



***Please feel free to use any of these messages and/or links
when communicating with your patients and families***

Ensuring no one has to face Facioscapulohumeral Muscular Dystrophy (FSHD) alone, the FSHD Society is here to empower patients while accelerating progress toward treatments and a cure. The FSHD community is strong; it will be even stronger with you in it. Together we can ensure every person diagnosed with FSHD has access to education, support, and empowerment. Together we will catalyze a global community to shorten the drug development timeline and get therapies to patients sooner.

Clinical trials are ongoing! There is an URGENT need to engage more FSHD families. To help:

- 1) [Sign up](#) to receive the FSHD Society's news alerts to stay up to date on key developments, conferences, future studies. You can forward our alerts to your patients.
- 2) Contact our national office to inquire about support groups, educational meetings, and assistance with clinical trial and study recruitment, etc.:
 - a. June Kinoshita, Director of Research and Patient Engagement
June.kinoshita@fshdsociety.org, 781-301-6649
- 3) Provide our web link www.fshdsociety.org to patients and families. Encourage them to sign up so that they can learn about enrolling in FSHD registries, receive valuable information and get alerts about clinical studies and trials.
 - We do not share patient data with anyone else, so you don't need to worry about loss of patient privacy or about their getting contacted directly by companies. By signing up, FSHD patients and their families will help accelerate the development of better treatments.
- 4) Share links or printed pamphlets (which we can send to you) with patients and families.

Helpful Links:

- FSHD Website: www.fshdsociety.org
- FSHD Society on Facebook: <https://www.facebook.com/FSHDSociety/>
- FSHD Contact Registry: www.FSHDSociety.org/FSHDRRegistry
- Join the FSHD Community: www.fshdsociety.org/Connect
- New patient brochure: www.fshdsociety.org/PatientBrochure
- PT for FSHD brochures: <https://www.fshdsociety.org/PTBrochure>
- Patient Library: www.fshdsociety.org/PatientLibrary

Many of the brochures, including the New Patient and PT for FSHD, are available as hard copies. Please let us know if you'd like any and we would be happy to pop them in the mail for you!