

Charter for the World FSHD Alliance

Purpose:

- To form a voluntary, international federation of patient advocacy organizations representing individuals and families with FSH muscular dystrophy. Our shared vision is to accelerate the development of therapies while empowering people living with FSHD. "Organizations" includes individuals wishing to start an FSHD patient organization or association.

Mission:

- To connect and activate the FSHD community globally in order to build a worldwide community of activists, empower patients, and advance our shared vision of accelerating the development of therapies.
- 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 toward the availability of an affordable and effective treatment for FSHD; and to advocate for reimbursement of such treatments.

Governance

- The World FSHD Alliance is 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 governance 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 as well as individuals wishing to form such an organization.
- Members may join by invitation by current members of the Alliance or by making a request to a representative of the Alliance governance committee. New member candidates will be announced by an email to the full Alliance members and ratified by e-voting.
- 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 may 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 share strategy and annual plans.
- Quarterly webinars will be held to discuss topics of special interest to members or to work on initiatives and projects.
- 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 establish a presence online (website, Facebook page, etc.) to enable like-minded organizations to find and join the Alliance.