

2017 World FSHD Day Video selfie project

Thank you for helping us with this project to raise public awareness of FSHD. All you need to do is make a video of yourself sharing the messages in the script below. Feel free to adapt it to your voice. Try to get good audio quality. Then send in your video to june.kinoshita@fshsociety.org via DropBox by **May 8th, 2017**. Questions? Email june.kinoshita@fshsociety.org.

SCRIPT

Hi, I'm _____.

I have Facio Scapulo Humeral muscular dystrophy, or F-S-H-D.

OR My _____ [someone I care about] has Facio Scapulo Humeral muscular dystrophy, or F-S-H-D.

OR I'm here to raise awareness for Facio Scapulo Humeral muscular dystrophy, or F-S-H-D.

One in 8,000 people have F-S-H-D.

That's nearly one million men, women, and children around the world.

It's a rare genetic disease that weakens your muscles.

People can lose the ability to walk, do simple tasks, or blink. F-S-H-D can even rob you of your smile.

Some develop difficulty breathing, which can be life-shortening.

F-S-H-D can be passed on to your children.

Most people have never heard of F-S-H-D.

To fight this disease, we **MUST** raise awareness.

This June 20th is World FSHD Day. Orange is our official color.

So, this June 20th, take an orange, cut out a slice, and give yourself an orange-slice smile! Post a selfie on Twitter, Instagram, or Facebook with the hashtag World FSHD day [*#WorldFSHDday*].

It's easy! SLICE. SMILE. SNAP. POST. [*Demonstrate doing this.*]

THANK YOU for making a difference!