

## FSHD Resource Form

Patients with FSHD may have had some difficulty finding information resources associated with their disease. A variety of valuable information resources are available, as outlined below. The internet offers a convenient method of securing information, answering questions and providing focused guidance on FSHD.

### The FSH Society

The FSH Society is the world's largest grassroots network serving facioscapulohumeral muscular dystrophy (FSHD) patients, their families and research activists. It offers on-line and in-person forums to exchange FSHD information across the world, sharing patient experience and recommendations that can help other patients. It also keeps pace with the many scientific advances in the field. This web site points to a variety of valuable resources, including:

- FSH Watch Newsletters
- FSHD Patient Brochure
- Physical Therapy Brochure
- Living with FSHD Series FSHD: A Guide For Schools Brochure

Access is provided via the following web site: <http://www.fshsociety.org/>

### FSH Society Yahoo Group Forum

The Yahoo Group Forum establishes a message exchange board enabling patients to raise questions, provide guidance, form friendships and discuss options for FSH. It is an active message board that delivers useful information. The message board has search capabilities that allow easy access to past posts on specific topics.

<https://groups.yahoo.com/neo/groups/fshsociety/conversations/messages>

### FSH Society Facebook page

This FSH Society Facebook forum enables message exchange on a wide range of FSHD topics. As with other Facebook forums, the string of comments on each message offers more insight into specific FSH topics.

<https://www.facebook.com/FSHSociety>

### Living with FSHD Facebook page

This Facebook forum provides a message exchange on a spectrum of FSHD topics. Many of the posts focus on specific methods individuals use to deal with FSH issues. There are also some focused forums that may be of interest, including FSH Friends, Teens/Young Adults with FSHD and the Women with FSHD Facebook groups. Membership in these groups is by invitation, which can be easily arranged by e-mailing June Kinoshita at [june.kinoshita@fshsociety.org](mailto:june.kinoshita@fshsociety.org).

<https://www.facebook.com/groups/livingwithfshd/>

These resources are extremely valuable and can help you to deal with different elements of FSHD. Participants on these internet-based media will raise questions, provide answers and offer guidance. In many cases, this guidance is not available from any other resource.

In addition to the internet resources, personal support is available. The FSH Society has a service that enables discussions with a Peer-to-Peer Team member. These individuals are FSHD patients and can support discussions on topics of interest. The peer-to-peer service spans the US and many other parts of the world. The Society can match patients to peers by various criteria, including age, gender, shared interests, occupation, geographic areas and others. For FSHD patients in the general Philadelphia area, you can contact Bill Maclean for a peer-to-peer discussion. Initial contact through e-mail is preferred, using: [wa.maclean@hotmail.com](mailto:wa.maclean@hotmail.com)

While this devastating disease has a real impact on our lives, know that you are not alone. Use these resources and the opportunity to have a personal conversation with others to help guide your future.