

What's happening in the Year of the Dragon! FSHD Society Initiatives...



The Global Initiative to Speed the Delivery of Therapies for FSHD - solving the biggest threats to keeping patients from accessing

affordable and effective treatments.

- FSHD Navigator The FSHD Navigator is a service dedicated to helping families with FSHD find what they need to live their best lives. Through this program, you can get connected to the information, resources, or contacts you're looking for. This is going to be a very conversational, relationship-focused program. "Journeying together."
- Hill Day, Washington DC advocacy day in mid-May



- HILTON DENVER CITY CENTER June 15-16, 2024
- FDA Listening Session on Upper Body Mobility
- BetterLife FSHD Platform for patients to connect them to clinical trials and research, symptom tracking, securely contribute your data to accelerate research and a cure. Public launch in fall 2024.

In the PNW...

• Summer Fun – Tacoma Rainiers Baseball Game around 🛁



• Fall FSHD Walk n Roll Fundraising Celebration - TO CURE