WELCOME

2025 FSHD CONNECT EUROPE

FSHD Connect Europe meeting

June 13-15, 2025

Leonardo Royal Hotel Amsterdam – Netherlands

FSHD Connect Europe 2025 –
The European Networking Meeting
for FSHD Patients and their Families

FSHD Europe

fshd-europe.info

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CONNECTING FOR A BETTER LIFE

FSHD Europe is delighted to welcome you to the first Conference for FSHD patients across Europe. We have an exciting program which will be relevant for everyone, whether you are newly-diagnosed or have been living with FSHD for a long time. We want to help you connect with other FSHD patients and families, in your own country and across Europe, as we recognise the value of sharing our experiences, challenges and triumphs with each other.

We will hear about the latest research, the progress towards finding a treatment for this condition and how you can contribute to this process. We also want to support people in living their best lives while waiting for a treatment. We want you to be in the best shape possible when a treatment does become available, and that in the meantime having a FSHD does not prevent you having a full life.

We want to raise the voice of FSHD Patients across Europe. We hope that by the end of this conference you will feel able to add your voice to our action, and contribute to activities within your own country and Europe to support finding a treatment for FSHD and making it available to all patients in Europe and across the world.

We hope you have a great time at FSHD Connect Europe meeting!

Sheila Hawkins
President FSHD Europe

PROGRAM COMMITEE

Lauri Pirinen FSHD Finland
María Vriens FSHD Spain
Ricardo Gerpe FSHD Spain
Laurence de Zeeuw AFM-Téléthon
Anke Lanser Spierziekten Nederland
Marieke Verbij Spierziekten Nederland
June Kinoshita FSHD Society
Sheila Hawkins FSHD Europe
Umesh Badrising
Leiden University Medical Center
Jan Groothuis
Radboud University Medical Center
Ilse Karnebeek
Radboud University Medical Center
Corrie Erasmus
Radboud University Medical Center

FRIDAY, JUNE 13 – **WELCOMING RECEPTION**

5:00 - 8:00 pm
Foyer 1st floor
REGISTRATION OPEN

7:00 - 9:00 pm
Foyer 1st floor
JOINT RECEPTION FOR THE INTERNATIONAL RESEARCH CONGRESS & FSHD CONNECT EUROPE

SATURDAY, JUNE 14 – **DAY 1**

8:30 - 9:00 am
WELCOME WALK-IN

9:00 - 9:10 am
Amstel 1 + 2 + 3
OPENING

Hicham Alaoui, Amis FSH France
Ria de Haas PhD, CEO FSHD Europe

9:10 - 9:40 am
Amstel 1 + 2 + 3
THE TRIGGER TO LIVE FULLY WITH FSHD

Marion Sellenet, Visual artist living with FSHD

Marion is a visual artist, born in France and living in Brussels, Belgium. She was diagnosed at the age of 15. Continuing along the path of her vocation, she creates today collages and mix media pieces, illustrations for magazines, and she also works in cinema and animated films. Thanks to an autobiographical documentary, she raises awareness of FSHD. This allow her to share her experience with others, carriers or not of FSHD, and to give further thought to the meaning of illness and health.

9:40 - 10:05 am
Amstel 1 + 2 + 3
FSHD EUROPE AND 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

Sheila Hawkins was diagnosed with FSHD in 1989. She had a career in Workforce Development and Transformation in charities and the UK National Health Service. After she retired she studied for a Diploma in Fashion and Footwear Design and now campaigns to encourage retailers to improve choosing and buying clothes for people with limited mobility. She was a Trustee of Muscular Dystrophy UK for nine years, and President of FSHD Europe since 2021.

Nicol Voermans is a distinguished neurologist specializing in neuromuscular disorders at Radboud University Medical Center (Radboudumc) in Nijmegen, Netherlands. Since joining Radboudumc as a medical specialist in 2008, she has focused on congenital myopathies and FSHD. Her research emphasizes genotype-phenotype correlations, trial readiness, natural history of rare inherited myopathies, patients' experiences in trials, and the development of optimal symptomatic treatments. She has a special interest in (exertional) rhabdomyolysis. She has collaborated with esteemed researchers, including Prof. Jungbluth in London and Prof. Treves in Basel. In 2021, she launched the FSHD European Trial Network, uniting researchers and clinicians across Europe to advance FSHD research and clinical trials. In recognition of her significant contributions, she was appointed Professor of Muscular Diseases at Radboudumc, effective October 1, 2023. Prof. Voermans's dedication to bridging the gap between neuromuscular research and clinical practice continues to enhance the understanding and treatment of rare genetic muscle disorders.

10:05 - 10:15 am
Amstel 1 + 2 + 3
Q&A

10:15 - 10:45 am
Amstel 1 + 2 + 3
RESEARCH HIGHLIGHTS FROM THE INTERNATIONAL RESEARCH CONGRESS ON FSHD

Alexandra Belayew PhD, Professor emerita, Research Institute for Health Sciences and Technology, University of Mons, Belgium

After a MSc in chemistry (UMons) and a PhD in biomedical sciences (1980, ULiège) in Belgium, Alexandra Belayew joined Shirley Tilghman's group for a post-doc in molecular biology (Fox Chase Cancer Center, PA, USA). She further studied gene expression as a co-PI of Joseph Martial (endocrinology, ULiège 1982-1993), and Désiré Collen (vascular biology, KULeuven 1994-1999) where her team discovered the DUX4 gene. With co-PI Frédérique Coppée, her laboratory (UMons; 1999-2015) investigated DUX4 and DUX4c functions, and developped antisense agents (with Steve Wilton, Murdoch University, WA, Australia) as therapeutic strategies for FSHD. Besides her scientific career (100 publications, >7400 citations) she often gives popularization talks for patient associations.

10:45 - 11:00 am
Amstel 1 + 2 + 3
Q&A

11:00 - 11:25 am
Amstel 1 + 2 + 3
PHYSIOTHERAPY AND EXERCISES IN FSHD – OPTIMISING FUNCTION AND MOBILITY

Ulrike Uta, Co-Lead Physiotherapist MDSC Coventry
Lynn Ward, Co-Lead Physiotherapist MDSC Coventry

Ulrike Uta trained as a physiotherapist in Germany in 1987, later working in hospital and private practice in Germany and Egypt. After moving to the UK, Ulrike started working in the NHS in 2002, specialising in Neurology. During this time she developed a love for supporting people with long term conditions and helping them to maximise function and mobility. Ulrike started a part-time Masters degree in Physiotherapy at Coventry University, focusing on the evidence behind neurological rehabilitation and service improvement. Her dissertation examined the experiences of people with neuromuscular conditions having aquatic therapy. After 4 years of study, she graduated with a first in 2016. She joined the MD Support Centre in 2014. In addition she works in private practice and with the MS Society in Solihull. As Co-Lead therapist at MD Support Centre, Ulrike provides patient-centred care and long-term support for adults with neuromuscular conditions and develops new services and projects.

Lynn Ward graduated from the University of Birmingham in 1997. After working in a variety of NHS clinical settings in the UK, she moved to Toronto, Canada in 2001 where she worked for 4 years in neurosurgery. Returning to the UK in 2005, she worked as a Senior Physiotherapist at an independent Neuro-Rehab Hospital in Godalming, Surrey and then in 2007 she decided to venture into the world of private neuro physiotherapy. In 2008, she moved back to the Midlands where she continued with private neuro physiotherapy. Lynn further developed hands on techniques as well as assistive technologies such as Functional Electrical Stimulation (FES) and SaeboFlex. She became a certified APPI Pilates Instructor in 2017. Lynn joined the MD Support Centre back in 2013 when it first opened providing their very first physiotherapy assessments and subsequent treatments. She enjoys being a part of the successful growth of the centre, being able to work with the service users on a long term basis and assist in enabling them to manage their condition.

11:25 am - 12:10 pm
Foyer
COFFEE BREAK

SATURDAY, JUNE 14 – **DAY 1**

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
Restaurant
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 - 5:45 pm
BREAK

5:45 - 6:45 pm
Amstel 1 + 2 + 3
MOVIE "MARION OR THE METAMORPHOSIS“

6:45 - 7:00 pm
BREAK

7:00 - 9:00 pm
Restaurant
DINNER

BREAKOUT SESSIONS – **AGENDA**

Rounds	Times	de Dam	Amstel 1	Amstel 2	Amstel 3	Restaurant
Session 1	12:10 - 12:55 pm	Genetic testing	Use it or Lose it	Nutrition and FSHD	Physical excercise class (standing)	FSHD Café
	Lunch					
Session 2	2:15 - 3:00 pm	Family-planning	Living Life to Fullest	Nutrition and FSHD	Energy self-management	FSHD Café
	Switch rooms/ break					
Session 3	3:15 - 4:00 pm	Parents of children with FSHD	Empowering Mobility	Living Life to Fullest	Physical excercise class (seated)	FSHD Café
	Switch rooms/ break					
Session 4	4:15 - 5:00 pm	Family-planning	Empowering Mobility	Use it or Lose it	Energy self-management	FSHD Café

BREAKOUT SESSIONS – **CONTENT**

Living Life to the Fullest

What is daily life like for you with FSHD? What challenges do you encounter? The continuous process of adapting to new circumstances – how do you ensure that you don't get stuck along the way? Connecting with others who share similar experiences can be a great source of comfort and have a positive impact.

Prof. Dr. Baziel van Engelen MD, PhD, Professor Emeritus of Muscular Medicine since April 1, 2024, Neurologist, philosopher, Radboud university medical center | Donders Institute for Brain Cognition & Behaviour

Baziel van Engelen, born in Eindhoven in 1957, is a neurologist and philosopher. He studied medicine at the Radboud University and philosophy at the University of Amsterdam, trained as a neurologist at the Free University of Berlin and the Radboudumc, and did research at the Mayo Clinic and Mayo Foundation in Rochester Minnesota, USA. Since 2024 he has been Professor Emeritus of Neurology at the Radboudumc and the Radboud University. Before that, he was director of the Muscular Disease Center Radboudumc, consisting of nurses, physicians, paramedics and researchers from the departments of neurology, rehabilitation and pediatrics. His focus was on the integration of care (the human touch) and (science-based) research towards a cure through bedside-to-bench translational research of neuromuscular diseases, in particular facioscapulohumeral dystrophy (Engel Award, Patient Organization Spierziekten Nederland) and myotonic dystrophy (Steinert Award, MD Foundation USA). He has held various administrative positions in national and international organizations (including Scientific Director of the European Neuromuscular Centre) in the field of research and care. He has published more than 700 scientific articles, has another 25 ongoing PhD projects, is a member of the Academia Europaea and since 2018 Knight of the Order of the Dutch Lion.

Parents of children with FSHD

Whether your child has recently been diagnosed or you've been living with FSHD for some time, there are moments when you simply want to speak with someone who truly understands. If you're approaching a new milestone, facing a challenging point in your child's care, or struggling to find the right information or resources, it can be reassuring to connect with another parent who has gone through similar experiences.

Assoc. Prof. Dr. C.E. Erasmus, Pediatric neurologist – neuromyologist – swallowing/drooling team coordinator – medical head pediatric muscle Busselman Radboudumc

Associate Professor Corrie Erasmus works as a paediatric neuromuscular neurologist and co-leads the multidisciplinary paediatric neuromuscular clinic at Radboud University Medical Center - Amalia Children's Hospital. Since 2015, she has led natural history studies in children and adolescents with Facioscapulohumeral Dystrophy (FSHD). Through her work, she has learned a great deal from both the children and parents she works with, as well as from conducting scientific research. She is committed to striving for the best possible life outcomes for children, parents, and siblings. This mission is at the core of her work.

Energy Self-Management

Managing an energy-driven schedule in a fast-paced world. How do I find balance while overcoming challenges like pain and fatigue? It can be very helpful to talk with others who share similar experiences and exchange insights.

Edith Cup, Occupational therapist, senior researcher Department of Rehabilitation Radboudumc | Lecturer Master Neurorehabilitation and Innovation, University of Arnhem and Nijmegen (HAN)

After her graduation as an occupational therapist, Edith worked in various hospitals in England from 1988 until 1990. She then started to work in Radboudumc and combined her work as an occupational therapist with a study in health sciences and combined clinical work with research. In 2011 she defended her PhD thesis entitled 'Occupational therapy, physical therapy and speech therapy for persons with neuromuscular diseases, an evidence based orientation'. From 2012 to 2021 she was head of the occupational therapy team of Radboudumc. Since 2021 she has been combining clinical work and research at the Rehabilitation department of Radboudumc with teaching at HAN University of Applied Sciences, Master Neurorehabilitation and Innovation. Her special interest and expertise lie in the area of self-managing fatigue and life balance. She was one of the developers of the interdisciplinary self-management program Energetic for persons with neuromuscular diseases, which proved to be effective on improving participation and physical endurance and is now being implemented in primary care in the Netherlands.

Use It or Lose It

Where is the line between too much and too little physical exercise? How do I continue to motivate myself, or my loved one with FSHD, to stay within that healthy balance?

Nicole Voet, MD PhD, Rehabilitation physician and senior researcher, Radboudumc | Klimmendaal

Nicoline (Nicole) Voet currently works as a rehabilitation physician and senior researcher at the Neuromuscular Diseases (NMD) Department of Klimmendaal Rehabilitation Center in Arnhem, and at the Radboud University Medical Center's Muscle Center in Nijmegen, the Netherlands. As a translational researcher, she is committed to producing meaningful and directly applicable results. Her work focuses on improving social participation in people with neuromuscular disorders, with a special emphasis on FSHD. Her current research projects concentrate on the assessment and treatment of muscle fatigue and pain in people with NMD. She recently established an international consortium on psychological interventions in NMD: the International group for Psychosocial INterventions to improve Quality of life in slowly progressive neuromuscular disorders (INSPIRE). She also chairs the Dutch national neuromuscular care network. Nicole is widely recognized as an international expert on FSHD, fatigue, mental well-being, and physical training in neuromuscular diseases.

Family-planning

With the knowledge we have today, the desire to have children as a carrier of FSHD is complicated and never without concern. Under the guidance of experts with lived experience, we will discuss this topic. This session is intended for young adults, but also for parents of young adults.

Anke Lanser, President FSHD diagnosis working group Muscular Diseases Netherlands | Advisor FSHD Foundation

Anke Lanser has been living with FSHD since 1996 and comes from a family where the condition is prevalent. She has been actively involved with the Dutch patient organization Spierziekten Nederland since 1997 and currently chairs the FSHD Diagnosis Working Group. In this role, she leads efforts related to research and treatment development, while serving as a vital link between the patient community and the organization. Anke also supports the FSHD board by advising on research and broader patient-related interests. A former nurse with a background in geriatrics, her lifelong mission is to improve quality of life for people with FSHD and their families, and to bring greater awareness and understanding of the condition.

Corrine Verwer, Director of the Dutch patient association for people with hearing and balance problems | patient representative for FSHD, Dutch Neuromuscular Diseases Association

For over twenty years I have worked for the Dutch NMD association as a professional. Amongst others I supported the FSHD working group. After I started working for the Dutch association for people with hearing problems (six years ago), I became a volunteer for FSHD. My areas of interest are research and drug development for FSHD.

Nutrition in FSHD

Good nutrition can be challenging for individuals living with neuromuscular diseases, many of whom may struggle with physical activity or experience difficulties with eating or swallowing. It's important to ensure proper nutrition to support optimal health and well-being.

Marianne Nordstrøm PhD, Clinical nutritionist, Frambu Competence Center for rare diagnoses and Live NOW

Marianne Nordstrøm is a clinical dietitian and researcher at the Frambu Resource Centre for Rare Disorders and at the Unit for Rare Neuromuscular Disorders, Oslo University Hospital. She also holds a part-time position in the Department of Neurohabilitation at Oslo University Hospital. Marianne currently serves as Chair of the Multidisciplinary Management and Care Working Group and is a member of the Executive Committee within the European Reference Network for Neuromuscular Diseases (ERN-NMD).

Empowering Mobility

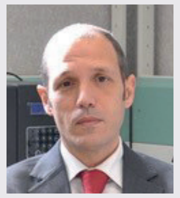
Assistive technologies, including robotic exoskeletons and orthotics, can greatly improve mobility and independence for individuals with neuromuscular diseases. These innovations help enhance movement and functionality, allowing people to perform everyday tasks more easily.

Rogier Barentz, CEO InteSpring

Rogier Barents is a Dutch engineer, entrepreneur, and innovator with over a decade of experience driving impactful solutions in the field of medical technology and human mobility. Trained as a mechanical engineer at Delft University of Technology, Rogier specializes in statically balanced mechanisms—systems that compensate for gravity without consuming energy. His early research laid the groundwork for several groundbreaking assistive technologies, particularly in the areas of exoskeletons and orthotics. Rogier is the former CEO and co-founder of Laevo B.V., known for its pioneering work in wearable exoskeletons that reduce strain during physically demanding tasks. He also leads InteSpring B.V., a company focused on energy-efficient movement systems, and has co-founded several ventures including Sprinq and Anchis, all with a shared mission: to enhance human functionality through innovation. As chairman of the Blue Sparrows MedTech fund, he actively supports early-stage medtech startups pushing the boundaries of rehabilitation and assistive technologies. Rogier's passion for empowering mobility is also deeply personal – as someone living with FSHD (Facioscapulohumeral muscular dystrophy), he understands firsthand the importance of innovative tools that support independence and quality of life. This personal connection fuels his commitment to creating technologies that truly make a difference for people facing similar challenges.

Genetic testing

Genetic testing for FSHD can provide valuable insights into diagnosis, family planning, and understanding the progression of the disease. Knowing when to pursue genetic testing and how to navigate the process is important for individuals and families affected by FSHD. This workshop will explore the reasons for genetic testing, the timing, and the steps involved to help you make informed decisions.



Professor Emiliano Giardina, PhD – Associate Professor of Medical Genetics (SSD MED/03) at "Tor Vergata" University of Rome since 2015.

He holds directorial positions at the Santa Lucia Foundation IRCCS in Rome, overseeing both the Laboratory Diagnostics and Medical Genomics and the Genomic Medicine Laboratory - UILDM (Italian Union Fight against Muscular Dystrophy). Since 2013, he also serves as the Director of the Forensic Genetics Laboratory at "Tor Vergata" University, collaborating with the Police Forensic Science Unit of the Anti-crime Central Direction on innovative identification systems. Professor Giardina's research primarily explores the molecular characterization of Mendelian and complex diseases, particularly focusing on ocular, dermatological, neurodegenerative, and neuromuscular disorders. His efforts have significantly advanced the genetic understanding of disease mechanisms, leading to the development of new diagnostic and prognostic protocols, and enhancing pharmacogenetic responses to treatment. At the Genomic Medicine Laboratory of the Santa Lucia Foundation, he established a unit for advanced genomic analysis, targeting both research and diagnostic uses, with particular attention to neuromuscular and neurodegenerative diseases, as well as various ocular disorders. Additionally, Professor Giardina coordinates the platform for sharing and consulting genomic and clinical data applied to Neurosciences within the Italian IRCSS Network of Neuroscience and Neurorehabilitation (RIN). He also serves as a forensic genetics consultant for major Italian courts and has contributed to the management and resolution of hundreds of judicial cases, offering expert support in complex criminal and civil proceedings. Professor Giardina has authored 180 papers in peer-reviewed international journals and is a regular invited speaker at national and international scientific conferences.

Physical Exercise Class (seated)

A perfect opportunity to get some exercise this weekend, led by a physiotherapist from the Muscular Dystrophy Support Center in the UK. After a brief introduction, there will be a seated exercise class focusing on core strength, a range of movement exercises and working your cardiovascular system. No equipment is required.

Ulrike Uta, Co-Lead Physiotherapist MDSC Coventry
(see her biography on page 5)

Lynn Ward, Co-Lead Physiotherapist MDSC Coventry
(see her biography on page 5)

Physical Exercise Class (standing)

A perfect opportunity to get some exercise this weekend, led by a physiotherapist from the Muscular Dystrophy Support Center in the UK. After a brief introduction, there will be a standing exercise class focusing on core strength, balance, range of movement exercises and working your cardiovascular system. No equipment is required.

Ulrike Uta, Co-Lead Physiotherapist MDSC Coventry
(see her biography on page 5)

Lynn Ward, Co-Lead Physiotherapist MDSC Coventry
(see her biography on page 5)

SUNDAY, JUNE 15 – DAY 2

8:30 - 9:00 am
WELCOME WALK-IN

9:00 - 9:05 am
Amstel 1 + 2 + 3
OPENING

9:05 - 9:30 am
Amstel 1 + 2 + 3
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

(see her biography on page 4)

Raj Badiani, Patient Representatives/ Co-Authors 30+ FSHD Clinicians, Researchers – on FSHD International Standards of Care FSHD UK

Founded in 2021 by Rajeshri Badiani, an FSHD patient herself, FSHD UK was established with a clear mission: to accelerate clinical trials and improve care for people living with Facioscapulohumeral Muscular Dystrophy (FSHD) in the UK. Through the development of a strong, multi-stakeholder collaborative network, FSHD UK has grown significantly with eight clinical sites. In 2023, FSHD UK became a registered charity. Three major clinical trials (one of which has since stopped globally) and two natural history studies are active in the UK, FSHD UK is proud to be part of several key international collaborations, including the FSHD World Alliance, FSHD Europe, and the Project Mercury Task Force — ensuring UK patients have a voice on the global stage. Rajeshri Badiani/ Mitsuru Honda (FSHD Japan and FSHD research scientist) served as patient representatives/co-authors in this landmark project- The International Standard of Care for FSHD, alongside over 30+ medical and research professional. This work is vital in establishing much-needed guidelines that will shape the future of FSHD care worldwide "It has been our honor to participate in this work — which is vital for the FSHD community everywhere."

9:30 - 9:55 am
Amstel 1 + 2 + 3
CLINICAL TRIALS IN FSHD AND THERAPEUTIC DEVELOPMENT UPDATES

Lucienne Ronco Ph.D., CSO FSHD Society

Dr. Ronco is the Chief Scientific Officer for the FSHD Society. Prior to this, she consulted the to the Society for more than 5 years. She has extensive experience in translational science, clinical trial design and implementation, drug discovery, and pharmaceuticals. She has global project management and collaboration experience. Lucienne earned a Ph.D. in Biological Chemistry from UCLA and did her post-Doctoral training at Harvard Medical School. She worked in both pharma and biotech as she advanced to become a Vice President. At Fulcrum Therapeutics, Lucienne participated in FSHD characterization using molecular and imaging techniques as she designed, and developed methods to assess how well new therapeutics impact disease in human clinical trials of FSHD. At the Broad Institute she oversaw the development of rare kidney disease small molecule therapeutics and biomarkers and previously she worked at Astra Zeneca for a decade on oncology drug development.

9:55 - 10:15 am
Amstel 1 + 2 + 3
HOW TO PREPARE FOR TRIAL PARTICIPATION

Umesh Badrising Md, PhD, neuromuscular neurologist Leiden University Medical Center (Dutch FSHD expertise center)

Dr. Badrising is a neurologist since 2004, specialized in neuromuscular disorders. His PhD was on inclusion body myositis (IBM). Now, his focus is also on patient care and scientific research in facioscapulohumeral muscular dystrophy. He is the clinical lead in Leiden for FSHD and collaborates with the group of Prof. dr. van de Maarel (department of Human Genetics) and the Radboud University Medical Center as part of the Dutch FSHD expertise center and the Dutch patient organization for muscle disorders among others.

Esmee Tournaij, second year medical Leiden University

My name is Esmee Tournaij and I am a 21 year old student living in Amsterdam. I was born and raised in Heemstede, where I lived with my parents, sister and my dog. I did High School in the city of Haarlem. In my gap year I travelled to South East Asia for five months. One and a half year ago I moved to Amsterdam to study medicine and I am now in my second year. I live with my sister in the centre of Amsterdam. In June 2021 I was diagnosed with FSHD Type 1, my father was also diagnosed then. From february 2023 till September 2024 I participated in a clinical trial to find a cure for FSHD. It was a phase 3 clinical trial, which was unfortunately stopped in September last year due to disappointing results. I am very honored to tell you a bit of my story today.

10:15 - 10:30 am
Amstel 1 + 2 + 3
Q&A

10:30 - 11:00 am
Foyer
MORNING BREAK

11:00 - 11:20 am
Amstel 1 + 2 + 3
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

Amanda Hill joined the FSHD Society in July 2022 after having been involved as a volunteer Chapter Director, writer, and fundraiser for over four years. As the Society's Senior Director of Research, Amanda brings deep professional expertise in biomedical research, including in clinical studies and clinical trials administration, scientific engagement and communication, and project management. Prior to joining the FSHD Society, she worked at the University of Colorado Anschutz Medical Campus for over a decade in the fields of cancer and Down syndrome as a research scientist, development manager, and program director. In 2016, Amanda's husband was diagnosed with FSHD, spurring her personal and now professional drive to serve and empower the FSHD community and advance research towards treatments and a cure. Amanda earned her BA in Molecular Biology from Scripps College in Claremont, CA, and her MBA in Bioinnovation and Entrepreneurship from the University of Colorado Denver in Denver, CO.

11:20 am - 12:20 pm
Amstel 1 + 2 + 3
PANEL DISCUSSION: FSHD A GLOBAL PERSPECTIVE – INSIGHTS AND STRATEGIES FROM AROUND THE WORLD

Patient representatives from Australia, Brazil, Netherlands and USA will share their experiences and insights on critical topics such as setting up registries, patient education, clinical trials, and the importance of strong country networks. Together, the participants will review key learnings from different countries and conclude with a united global vision for FSHD.

MODERATOR

Miriam Wagner Long, General Manager Agentur Zielgenau GmbH

Miriam Wagner Long has been a dedicated professional in healthcare and nonprofit management since 2005. She has worked extensively in the U.S., focusing on sustainable funding strategies and patient care services. Since returning to Germany in 2011, Miriam has continued to contribute to the healthcare sector through various nonprofit organizations. Currently, she is the CEO and partner at Agentur Zielgenau GmbH, specializing in fundraising, strategic planning, and leadership. Miriam supports the FSHD World Alliance and co-facilitates the Global Task Force for Project Mercury.

PANELISTS

Australia: Emma Weatherley

Emma is the purpose-driven CEO and Managing Director of Australian peak body and medical research funding institution, FSHD Global Research Foundation, where she has been instrumental in advancing Australian diagnostics and driving clinical trial readiness. Living with FSHD herself, Emma has a unique and empathetic understanding of the challenges faced by individuals with FSHD, their families, carers, and loved ones. Emma is unwavering in her commitment to finding effective treatments and an eventual cure for FSHD. She is dedicated to ensuring that all Australians living with FSHD, now and in the future, have access to these advancements. She also serves on the board of FSHD-focused biotech, Facio BioTherapies and is the Australian Working Group leader on Project Mercury.

South America: Fábio Figueiredo
President of ABRAFEU – Brazilian Association for FSHD – Brazil

Fábio is a co-founder of ABRAFEU – the Brazilian Association for FSHD – and a devoted father committed to helping his son and all Brazilians affected by facioscapulohumeral muscular dystrophy. Founded in 2019, ABRAFEU has set an ambitious goal: to bring FSHD treatment to Brazil by 2025. With over 30 years of experience in business strategy, Fábio has built strong, lasting relationships in the B2B market, working with national and multinational companies in the consumer goods and services sectors. He has led and developed multidisciplinary teams across various regions.

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

Kees is married with Renee and have 3 Sons of which the eldest has FSHD. Kees has created the FSHD foundation, FSHD Europe, Spieren voor Spieren. Facio therapies, all with one purpose:to accelerate the development of a therapy of FSHD. In his business life Kees spent 32 years with Unilever. The last 6 years as a member of the Board and the Executive Committee. After retirement he held several non-executive board roles and spend 4 years with the business school IMD in Lausanne as an executive-in-residence. Kees loves sailing, golf skying and travelling.

North America: Amanda Hill

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

See her biography on the top of this page.

12:20 - 12:30 pm
Amstel 1 + 2 + 3
Q&A

12:30 pm
Amstel 1 + 2 + 3
ADJOURN SEE YOU IN 2027!

SEE YOU IN 2027

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