FSHD Europe and TREAT-NMD collaborate in PaLaDIn to develop an FSHD disease model for health technology assessment and patient advocacy toolkits

The Hague, The Netherlands, March 2026, FSHD Europe, a non-profit umbrella organisation of Facioscapulohumeral muscular dystrophy (FSHD) patient organisations from across Europe, today announced its collaboration with TREAT-NMD and the PaLaDIn consortium to support the delivery of Work Package 9, "Maximising Interactium® Benefits: FSHD as a case study."

After a comprehensive procurement process, FSHD Europe was selected as the partner to generate an FSHD disease progression model for health technology assessment (HTA), develop a model FSHD patient journey, and develop toolkits to support FSHD patient advocacy organisations.

About PaLaDIn
PaLaDIn (Patient and Lifestyle Disease Data Interactium®) is an ambitious Innovative Health Initiative (IHI)-funded project launched in 2024. The project brings together leading universities, small and medium enterprises, and patient organisations to create the Interactium®, a state-of-the-art data platform focused on rare neuromuscular diseases (NMDs). PaLaDIn is supported by the Innovative Health Initiative Joint Undertaking (IHI JU).

In rare disease research, most of the data currently collected comes from clinical settings, such as hospitals and medical facilities. This type of data often focuses on the medical aspects of the condition, like diagnostic tests and treatments, but it doesn't always capture the personal experiences of patients. PaLaDIn aims to change this by developing the Interactium®, which will link clinical data collected in registries with patient-reported data. For more information, visit www.project-paladin.eu.

FSHD as a Case Study
Within PaLaDIn, Work Package 9 aims to harness the power of patient advocacy organisations as drivers of scientific and clinical progress in rare disease, using FSHD as a case study. Led by the **FSHD Society**, and in collaboration with TREAT-NMD, this work package recognises that as the Interactium® develops new tools for patients and unlocks insights into FSHD and other NMDs, patient organisations must be suitably equipped to utilise and translate this knowledge.

To achieve this, Work Package 9 will leverage and advance **Project Mercury**, a global advocacy-led collaboration launched by the FSHD Society in 2023 to strengthen clinical trial readiness and future therapy access for FSHD. Project Mercury brings together patient organisations, clinicians, researchers, and industry partners to build the infrastructure needed for patient registries and clinical trial capacity, as well as the health economic evidence required for health technology assessments and reimbursement decisions. Together, PaLaDIn Work Package 9 and Project Mercury will produce reusable toolkits, standard operating procedures, and an HTA disease model for FSHD designed to interface with Interactium® data elements. These resources will be created for adaptation by patient organisations across rare disease communities worldwide.

About FSHD Europe's Role

FSHD Europe strengthens its capacity in HTA evidence generation through a partnership with the **Institute for Medical Technology Assessment (iMTA)**, a globally recognised leader in HTA research and part of Erasmus University Rotterdam, in the Netherlands. iMTA brings extensive experience in health economic modelling and cost studies for rare genetic NMDs, including Pompe disease and Friedreich's ataxia. Its work spans illness and caregiver burden studies, cost-effectiveness models (both newly developed and adapted), and budget impact analyses. These models, often incorporating real-world evidence, are tailored to meet the specific requirements of national reimbursement submissions. FSHD Europe will collaborate with iMTA by providing FSHD-specific expertise and to ensure involvement and direct support of national patient organisations as well as clinical experts across Europe.

FSHD Europe will also lead the development of an FSHD patient journey, a toolkit for patient support programs, and a toolkit for engagement in HTA. These resources will be adaptable, scalable, and relevant for various national contexts within Europe. Toolkits and educational resources will be co-developed with input from a broad range of stakeholders (e.g., patients, clinicians, and HTA experts) and structured to enable easy future adaptation by other NMD and rare disease groups.

David Allison, CEO of TREAT-NMD, said, *"TREAT-NMD aims to add value at each stage of the drug development pipeline. As treatments are developed, post regulation activities are ever more critical, and so we are delighted to work with FSHD Europe and iMTA to develop material that assists in health technology assessment and better supports patient advocacy. Integrating this with the work of the FSHD Society will create a powerful case study in FSHD, which can then be scaled to benefit neuromuscular disease more broadly. We are very excited to be addressing these unmet needs."*

Ria de Haas, CEO of FSHD Europe, said, "*We are honoured to collaborate with TREAT-NMD and PaLaDIn partners like the FSHD Society. Working together reinforces our shared goal to enhance the quality of life for patients and their families, while accelerating access to treatments for FSHD.*"

This collaboration represents a major step forward in connecting patient experiences with HTA evidence in FSHD and in rare diseases. By uniting FSHD Europe's advocacy expertise, the international TREAT-NMD network, and PaLaDIn's data innovations, the partnership seeks to establish a new benchmark for how patient organizations can advocate for access to therapies.

About FSHD Europe

FSHD Europe is a non-profit umbrella organisation established in 2010 by individuals living with FSHD and their close relatives, united by a powerful belief in the strength of cross-border collaboration. Today, FSHD Europe proudly represents 14 member organisations across 12 European countries, each dedicated to supporting people with FSHD in their unique national contexts. The organisation is recognised for implementing effective, patient-focused projects. In 2021, FSHD Europe launched the FSHD European Trial Network (ETN) to enhance collaboration and support trial readiness, building upon existing FSHD research in Europe. The ETN currently features five active working groups, each co-led by prominent experts. FSHD Europe uniquely connects both a patient community and a network of clinicians across the continent. For more information, visit www.fshd-europe.info.

About TREAT-NMD

TREAT-NMD is a global network for translational research in rare neuromuscular disorders, supporting patient registries across 50 countries and uniting patients, clinicians, researchers, and industry stakeholders. Established in 2007, TREAT-NMD has been instrumental in advancing research, care guidelines, and clinical trial readiness for neuromuscular diseases through a range of initiatives. These include the TREAT-NMD Education Committee (TEC), who facilitate and provide a range of specialist educational masterclasses, and the TREAT-NMD Advisory Committee for Therapeutics (TACT), a unique multi-disciplinary group of international experts that takes on the challenge of evaluating the therapeutic potential of drugs across neuromuscular diseases with the aim of applying learnings from previous experience to optimise drug design and development programmes. For more information, visit www.treat-nmd.org.

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PaLaDIn
Patient Lifestyle & Disease Data Interactium