## PNW Chapter—Notes and News, Fall 2024



PNW Fall Fundraising Celebration, Owen Beach Pavilion

## Well, here we are. Leaves are turning

golden on the trees, rain has started to fall again, and we are hopeful for "sun breaks" during our days. Let's start with a bit of gratitude for those who helped make our PNW Walk and Roll Fall Fundraising Celebration a success with donations topping \$30,000. Nancy Payton, our event chair, created a warm and inviting event filled with the beautiful tunes from her talented brother, Chris Garrett, delicious food, and fun mocktails. Our opportunity drawing was another chance for a lucky day. Thank you to Mike Willis and Dr. Wang, from the UW Clinical Research Center for taking time out of their busy weekend to spend time with our community. Also, let's give a shout out to all the volunteers who helped with setting up our festive venue. Finally, thank you to all the FSHD patients and supporters who came to enjoy the day on the waterfront. Donations to our PNW event can still be made at here. Use this link to view event photos.

NEXT UP... Our next education meeting is on November 2<sup>nd</sup>, noon to 2pm on the topic of Strength Training for Rehabilitation and Maintenance in FSHD. Personal Trainer Alex Walker of Walker Weightlifting will discuss the benefits of strength training for FSHD along with a few of his FSHD clients. We will gather at the home of Chris and Tony Haven. Click here for details and registration. The meeting will be held both in person and via ZDDM.

SAVE THE DATE for our next winter meeting! Once again we will be gathering in Portland, OR for Shaking QiGong with Trish Kean the weekend of January 25-26, 2025. Our exercise session will be followed with a Chinese New Year brunch, Year of the Snake!

Selina Lai, PNW Chapter Leader Nancy Payton, Walk and Roll Coordinator

## Stuff you should know about...

- Get connected to the BetterLife
  Platform TODAY! Stay on top of clinical
  trial activities, track your FSHD
  symptoms and participate in research
  projects that will provide pivotal data to
  FSHD researchers. JOIN HERE
- Tim Hollenbeck's International Walk & Roll Podcast Special - <u>Listen Here</u>



## **FSHD Society**

October 24 - Feeling Fit with FSHD, 9am PT

October 29 - CarePartner Hour, 5pm PT

Nov. 1 – Everything Early Onset, 5pm PT

Nov 2 – <u>PNW CHAPTER EDUCATION MTG</u>, 12 -2pm– inperson and via Zoom.

Nov. 2 - New England FSHD 360

Nov 6 – Women On Wellness, 2pm PT

Nov. 11 - Wellness Hour, 2am PT

Nov. 18- Young Adults, 5pm PT

Nov. 19 – Early Onset Parent Roundtable, 5pm PT

Nov. 21 – <u>FSHD University</u>: ReSolve- What We Have Learned, 10am PT

Nov. 26 - CarePartner Hour, 5pm

January 25-26, TBD – PNW CHAPTER Meeting Portland, OR-QiGong and Chinese New Year Lunch

**FULL FSHD SOCIETY CALENDAR LINK** 

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