



RESOURCES FOR INDIVIDUALS LIVING WITH FSHD

The FSH Society (<http://www.fshsociety.org>)

The FSH Society is the world's largest grassroots network serving facioscapulohumeral muscular dystrophy (FSHD) patients, their families, and research advocates. It offers online and in-person forums to exchange FSHD information around the world, sharing expert guidance, patient experiences, and recommendations that can help other patients and families. It also reports on scientific and medical advances in the field, including clinical trials. All information on the site is reviewed by established experts. The FSH Society's website offers downloadable resources, including the following:

- FSH Watch newsletters
- About FSHD patient brochure
- Physical Therapy brochure
- Living with FSHD Series, FSHD: A Guide for Schools
- A Guide for Family and Friends
- Health Tips for FSHD patients

FSH Society Yahoo Group Forum (<https://groups.yahoo.com/neo/groups/fshsociety>)

This Yahoo Group Forum's message board enables patients to raise questions, provide one another with guidance, form friendships, and discuss options for managing health issues and living with FSHD. It is an active message board that delivers useful information. The message board has search capabilities for easy access to past posts.

The FSH Society (<https://www.facebook.com/FSHSociety>)

This FSH Society Facebook page posts news and events, and enables message exchange on a wide range of FSHD topics.

Private Facebook groups

There are a number of private, moderated Facebook groups for individuals affected by FSHD (FSH Friends), young people (Teens/Young Adults with FSHD), women (Women with FSHD), and parents of children affected by FSHD. Messages posted in these private groups cannot be seen by non-members. Membership is by invitation, which can be easily arranged by emailing info@fshsociety.org.

These resources are extremely valuable and can help individuals deal with different aspects of FSHD.

In addition to the Internet resources, the FSH Society has a service to connect individuals with a Peer-to-Peer Team member. This service spans the U.S. and many other parts of the world. The Society can match patients to peers by various criteria, including age, gender, shared interests, occupation, and geographic area.

While this devastating disease has a real impact on patients and families, it can be immensely comforting for them to know that they are not alone. These resources give individuals opportunities to have personal conversations with others and receive encouragement and support to help guide their future.

The FSH Society thanks Bill Maclean for helping to create this resource page. This Clinician Guideline is distributed by the FSH Society with permission of the American Academy of Neurology.

For further information, contact:

FSH Society
450 Bedford Street
Lexington, MA 02420
Phone: (781) 301-6060
Email: info@fshsociety.org
www.fshsociety.org