



Charter for the World FSHD Alliance

Renewed and ratified, July 1, 2023

Overview

- The World FSHD Alliance is a voluntary, international federation representing diverse stakeholders who share the mission of accelerating the development of therapies, ensuring access to all patients, and empowering people living with FSHD. Stakeholders include individuals wishing to start FSHD patient groups, patient advocacy organizations, funders, clinicians, and research networks.

Mission:

- 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.
- To share best practices and resources to help members develop into impactful, self-sustaining organizations.
- To work collaboratively to promote international awareness of FSHD.
- To collaborate with clinicians to improve diagnosis, promote high standards of clinical care, and connect patients to support organizations.
- To promote patient engagement in advocacy and research.
- To coordinate messaging around FSHD education, research, and clinical trial participation.
- To work effectively with industry and regulators to bring the patient voice into the drug development process.
- To work collaboratively toward the availability of an affordable and effective treatment for FSHD; and to advocate for reimbursement of such treatments.

Steering Committee

- The World FSHD Alliance currently exists as a voluntary federation of FSHD patient advocacy groups. The Alliance has no constitution nor bylaws. It has no budget nor specific authorities. The contract among Alliance members is moral, rather than legal.
- FSHD Society will serve as the convenor and provide administrative support for the Alliance.
- A steering committee will be formed to provide oversight of Alliance membership and activities.
- Task forces will be formed on an as-needed, temporary basis to work on specific projects.
- Information will be openly shared to the benefit of the Alliance members.

Membership

- The Alliance is open to all FSHD patient advocacy organizations, individuals wishing to form such an organization, and allied, non-commercial stakeholders.
- Individuals or organizations that have commercial interests in FSHD patients or therapies may partner with the Alliance but are not eligible for membership.
- Members may join by invitation by current members of the Alliance or by making a request to a representative of the Alliance steering committee. Member requests will be approved by the steering committee. New members will be announced at quarterly member meetings.
- Each member organization is expected to:
 - Share an annual plan
 - Conduct outreach through clinics, social media, etc. to develop its membership
 - Convene at least one educational meeting per year for its members
 - Develop relationships with researchers and institutes
 - Engage in awareness-raising activities such as World FSHD Day
 - Develop teams and resources (e.g. funds, sponsor relations) to help sustain its activities
- Members are encouraged to display the World FSHD Alliance logo on their websites and literature.
- Members that do not fulfill any of the expected activities within 2 years of joining will be considered inactive.

Meetings

- An annual summit will be held to convene all members to review and evolve organizational strategy, share annual plans, and discuss new initiatives.
- Quarterly webinars will be held for task forces to report on progress and seek input from members, to discuss organizational tactics and strategy and to share educational and research topics of general interest.
- When appropriate, additional virtual meetings will be organized.

Communication

- The Alliance will establish a channel for exchanging information and discussion on an ongoing basis.
- A newsletter will be sent quarterly with participation of all members on subjects regarding their organization that could interest the community.
- We will maintain a presence online (website, Facebook page, etc.) to enable like-minded organizations to find and join the Alliance.