

## 2022-2023 World FSHD Alliance Annual Plan (Updated 09/29/22)

*Vision – Treatments and a cure for FSHD*

*Mission – Accelerate the development of treatments while empowering people living with FSHD*

The primary purpose of World FSHD Alliance is to **connect and activate the FSHD community globally** in order to build a worldwide community of activists, empower patients, and advance our shared mission of accelerating the delivery of therapies to everyone who needs them. A global program empowers activists everywhere by sharing resources, tools, strategy, and “speaking in one voice.” Importantly, FSHD clinical trials will be international in scope. Coordinating our messages and outreach efforts will result in more timely, cost-effective ways to engage with industry around drug development, clinical trials, regulatory approval, and patients’ access to therapies.

### **Benefits to the alliance members**

- Enhances credibility and influence of organizations as members of a global alliance;
- Builds networks locally and nationally to improve the quality of patients’ lives;
- Gives communities greater influence;
- Shares educational resources and best practices;
- Shares knowledge and best practices around fundraising;
- Creates opportunities for diverse patient populations to participate in research;
- Provides guidance and support for local/national communications and marketing;
- Provides the network to operationalize global campaigns;
- Enables the global patient community to collaborate effectively with industry;
- Provides frameworks to engage with regulatory agencies on drug pricing and access.

### **Leadership**

Alliance activities are organized and led by a steering committee of leaders from member organizations. Current committee members are:

- Raj Badiani (FSHD UK initiative)
- Fabiola Bertinotti (UILDM Italy)
- Fabio Figueiredo (ABRAFEU Brazil)
- Sylvie Genet (AFM France)
- Ricardo Gerpe (FSHD Spain)
- Sheila Hawkins (FSHD EU)
- June Kinoshita (FSHD Society)
- Robert Matthezing (FSHD Stichting Netherlands)

## Current member organizations

### The Americas

- Argentina: FSHD Argentina
- Bolivia: FSHD Bolivia
- Brazil: [ABRAFEU \(Associação Brasileira Distrofia Muscular Facio-Escaulo-Umeral\)](#)
- Canada: [FSHD Canada Foundation](#)
- Canada: [Muscular Dystrophy Canada](#)
- Chile: [Distrofia Muscular FSH en Chile](#)
- USA/International: [FSHD Society](#)

### Europe

- EU: [FSHD Europe](#)
- France: [AFM Téléthon FSHD support group](#)
- France: [Amis FSH](#)
- Germany: [FSHD Diagnosis Group within the DGM](#)
- Italy: [UILDM \(Unione Italiana Lotta alla Distrofia Muscolare\)](#)
- Italy: [FSHD Italia](#)
- Netherlands: [Spierziekten Nederland : Facioscapulohumerale spierdystrofie](#)
- Netherlands: [FSHD Stichting](#)
- Russia: FSHD Russia
- Spain: [FSHD Spain](#)
- Turkey: FSHD Turkey
- UK: [FSHD-MD Support Group UK \(affiliated with MD UK\)](#)

### Africa, Asia & Oceania

- Australia: [FSHD Global Research Foundation](#)
- China: [FSHD China](#)
- Hong Kong: FSHD Hong Kong
- India: [FSHD India](#)
- Israel: [FSHD Israel](#)
- Japan: [FSHD Japan](#)
- Japan: [Japan Muscular Dystrophy Association](#)
- South Africa: [Muscular Dystrophy Foundation of South Africa](#)

## **2022-2023 activities**

1. World FSHD Alliance will:
  - a. Develop a charter and strategic plan to be updated annually
  - b. Set priorities, goals, and establish task forces
  - c. Develop and maintain infrastructure for communications and shared resources
  - d. Promote leadership training and best practices for members
  - e. Activities for implementing the above include
    - Annual summit
    - Maintain website and online forums for the Alliance
    - Quarterly meetings of all Alliance members. Task force updates.
    - Quarterly newsletter

## **Meeting schedule for 2022-2023**

### **Steering committee**

- October 12, 10 AM ET – Fall meeting agenda planning
- January 11, 10 AM ET – Winter meeting agenda planning
- April 12, 10 AM ET – Spring meeting agenda planning
- May 24, 10 AM ET – Annual summit meeting agenda planning
- July 12, 10 AM – Summer meeting agenda planning

### **World FSHD Alliance member meetings**

- October 29, 8AM ET – Quarterly meeting
- January 28, 8 AM ET – Quarterly meeting
- April 29, 8AM ET – Quarterly meeting
- June 15-17 – IRC and Annual summit TBD
- July 29, 8 AM ET – Quarterly meeting

## Task forces

Based on responses to our online organizational survey conducted early in 2022, seven topics emerged as high-priority goals. We have merged these into three focus areas for 2022/23. We have organized task forces to expedite progress toward organizations' goals for each of these areas.

<b>Task force 1</b>	<b>Patient Engagement and Communications</b>
<b>Members</b>	Bolivia, AFM France, FSHD Hong Kong, FSHD India, FSHD Israel, FSHD Italia, FSHD Turkey, FSHD EU, MD South Africa
<b>Leaders</b>	Gerda Brown (South Africa) <a href="mailto:gmnational@mdsa.org.za">gmnational@mdsa.org.za</a> Manav Goel (FSHD India) <a href="mailto:manav.goel1@gmail.com">manav.goel1@gmail.com</a>
<b>Advisors</b>	Sheila Hawkins and Sylvie Genet
<b>Goals</b>	1. Develop a Patient Engagement Strategy fit for purpose by organisation development status 2. Collate and Prioritise – a short list of key patient communications mechanisms for all organisations by organisation development stage 3. Identify key mechanisms used successfully by organisations to enable sharing of these techniques across the World Alliance

<b>Task force 2</b>	<b>Registries, Research and Trial Readiness</b>
<b>Members</b>	FSHD Global (Australia), ABRAFEU (Brazil), MD Canada, FSHD Israel, UILDM (Italy), FSHD Japan, FSHD Society, FSHD Stichting (Netherlands), FSHD EU
<b>Leaders</b>	Bine Haase (Germany/EU) <a href="mailto:bine@fshd-europe.info">bine@fshd-europe.info</a> Emma Weatherly (Australia) <a href="mailto:emma@fshdglobal.org">emma@fshdglobal.org</a>
<b>Advisors</b>	Fabio Figueiredo, Fabiola Bertinotti, Robert Mattheizing
<b>Goals</b>	1. Pull together a guideline of key elements of clinical trial readiness for FSHD and an outline action plan for readiness 2. FSHD Registry – review mechanisms to improve FSHD registration (note this overlaps with patient engagement) so this should be more focused on what a registry team could/should do 3. Review Research Funding options and opportunities in line with research gaps, opportunities and priorities.

<b>Task force 3</b>	<b>Health Care Resources and Medical Education</b>
<b>Members</b>	FSHD Argentina, FSHD Chile, China FSHD, FSHD Israel, Netherlands, Spain, FSHD UK
<b>Leaders</b>	Macarena Francisca Diaz Ubilla (Chile) <a href="mailto:maquita.du@gmail.com">maquita.du@gmail.com</a> Ning Baisheng (China) <a href="mailto:ningbaisheng001@163.com">ningbaisheng001@163.com</a>
<b>Advisors</b>	Raj Badiani and Ricardo Gerpe
<b>Goals</b>	1. World Registry of FSHD Clinicians – Collate and establish a registry of medical professionals by country (Salesforce an option to hold this data?) 2. Strategy & Plan for Clinician Training in particular for start-up, development organisations