



**2022
FSHD
CONNECT**

Orlando, Florida
June 18–19, 2022

We had a small but mighty group come out for our FSHD Connect viewing party at the Boeing Museum of Flight. It was a positive experience listening to the speakers together, looking up information that we could share in real time. We welcomed John and Ruth to our PNW family of FSHers. It was an inspiring day! We got a nice photo with our new World FSHD t-shirts.



Stuff you should know about...

- **True Cost of FSHD survey.** The “True Cost of FSHD” survey is the first of its kind in the United States. Its purpose is to learn about the “hidden” costs to patients with FSHD and their family members. This data will help inform how insurers and Medicaid will reimburse for future FSHD treatments. Use the link above to take the survey.
- Use the QR Code below to Register for our PNW Walk and Roll to Cure FSHD! Once again, we will be having the event at Town Square Park in Federal Way, WA. Please get your friends and family involved by becoming a TEAM CAPTAIN! Happy Hour Team Captain event is on July 21st.

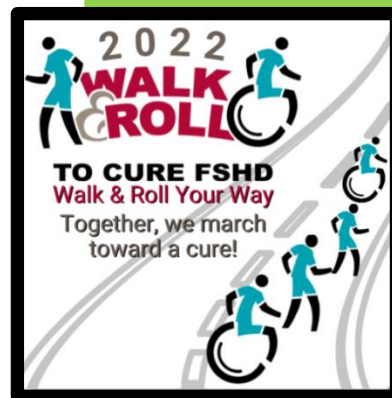
September 10, 2022

MARK YOUR CALENDAR!



FSHD Society

- [Early Onset FSHD Parent Roundtable](#), July 19
- [FSHD Walk & Roll Team Captain Happy Hour](#), July 21
- [CarePartner Hour](#), July 26, 5pm PT
- [FSHD Radio: Hot Off The Press](#), July 28, 6pm PT
- [Women on Wellness](#), August 3, 2pm PT
- [LINK to AUGUST CALENDAR](#)



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