

## FSHD<sub>SOCIETY</sub> PNW Chapter—Notes and News, Winter 2023













## We had a busy fall season hosting both

our fundraising celebration, "Sips, Smores, & Songs for Smiles", and the PNW FSHD 360 Research Day at the Boeing Museum of Flight. We were pleased to have several new people join in at both events. A plethora of information was shared at the FSHD 360 Day and I made a brief summary of the day's events which you can access here. I couldn't help but feel gratitude that our University of Washington, Wellstone Muscular Dystrophy Specialized Research Center, has been instrumental in expanding our knowledge of FSHD. It was a day of building connections and finding hope for the future. Thank you to the FSHD Society team for compelling the participation of so many local experts as well as bringing pharmaceutical representatives to the discussions.

Now, all of us are mostly focused on holiday celebrations with family. I want to thank each of you for being a part of our PNW FSHD family. Together, we have made great strides this year in keeping our community informed and helping you feel welcome and supported. As always, I encourage you to contact me with any questions and to get involved with activities of the FSHD Society that interest you. Wishing you a warm and wonderful holiday season!

## Stuff you should know about...

- Plans are formulating for our winter meeting in Portland! The date will be Feb. 10th and includes a Qi Gong session to build energy for the coming of spring and to celebrate Chinese New Year! Details on location and time will be shared in January. This meeting will be broadcast via ZOOM!
- A summary of the FSHD Society's Research conference in Milan 2023 is available for download only until January 6, 2024. Click here for download information.
- A nod to participating in support groups from a wise FSHDer - Benefits of Support Groups
- Educate yourself to reduce your risk of falls -An Ounce of Prevention...



## **FSHD Society**

Dec 11 - Wellness Hour - Chair dance party.

Dec 12 - FSHD Radio - Community Profiles

Dec 14 - Feeling Fit with FSHD - Shaking Qigong with Trish Kean

Dec 18 - Young Adults - Mindfulness with Jen Egert

Dec 19 - Early-Onset Parent Roundtable

Dec 21 – FSHD University – Annual Drug Development Update

Dec 26 - CarePartner Hour

Dec 28 - FSHD Radio: Hot Off the Press

Feb 5 - Friends of FSH Research Gala, Bellevue, WA

Feb 10 – PNW Chapter Meeting – Qi Gong for the New Year

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