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FSHD Europe

- The voice for FSHD patients across Europe
- Promote awareness, understanding and knowledge of FSHD
- Stimulate and share knowledge in the field of care, welfare, patient support, diagnostics, research and drug development.
- Currently 10 member organizations from 9 countries

FSHD Europe Member organizations



FSHD European Trial Network (ETN)

The ETN, initiated by FSHD Europe in 2021⁽¹⁾, has been working on the following aims:

- Increase the commitment of and exchange between clinicians and researchers;
- Harmonize criteria for clinical and genetic diagnosis, for clinical outcome measures, biomarkers and imaging outcome markers;
- Engage Pharma and EMA for a Europe wide collaboration;
- Harmonize treatment and care for all European FSHD patients.

ETN Working Groups

The European Neuro Muscular Centre (ENMC) has a unique concept of facilitating and organizing workshops initiated by experts in the field of neuromuscular conditions. Several ENMC workshops had previously been organized focusing on FSHD.

As a result, of the ENMC workshops five ETN working groups have been initiated. We are very pleased with the steps taken and workshop reports that have been published^(2,3). Recently, WG 1 published the 'Best practice guidelines on genetic diagnostics of FSHD: Update of the 2012 guidelines.'⁽⁴⁾

FSHD European Trial Network working groups

Clinical and genetic diagnosis	Clinical outcome measures	Biomarkers	Imaging	Pediatrics
Richard Lemmers Emiliano Giardina	Enrico Bugiardini Elena Carraro	Julie Dumonceaux Yann Peron	Giorgio Tasca Mauro Monforte	ENMC workshop organizers
WG 1	WG 2	WG 3	WG 4	WG 5

The ETN working groups each have a group leader and co-leader and work in close collaboration with the Clinical Research Trial Network (CTRN), FSHD Society, TREAT-NMD and the European Reference Networks EURO-NMD.

Background

Developments within the international FSHD field are moving fast, a drastic increase in the number of trials is expected. This indicates the urgency of trial readiness and underscores the importance of the global initiative Project Mercury in which FSHD Europe is partnering with the FSHD Society.

In 2021, FSHD Europe established the FSHD European Trial Network (ETN) to support collaboration to reach trial readiness, building on current research on FSHD in Europe.

Performing trials in Europe is challenging because:

- Europe's diversity and multilingual situation.
- Guidelines for clinical trials, pharma regulation and participation, and health care provisions in European countries differ in various subtle ways.

Collaboration in Project Mercury

Project Mercury is a global collaboration program led by FSHD patient advocacy organizations in partnership with experts, biopharma companies and researchers. Oversight of Project Mercury is facilitated by the Global Task Force.

- The Global Initiative to Speed Delivery of Therapies for FSHD.
- FSHD Europe coordinates Project Mercury with multiple FSHD groups across Europe and is member of the Global Task Force.

Get involved!

We aim to have open membership and to involve experts from all European countries.

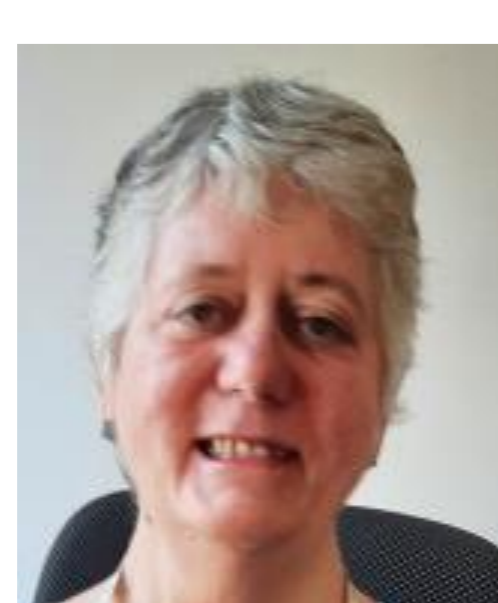
If you are a clinician or researcher and interested to join one of the ETN working groups, please let us know and reach out to us.

You might be contacted by clinicians or researchers in your country who are interested or know (future) FSHD experts in European countries not yet involved in the ETN. Please refer them to us.

Contact: ria@fshd-europe.info



Ria de Haas
Project manager



Sheila Hawkins
Chair FSHD Europe



Nicol Voermans
Chair ETN

1) N.C. Voermans et al. 1st FSHD European Trial Network workshop: Working towards trial readiness across Europe. Neuromuscular Disorders 31 (2021) 907-918

2) M. Monforte et al. 265th ENMC International Workshop: Muscle imaging in Facioscapulohumeral Muscular Dystrophy (FSHD): relevance for clinical trials, 22-24 April 2022, Hoofddorp, The Netherlands. Neuromuscular Disorders 33 (2023) 65-75

3) F. Montagnese et al. 268th ENMC Workshop – Genetic diagnosis, clinical classification, outcome measures, and biomarkers in Facioscapulohumeral Muscular Dystrophy (FSHD): Relevance for clinical trials. Neuromuscular Disorders 33 (2023) 447-462

4) E. Giardina et al. Best practice guidelines on genetic diagnostics of facioscapulohumeral muscular dystrophy: Update of the 2012 guidelines. Clinical Genetics 2024 Apr. 29