#FSHDselfies: Take a Selfie, Raise Awareness & Funds for FSHD

<u>selfie</u> noun, informal – a photograph that one has taken of oneself, typically one taken with a smartphone or webcam and uploaded to a social media website – Oxford Dictionary

This week we are launching a major national social media campaign to raise awareness and funds for FSHD and Max Adler, of "Glee" and ABC Family's "Switched at Birth" will be kicking it off with us! Max's mother and grandmother were affected by the disease and he has been one of the most vocal celebrity advocates for the disease.

The ever popular social meme of the selfie is considered rather narcissistic, but we're taking the term and making it into a positive force to raise awareness about FSHD. As you know, many people affected by FSHD are unable to smile, and that's where the impetus for the campaign started.

We want to share selfies of those affected by FSHD smiling and not smiling (or smiling on the inside) and give others a chance to smile for us and share these faces – the whole array of them – on Facebook, Twitter and Instagram.

A New York based philanthropist has pledged to donate \$1 for each selfie posted with the campaign hashtag, #FSHDselfies, to the FSH Society. The donor has generously offered to give up to \$5,000 toward the cause.

Please help us spread awareness, starting today on July 7. Here's how to get involved:

- Take a selfie with your smartphone
- Post or tweet your selfie using the hashtag #FSHDselfies (see sample tweets below)
- Encourage your friend and colleagues to do the same
- Change your social media profile image(s) to the #FSHDselfies campaign logo (downloadable below)
- Follow @FSHsociety on Twitter and Facebook

The goal of the campaign is to get folks talking about FSHD and driving those who don't know what it is to find out and spread the word to others.

Please make sure to connect with us via Twitter (add link) and Facebook (add link) and join our #FSHDselfies today! Help us reach our goal of 5,000 #FSHDselfies!

1. Proud to share my first selfie for #FSHDselfies to raise awareness for the rare incurable disease #FSHD and the @FSHsociety. [insert selfie]

- 2. I'm taking part in the #FSHDselfies campaign. To learn more about FSHD and how you can help go to www.FSHsociety.org
- 3. More than 500K people worldwide are affected by #FSHD. Help me raise awareness the #FSHDselfies campaign & learn more
- 4. Do you know what #FSHD is? Post a selfie with #FSHDselfies to spread the word about this rare incurable disease. [insert selfie]
- 5. My [friend or family member] is affected by #FSHD. Help me raise awareness for this rare incurable disease with #FSHDselfies and @FSHsociety
- 6. On [insert date] I was diagnosed with #FSHD. Help the @FSHsociety raise awareness and find a cure by sharing a selfie #FSHDselfies



#FSHDselfies campaign logo