

PNW Chapter—Notes and News, June 2022



Orlando, Florida June 18-19. 2022

We are so excited to announce our own Pacific Northwest FSHD viewing

party! It will be on June 18th from 9am to 3pm at the Boeing Museum of Flight. Please register for the event <u>HERE</u>. This free event includes your morning coffee/tea, lunch and admission to the Museum of Flight following our viewing event.

Calendar

FSHD Society Calendar

Wellness Hour. Ask Me Anything. June 13, 2pm PT

Early Onset FSHD Parent Roundtable. June 18

FSHD Connect Conference, June 18-19

PNW FSHD Connect Party, June 18, 9am-3pm PT

World FSHD Day, June 20

Sharegiver Hour. June 28, 5pm PT

LINK to FULL CALENDAR

Stuff you should know about...

- Learn more about the P.A.C.T. Initiative!
 P.A.C.T. stands for Patients Accelerating
 Clinical Trials. It is a collection of activities
 aimed at facilitating patient and family
 involvement that will increase our
 understanding of FSHD to accelerate
 progress.
- What YOU can do now to help? Learn about the P.A.C.T. Projects— <u>TestFSHD</u>, <u>MOVE and</u> <u>MOVE+</u>, <u>Health Economics Outcomes Research</u>, and the P.A.C.T. Patient Registry (info coming soon!).



Plans are coming together 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.

Save the Date! September 10, 2022

