



Job Vacancy Programme Manager

Location: Remote (Europe-based)

Contract: Full-time (1 FTE), 18–24 months

Language: Fluent English (spoken and written)

Salary: Depending on the location and experience

About FSHD Europe

FSHD Europe is a non-profit umbrella organisation of fourteen national FSHD and neuromuscular disease patient organisations across Europe. Our mission is to improve quality of life for all FSHD patients and their families, through diagnosis, treatment access, patient empowerment, and cross-border collaboration.

Scope of the position

FSHD Europe is seeking a (senior) **Programme Manager** to lead the delivery of the work related to a multi-country initiative focused on improving patient engagement and health technology assessment (HTA) readiness for facioscapulohumeral muscular dystrophy (FSHD). This is an exciting opportunity to drive impact across Europe by coordinating stakeholders, building patient organisation capacity, and shaping best practices for patient support. You will be working closely with the FSHD Europe team (CEO, staff members and volunteers), member organisations and external partners.

Key Responsibilities

- **Project Coordination:** Oversee all aspects of the project across multiple countries, ensuring timely delivery, budgeting, reporting, communication and alignment with objectives.
- **Stakeholder Engagement:** Lead collaboration with patient organisations, healthcare professionals, and industry partners.
- **Toolkit Development:** Co-develop the HTA patient toolkit and create a patient support toolkit incorporating best practices.
- **Patient Journey Mapping:** Coordinate mapping the FSHD patient journey to develop in-depth understanding of the challenges faced by FSHD patients.
- **Capacity Building:** Facilitate training and resources to strengthen patient organisations' capabilities.

Qualifications & Skills

- Master's degree in Public Health, Social Sciences, Project Management or similar.
- Excellent English (written and spoken).
- Fluency in additional European languages such as French, German, Spanish and Italian (preferred, not required).
- Strong communication and collaboration skills.
- Experience with EU multi-national and multi-sectoral project management, preferably in healthcare, patient engagement and/or non-profit sectors.
- Organization and time management skills.
- Experience working with different stakeholders including academia, researchers, not-for-profit organisations, pharmaceutical industry, patient advocates and patients.
- Hands on experience in budgeting, administration and reporting.
- Good knowledge of Microsoft Office (Word, Excel, PowerPoint, Teams).
- Ability to manage and keep oversight on multiple activities.
- Proactive and independent.

Contract Details

- **Duration:** 18–24 months, depending on start date
- **Commitment:** Full-time (1 FTE)
- **Location:** Remote (with occasional travel within Europe)

To apply

Please send your CV and motivational letter (max 2 pages each) in English to secretariat@fshd-europe.info before December 31st. Virtual interviews are scheduled to take place on January 8th and 9th. For additional information about this project, please contact Ria de Haas (Ria.deHaas@fshd-europe.info).

FSHD Europe provides equal opportunities to all, regardless of disability, nationality, race, colour, religion, gender, sexual orientation, age and marital status.