PROJECT MERCURY

The Global Initiative to Speed the Delivery of Therapies for FSHD

Interim Progress Report 2023-2025

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Table of Contents

1. Executive Summary

Although the pipeline for FSHD therapeutic development is promising, critical challenges could hinder new treatments from reaching patients. Clinical trials in rare diseases frequently fail due to a shortage of sites and patients, and approved therapies are often inaccessible to patients worldwide due to payor delays and coverage gaps. No single organization alone has the global reach or resources to address these problems.

Project Mercury was established in 2023 to address these critical challenges – ensuring safe and effective treatments reach patients quickly, equitably, and at scale. Project Mercury is a patient-led, global initiative that operates through a Global Task Force (GTF) and Country Working Groups (CWGs) across ten countries. Its work is organized into three workstreams: Trial & Treatment Readiness, Patient Access, and Sustainability.

From 2023 to 2025, Project Mercury built FSHD into one of the leading global ecosystems for rare disease preparedness. FSHD patient registries were launched or expanded in six countries, representing more than 10,000 patients; the number of qualified clinical trial sites more than doubled; and a toolkit for new FSHD trial sites was published. Recognizing that trial readiness alone is insufficient to ensure treatment delivery, a new strategic aim was introduced in 2025 to prepare healthcare systems and professionals for the first FSHD therapies.

Project Mercury also succeeded in shifting the patient-access paradigm from sponsor-led, product-level evidence to advocacy-led, disease-level readiness. Work focused on building a shared evidence infrastructure across stakeholders, including beginning development of an HTA disease progression model, agreeing on a burden-of-illness evidence roadmap, and assessing health-related quality-of-life measures used in FSHD.

In the Sustainability workstream, Project Mercury successfully established locally adapted operating models across participating countries, secured biopharma partnerships and sponsorship, and won a significant public-private grant through the European Union Innovative Health Initiative.

Together, these achievements position Project Mercury as a globally coordinated, end-to-end model for rare disease trial readiness and access—one that is accelerating progress in FSHD while establishing a blueprint applicable to other rare diseases facing similar systemic barriers. With the first generation of FSHD therapies now entering phase three clinical trials, the focus turns to scaling, delivering, and ensuring that patients and health systems are prepared when treatments arrive. Project Mercury aims to complete its work in 2027, with the final impact report to be published in 2028.

2. About Project Mercury

2.1. The Challenge

With dozens of biopharmaceutical companies actively developing therapies for Facioscapulohumeral Muscular Dystrophy (FSHD), the prospect of effective, approved therapies for people affected by FSHD worldwide has never been more promising.

Unfortunately, there are specific challenges that, if left unaddressed, will slow or prevent these therapies from reaching the people who need them. Three serious challenges must be solved if these therapies are ever to reach patients everywhere.

Challenge 1: Insufficient FSHD clinical trial readiness. Promising therapies in clinical trials fail to get to market almost 95% of the time. Some fail due to lack of efficacy, but other reasons include insufficient patient involvement in clinical trials and too few trial sites capable of conducting them.

Challenge 2: Patients may never be able to access approved therapies. Even if a therapy for FSHD gains regulatory approval, it does not guarantee that patients worldwide will be able to access it. Once a therapy treatment is granted regulatory approval, payers in many countries may not cover the costs or will seriously delay their decision to do so.

Challenge 3: The global collaboration required to solve the first two challenges does not currently exist. Success requires specialized resources and active, focused collaboration on a global scale that does not currently exist. No single organization can succeed at doing this on its own.

Solving these challenges is the remit of Project Mercury, the new global initiative to speed up the delivery of therapies for FSHD.

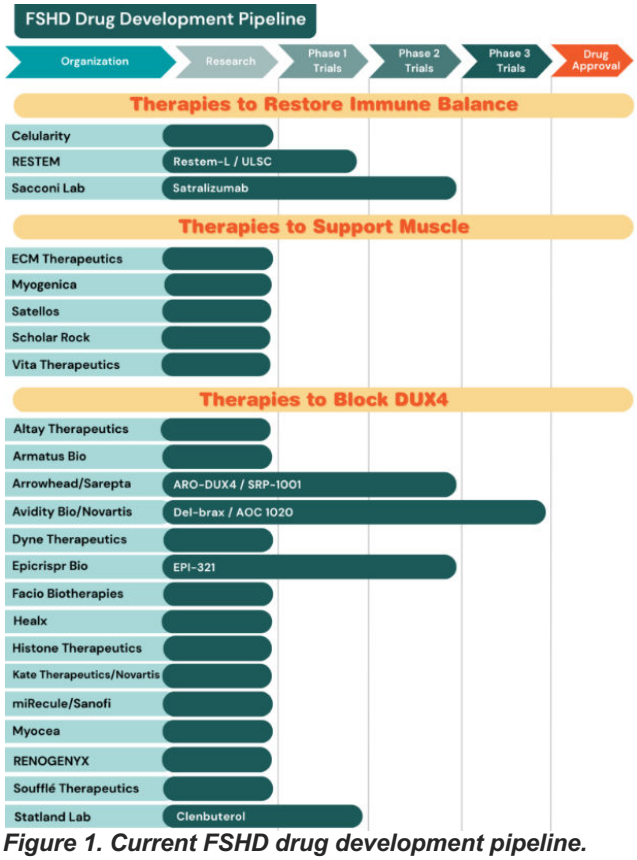

Figure 1. Current FSHD drug development pipeline. *Retrieved March 26th, 2026, from the FSHD Society website at: https://bit.ly/DrugDevPipeline.*

2.2. Operating Framework

Foundational to Project Mercury's success is enabling focused, intentional, and beneficial collaboration among all stakeholders through a "shared value" and mission-driven approach.

The Global Task Force (GTF) provides overarching oversight for Project Mercury. It operates at both the macro and micro levels: identifying global priorities, launching cross-cutting initiatives, and enabling the sharing of resources and best practices across countries, while also supporting Country Working Groups (CWGs) with guidance on local strategy and implementation. The GTF plays a central role in shaping governance, ensuring a strong global perspective, and determining where and when new CWGs should be formed to advance the program.

The GTF comprises a diverse group of stakeholders, including patient advocacy organization (PAO) leaders, biopharma representatives, clinical experts, and subject-matter experts (SMEs) in areas such as health economics and patient access.

CWGs are led by an FSHD PAO leader and include experts from various fields, as well as volunteer patient engagement leaders.

Ten countries participate in Project Mercury through CWGs:

- Australia
- Brazil
- Canada
- France
- Germany
- Italy
- Netherlands
- Spain
- United Kingdom
- United States

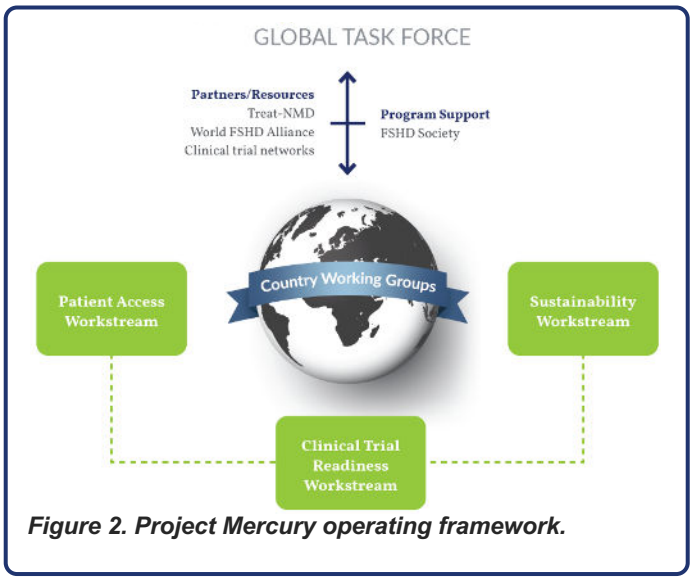

Figure 2. Project Mercury operating framework.

CWGs have bespoke needs based on their capabilities and resources to manage the three workstreams. Collaboration between CWGs, with guidance and other resources provided by the GTF, ensures optimal execution and efficiencies. The lead of each CWG also serves on the GTF. Various partners, tools, and resources are available to all as needed.

2.3. Workstreams & Aims

Project Mercury is organized around three workstreams to achieve five aims:

Workstream 1: Trial & Treatment Readiness
(Formerly "Trial Readiness")

Aim 1: Grow a global cohort of patients, starting with 10,000 patients in registry databases across Project Mercury countries who:

- have completed a core dataset,
- have engaged with educational materials from their registry or local PAO,
- are willing and able to participate in clinical research,
- and are currently receiving clinical care.

Aim 2: Grow and enhance the existing clinical trial site infrastructure, starting by doubling the number of qualified clinical sites within current site networks (e.g., the Clinical Trial Research Network (CTRN) and European Trial Network (ETN)) and ensuring sites can meet or exceed sponsor timelines for study start-up.

Aim 3 ***(newly added in 2025)*****:** Prepare healthcare communities, including clinicians, allied health professionals, and clinic staff, for future FSHD treatments by increasing awareness of FSHD, its progression severity, care standards, and upcoming treatments.

Workstream 2: Patient Access

Aim 4: Remove barriers that slow or delay patient access to approved therapies and enable FSHD therapies to beat average times from first global approval to local reimbursement in Project Mercury countries.

Workstream 3: Sustainability

Aim 5: Establish sustainable operating structures and secure the resources needed to achieve Aims 1-4 at the global and local levels through multi-stakeholder partnerships and resource sharing.

2.4. Vision

We envision a world where people living with FSHD can access approved therapies more quickly, with reduced delays between regulatory approval and reimbursement across participating countries.

This will be enabled by a coordinated, end-to-end system where:

- Patients are engaged, informed, and trial- and treatment-ready, supported by high-quality registries, education, and access to clinical care.

- Clinical trial networks are sufficiently resourced and connected to deliver studies efficiently, reducing delays in trial start-up and execution.
- Healthcare systems are prepared to introduce new therapies, with clinicians, allied health professionals, and care pathways equipped to support treatment delivery and ongoing management.
- Patient advocacy organizations are empowered with the tools, data, and expertise to engage effectively with regulators, payors, and industry.
- Biopharma organizations can design and deliver more efficient clinical trials through improved patient participation, standardized data, and strengthened site infrastructure.
- Regulators and payers have access to robust, patient-centered evidence, including disease progression models, burden-of-illness data, and validated quality-of-life measures, enabling faster and more consistent decision-making.
- Evidence frameworks support populations historically underrepresented in clinical trials, such as pediatric and non-ambulatory patients, ensuring equitable inclusion in advances in patient access.

2.5. Defining Success

Success for Project Mercury is defined by a measurable acceleration in the pathway from therapy development to equitable patient access. Over time, success will be demonstrated through:

- Increased patient participation in registries and clinical research.
- Expansion and utilization of clinical trial sites across participating countries.
- Adoption of shared data standards and evidence frameworks.
- Reduced time from first global regulatory approval to local reimbursement.
- Improved alignment between patient needs, clinical practice, and payor decision-making.
- Established local, regional, and global PAO sustainability, networks, and collaboration.

Together, these outcomes reflect a shift from fragmented efforts to a coordinated global model—one that not only accelerates progress in FSHD but provides a scalable blueprint for rare disease trial readiness and access.

3. Progress & Key Results

3.1. Workstream 1: Trial & Treatment Readiness

Aim 1: Grow & Engage a Global Cohort of Patients

Treatment development in rare diseases such as FSHD requires multi-center and multi-national execution. Delays in trial sites and patient and clinician readiness are well-documented barriers. Project Mercury addresses this by strengthening registries, education, data standards, and country-level implementation capacity, thereby reducing trial delays and accelerating the transition from trials to access.

Aim 1: *Grow a global cohort of patients, starting with 10,000 patients in registry databases across Project Mercury countries who:*

- *have completed a core dataset,*
- *have engaged with educational materials from their registry or local PAO,*
- *are willing and able to participate in clinical research, and are currently receiving clinical care.*

Strategies	Key Results
1. Build a global FSHD patient cohort, anchored in high-quality registries and engaged with local PAOs.	**Progress To-Date** • New FSHD registries launched in Australia, the United States, Brazil, Spain, and Italy, all in partnership with local PAOs. • Canada expanded its clinician-reported neuromuscular registry to include patient-reported FSHD data. • CWGs expanded patient reach, engagement, and educational events and activities across all Project Mercury countries. • FSHD Europe hosted the very first European FSHD Connect conference, providing education and connection for patients and families. • In 2025, the total count of FSHD patients enrolled in Project Mercury country registries exceeded 10,000. **What's Next** • European CWGs will develop a patient journey map detailing the European FSHD patient journey from first symptoms through end-of-life. • CWGs will deploy education tools (developed for outcome 3 below) to engage patients in registries, clinical trials, and treatment readiness.

2. Revise the core FSHD registry dataset to ensure it is suitable for clinical trials, health technology assessment (HTA), payor decision-making, and long-term monitoring.	**Progress To-Date** • A revised FSHD registry dataset was drafted. However, a challenge was identified in that there is no clear clinical consensus on which assessments should be performed during clinic visits with FSHD patients. • To address this, a clinician team applied for and secured funding for an ENMC (European Neuromuscular Centre) workshop focused on clinical monitoring of FSHD, to be held on May 1-3, 2026. • A multi-stakeholder group was convened to begin a Delphi consensus process on the dataset. **What's Next** • Project Mercury will create and publish a multi-stakeholder consensus framework guiding future FSHD real-world data collection, including core principles, top use cases, and recommended data domains, and integrating outcomes from ongoing efforts (the dataset update, natural history studies, ENMC workshop, etc.). • Multiple Project Mercury members will participate in the ENMC workshop and contribute to the recommendations for clinical monitoring. • ENMC workshop outputs will be incorporated in the FSHD registry dataset draft, and the Delphi consensus will be completed, with the revised dataset being ready for implementation in 2026.
3. Create globally accessible education templates for patients to understand participation in registries and clinical trials and to prepare for treatment approvals.	**Progress To-Date** • Work on a globally accessible education resource hub is underway, with a technical solution identified and selection of the 30 most relevant and high-quality existing resources underway. **What's Next** • Complete the initial build of the global education resource hub, which will be hosted on the World FSHD Alliance website. • Research and horizon scanning is underway on existing patient support programs and organizations as first steps to developing a comprehensive FSHD patient support toolkit for patients and PAOs across the patient journey.

Aim 2: Expand and Optimize Global Clinical Trial Infrastructure

Optimizing global clinical trial capacity and infrastructure is a major aim of Project Mercury, especially given that multiple trials are already running simultaneously, trial sponsors are reporting delays in getting their trials underway, and more trials are on the way.

Aim 2: *Grow and enhance the existing clinical trial site infrastructure, starting by doubling the number of qualified clinical sites within current site networks (e.g., the CTRN and ETN) and ensuring sites can meet or exceed sponsor timelines for study start-up.*	
Strategies	**Key Results**
1. Convene a forum to address current issues and prioritize future innovations in trial design and execution, including sharing lessons learned from previous and current trials.	**Progress To-Date** • A workshop was convened and recommendations were published for addressing immediate operational challenges and for modernizing future trial designs. Recommendations are available on the Project Mercury website at: http://bit.ly/48DXh8x. **What's Next:** This strategy is complete.
2. Support trial site creation, selection, and start-up through development of targeted resources and local PAO relationships.	**Progress To-Date** • A manuscript was published in *Journal of Neuromuscular Diseases* detailing a toolkit for new FSHD clinical trial sites. The manuscript is available at: https://doi.org/10.1177/22143602251399244. **What's Next** • A quick-reference guide companion to the manuscript is under development, designed to be an introductory tool for clinicians and sites new to FSHD clinical trials.
3. Identify new trial sites through CWG relationships and innovative partnerships.	**Progress To-Date** • Through a mix of new sponsored clinical trials, increased clinician and site engagement, and patient advocacy efforts, the number of clinical trial sites in Project Mercury countries more than doubled, increasing from 25 sites in 2023 to 53 sites in 2025. **What's Next** • CWGs will employ the resources developed in strategy two above to engage new clinicians and sites in FSHD clinical trials.

Aim 3: Prepare Healthcare Communities for Future FSHD Treatments

Over the past two years of executing Project Mercury, the team identified additional access barriers beyond those originally anticipated — a natural and expected outcome of real-time, multi-stakeholder collaboration. These barriers, which will vary by country, broadly reflect the systemic strain that a first-approved FSHD treatment will place on the entire care pathway. From surging demand on neuromuscular specialists and genetic testing infrastructure, to gaps in clinic capacity and broad healthcare provider (HCP) readiness, to the logistical realities patients will face in accessing ongoing treatment and monitoring, the healthcare system will need to adapt rapidly and at multiple levels simultaneously — all while many HCPs are already navigating significant demands from the broader wave of novel neuromuscular therapeutics. To address these challenges, the Project Mercury GTF ratified a new aim in 2025 to prepare healthcare communities for future FSHD treatments.

Aim 3: *Prepare healthcare communities, including clinicians, allied health professionals, and clinic staff, for future FSHD treatments by increasing awareness of FSHD, its progression severity, care standards, and upcoming treatments.*	
Strategies	**Key Results**
1. Coordinate global dissemination of the new international care guidelines, including patient and clinician education and marketing.	**Progress To-Date** • The full text version of the care guideline was completed by the author group, with revisions and resubmission underway on an abridged version for publication in *Lancet Neurology*. • Key updates to the guideline were presented by Project Mercury authors at the FSHD International Research Congress and the World Muscle Society Congress in 2025. **What's Next** • A comprehensive plan is under development for dissemination and education, which will be executed by a global, multi-stakeholder group including Project Mercury, World FSHD Alliance, and HCP representation. The plan will include development of accredited education for HCPs, general education resources and events for HCPs and patients, and multi-channel marketing approaches.
2. Define and publish minimal standards for FSHD care centers.	**Progress To-Date** • None to report. **What's Next** • Initial scoping and research are underway to understand

	care standards in related neuromuscular diseases and define Project Mercury's approach.
3. Create templates to assess treatment readiness for CWGs to use locally, for example via surveys or workshops.	**Progress To-Date** • The United States CWG drafted a survey to assess national clinical capacity, diagnostic pathways, operational readiness, and access barriers in FSHD. **What's Next** • The United States CWG will disseminate the clinical landscape survey and share data, learnings, and templates with Project Mercury CWGs for adaptation.

3.2. Workstream 2: Patient Access

Aim 4: Remove Barriers that Slow or Delay Patient Access

Project Mercury focuses on advancing disease-level access readiness, not just at the level of individual products. This approach is designed to complement, rather than replace, manufacturer-led, product-specific health technology assessments (HTA) submissions and activities. It also enables patient advocacy organizations, clinicians, and manufacturers to engage earlier, more consistently, and more effectively with HTA bodies, payers, and healthcare systems. By fostering these connections, stakeholders are better positioned to address barriers to access and ensure that the needs and perspectives of patients and clinicians are represented throughout the assessment and reimbursement processes.

Aim 4: *Remove barriers that slow or delay patient access to approved therapies and enable FSHD therapies to beat average times from first global approval to local reimbursement in Project Mercury countries.*	
Strategies	**Key Results**
1. Create and publish a consensus FSHD disease model for HTA and payor decision making.	**Progress To-Date** • A steering committee was established, comprised of patient and caregiver advocates and clinicians from Europe, Canada, and the United States; advisors from Project Mercury and the FSHD Society; and representatives from pharmaceutical companies developing FSHD treatments. • A feasibility assessment was completed for the disease model, which evaluated available data sources and gaps and provided recommendations for model development. • An SME partner was identified to build a conceptual and

	mathematical model to describe, predict, and analyze FSHD disease progression over time. **<u>What's Next</u>** • Expansion and re-engagement of the steering committee is underway, along with identification of data sources that will be used to build the HTA disease progression model. • A workplan has been established for the SME partner to develop the HTA disease progression model by the end of 2027, with anticipated publication and dissemination in early 2028.
2. Perform and publish FSHD economic and cost model studies.	**<u>Progress To-Date</u>** • A burden of illness scoping workshop was held, which included stakeholders across sponsors, HEOR experts, clinicians, and patients and advocacy organizations. The workshop identified and prioritized evidence gaps and resulted in a consensus recommendation for burden of illness evidence generation. **<u>What's Next</u>** • A patient survey will be developed and administered by the SME partner in two European countries to quantify patient, economic, and societal burden and unmet needs. • Results from the survey will be used to inform the HTA disease progression model. • The survey will be used to create a template for other countries to use and replicate studies locally.
3. Perform and publish a review of HR-QoL measures for FSHD, including recommendations for the development and/or use of HR-QoL tools in future clinical trials and HTA and payor decision making.	**<u>Progress To-Date</u>** • A literature review assessing validity and suitability of health-related quality of life (HR-QoL) measures used in FSHD was completed and published in *Health and Quality of Life Outcomes*. The manuscript is available at: https://doi.org/10.1186/s12955-026-02519-7. • Concurrent with the literature review, the project team worked with a group of FSHD patients to propose a framework for quality-of-life domains that are most important in FSHD. • Together, the review and framework will help inform recommended patient-reported outcome measures in the new FSHD registry dataset as well as the HTA disease model.

	What's Next • This strategy is complete.
4. Create and implement an HTA toolkit, guiding PAOs through engagement with HTA and payor decision making.	**Progress To-Date** • An outline of toolkit modules has been completed. • An initial "learn your system and stakeholders" trainings module was completed with CWGs. **What's Next** • A workplan has been established for the SME partner to develop the toolkit by mid-2027, with implementation in CWGs to follow.

3.3. Workstream 3: Sustainability

Aim 5: Acquire Resources Needed to Execute Aims 1-4

In early 2023, Project Mercury successfully transitioned from concept to an operational, multi-country global program with defined work packages, governance, and funding mechanisms. Now, securing sufficient resources and engaged partners is crucial for Project Mercury's success.

The GTF determines the necessary resources, oversees their distribution, and ensures effective use. This workstream focuses on securing funding, establishing sustainable in-country structures, minimizing global costs, and preventing resource waste. Developing multiple funding pathways and strategic partnerships at both global and local levels is vital and actively pursued.

> *"Italy represents a strong example of successful in-country sustainability within Project Mercury. Through the establishment of a formal Country Working Group, integration with national patient organizations and clinical partners, and the development of a costed sustainability and revenue model, Italy has transitioned from start-up phase to ongoing implementation. This model demonstrates how Project Mercury can be sustained locally while remaining aligned with global strategy.*
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> Domenico Muratori, FSHD Italy

Aim 5: *Establish sustainable operating structures and secure the resources needed to achieve Aims 1-4 at the global and local levels through multi-stakeholder partnerships and resource sharing.*	
Strategies	**Key Results**
1. Prepare a business development plan to support Project Mercury work at both the global and country/regional levels.	**Progress To-Date** • Global work packages (e.g. access, readiness, sustainability) were identified, costed, and actively implemented across regions. **What's Next** Create a sustainable framework to shift from a project-based model and expand involvement with the World FSHD Alliance to include more countries.
2. Establish public-private partnerships to generate revenue, such as government grants.	**Progress To-Date** • TREAT-NMD and the FSHD Society, along with other European partners, were successful in securing grant funding through an Innovative Health Initiative-funded project launched in 2024 called PaLaDIn (Patient Lifestyle and Disease Data Interactium). • Within the PaLaDIn framework, FSHD and Project Mercury serve as a case study to demonstrate how advocacy organizations can effectively engage patient communities, leverage real-world data to lead cross-sector collaboration, and generate HTA-ready evidence. **What's Next** • FSHD Europe was recently onboarded as a sub-contractor to support the PaLaDIn grant beneficiaries in developing an FSHD disease progression model for HTA, the European FSHD patient journey, and toolkits to support FSHD patient advocacy organizations.
3. Establish biopharma industry partnerships to generate revenue and resources.	**Progress To-Date** • Biopharma partnerships contributed direct financial support and in-kind expertise through GTF participation. • Industry partnerships (Avidity, Fulcrum) contributed to start-up funding for global coordination and key projects. **What's Next** • Exploring to expand industry partnership to involve growing number of emerging biopharma companies for potential collaboration. Involving subject matter expertise through representation is key in shaping global strategy.

4. Establish partnership with PAOs and others to generate in-kind resources and support.	**Progress To-Date** • Significant in-kind investment (personnel, leadership, expertise) by all GTF members was leveraged as equity, maximizing impact per dollar spent. • FSHD Society and FSHD Canada invested in start-up funding for global coordination and key projects. **What's Next** • Continue to leverage in-country expertise by providing in-kind guidance and support to sustain local and regional implementation and enhance ROI at global level.
5. Create local sustainability through advice, support and consultation.	**Progress To-Date** • Countries participating in Project Mercury now operate through locally adapted sustainability models, rather than a one-size-fits-all approach. • A landscape analysis approach was implemented to assess each country's existing patient advocacy capacity, regulatory and funding environment and readiness for clinical trial and access activities. • The FSHD Society provided direct consultation, templates, systems, and training to CWGs, reducing duplication and accelerating implementation. • Centralized global coordination reduced duplication of patient education materials, advocacy tools, and engagement strategies across countries through quarterly meetings and work group set-up structure. • CWGs took responsibility for strengthening their regional networks, enhancing patient engagement through strategic communication and educational events. **What's Next** • Project Mercury is in the process of transitioning from a time limited pilot to a scalable, long term global platform within the World FSHD Alliance. Governance and asset discussions (e.g. relationship with the World FSHD Alliance) were initiated to ensure long-term stewardship.

4. Summary of Impact

Between 2023 and 2025, Project Mercury played a crucial role in preparing the world for FSHD trials and treatments. By creating coordinated educational programs, updating registry standards, and supporting CWGs, the project helped improve readiness among patients, healthcare providers, and research sites across many countries. Notably, country registries exceeded 10,000 patients, and the number of clinical trial sites more than doubled—from 25 in 2023 to 53 in 2025—laying important groundwork for international clinical trials. Recognizing that expanding sites alone isn't enough to eliminate all access barriers, the GTF set a new goal in 2025 to strengthen the healthcare system's overall readiness.

During this period, Project Mercury also built a coordinated framework for access and HTA readiness. This included: a comprehensive literature review of HR-QoL measures in FSHD, paired with a patient-centered quality-of-life framework to guide future trial endpoints and HTA submissions; a feasibility assessment of an FSHD HTA disease-progression model; and a burden-of-illness scoping workshop that produced a clear, consensus-driven roadmap for evidence generation. These efforts are helping health systems, clinicians, and patient organizations work together more effectively. This approach aims to accelerate trial processes, reduce delays after therapy approval, and ensure fair access to new treatments as they become available.

Finally, Project Mercury has successfully established a sustainable, resource-efficient global operating framework. Designed to allow new countries to join easily through existing structures, it minimizes start-up costs and shortens the time to impact. Additionally, it acts as a template for addressing other rare diseases. By conducting strategic landscape analysis and establishing CWGs, the initiative has reduced duplication, accelerated progress, and improved patient support globally.

Project Mercury aims to transition to a scalable global platform within the World FSHD Alliance, promising long-term impact by ensuring investments support a strong, coordinated international effort. This effort advances clinical trials, access, and patient outcomes. Supporting Project Mercury means endorsing a proven, flexible model that promotes tangible progress in rare disease advocacy and research.

This report highlights two years of relentless effort, an extraordinary foundation for a future in which hope and effective treatments for FSHD are within reach for every patient. The journey continues, stronger than ever.

5. Acknowledgements

Acknowledgements
We extend our deepest gratitude to the patient advocate leaders whose vision and commitment drive progress; to GTF members for their tireless coordination and leadership; to SMEs for their invaluable insights; to our industry partners for their steadfast collaboration; and to the funding parties whose generosity makes this work possible. The unwavering commitment to Project Mercury has laid the groundwork for transformative progress in accelerating the development of therapies for FSHD.

We thank our sponsoring industry partners for their participation and financial support:

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Guidance documents, recommendations, and publications can be downloaded from the Project Mercury website at: https://projectmercuryfshd.org/publications/

7. Appendices

7.1. Participating Patient Advocacy Organizations

FSHD Global Research Foundation Australia	ABRAFEU Associação Brasileira de Facio-Escápulo-Umeral Brazil
FSHD CANADA FOUNDATION Curing the #1 Form of Muscular Dystrophy Canada	FSHD Europe Europe
AFM TELETHON INNOVER POUR GUERIR / AMIS FSH France	DGM Deutsche Gesellschaft für Muskelkranke e. V. Germany
FSHD ITALIA APS Italy	FSHD STICHTING Netherlands
fshd SPAIN Spain	FSHD UK, United Kingdom
FSHD SOCIETY United States of America	World FSHD Alliance Stronger together World FSHD Alliance

7.2. Current Global Task Force Members

Name	Organisation	Country
Mark Stone ***Chair, 2023-2025***	FSHD Society	United States of America
Emma Weatherley ***Incoming Chair, 2026-2027***	FSHD Global Research Foundation	Australia
Fabio Figueiredo	ABRAFEU	Brazil
Blaine Penny	Lumiio	Canada
Lawrence Korngut	University of Calgary	Canada
Neil Camarta	FSHD Canada Foundation	Canada
Alexandre Méjàt	AFM-Téléthon	France
Teresinha Evangelista	EURO-NMD	France
Miriam Wagner Long	World FSHD Alliance	Germany
Domenico Muratori	FSHD Italia	Italy
Kees van der Graaf	FSHD Stichting	Netherlands
Nicol Voermans	FSHD ETN	Netherlands
Ria de Haas	FSHD Europe	Netherlands
Ricardo Gerpe	FSHD Spain	Spain
Andrew Graham	FSHD UK	United Kingdom
David Allison	TREAT-NMD	United Kingdom
Rajeshri Badiani	FSHD UK	United Kingdom
Amanda Hill	FSHD Society	United States of America
Anna Gilmore	FSHD Society	United States of America
Ashley Ferreira	FSHD Society	United States of America

7.3. Past Global Task Force Members

Name	Organisation	Country
Laura Issa	FSHD Global Research Foundation	Australia
Sylvie Genet	FSHD Europe, AFM-Telethon France	France
Maryna Kolochavina	Independent Consultant	Germany
Robert Matthezing	FSHD Stichting	Netherlands
Josie Godfrey	JG Zebra Consulting	United Kingdom
Amy Winnen	Fulcrum Therapeutics	United States of America
June Kinoshita	FSHD Society	United States of America
Ken Kahtava	FSHD Society	United States of America
Kristi Clark	Avidity Biosciences	United States of America
Mel Hayes	Fulcrum Therapeutics	United States of America
Nathan Weedin	Avidity Biosciences	United States of America
Olga Mitelman	Fulcrum Therapeutics	United States of America
Rocio Martin	Avidity Biosciences	United States of America