15 - 10:30 am

Q&A

10:30 - 11:00 am

MORNING BREAK

11:00 - 11:20 am

GLOBAL COLLABORATION TO ACCELERATE CLINICAL TRIALS AND ACCES TO FUTURE THERAPIES IN FSHD

Amanda Hill MBA, ACRP-CP, Senior Director of Research and Care FSHD Society

11:20 am - 12:20 pm

FSHD A GLOBAL PERSPECTIVE - INSIGHTS AND STRATEGIES FROM AROUND THE WORLD

Miriam Wagner Long, General Manager Zielgenau GmbH

Panelists:

North America: *Amanda Hill, MBA, ACRP-CP, Senior Director of Research and Care FSHD Society*

South America: *Fabio Figueiredo, President of ABRAFEU – Brazilian Association for FSHD – Brazil*

Australia: *Emma Weatherley, Managing Director of FSHD Global Research Foundation.*

Europe: *Kees van der Graaf, President FSHD Stichting | member FSHD Europe | member Dutch FSHD diagnose group | member global Taskforce Mercury*

12:20 - 12:30 pm

Q&A

12:30 pm

ADJOURN SEE YOU IN 2027!!