

## PNW Chapter—Notes and News, Winter 2022/23





is the Season for family, friends and décor extraordinaire. November

started with the Northwest Chocolate Festival for our family. We were happy to meet up with fellow FSHer, Jane Herzog, and her daughter. The day was an excellent excuse to consume lots of antioxidants and get the endorphins flowing. Behind the scenes I've been working with Chris Haven, FSHD advocate and local chapter member, to organize our upcoming "Cocktails and Clinical Trials" event. The date is set for February 11, 2023. Watch for a registration email from the FSHD Society.

Another opportunity for us to gather will be at the Friends of FSH Gala on Jan. 28<sup>th</sup>, being held in Bellevue, WA. It would be great to fill a table with PNW Chapter members!

I am also a member of the PACT Registry Focus Group. We meet periodically to help design the new PACT patient registry platform that will be an important resource for FSHD patients wanting to get involved in clinical trials. PACT = Patients Accelerating Clinical Trials. You want to be one of those, right??? Watch for the PACT Registry reveal in the new year. Looking forward to seeing you in 2023! *Setina Lai, PNW Chapter* 



## Stuff you should know about...

- Here are links to 3 short articles about how the FSHD Society has invested \$3.4 million on the journey to a treatment or cure. <u>Part 1, Part 2, Part 3</u>
- From the FSHD YouTube channel, Jeffery Statland, MD, provides a <u>video update on drug development</u>.
- The latest video from "Feeling Fit with FSHD" focus group is about <u>neck and shoulder exercises</u>.
- Trying to stay warm this winter? Hints from Mark Tarnopolsky, MD. <u>Staying Warm with FSHD</u>.
- Could be a fun night out in support of FSHD research...<u>Friends of FSH Research Gala</u>



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