



Notes from the Day – Follow along with photos at #SEAFSHD360 on Instagram

Warm-up exercises with Coach Alex Walker – Coach Alex and Chris Haven shared a short video on #SEAFSHD360 about their training and strengthening journey together. This was followed up with 15 minutes of warm up exercises that could be done either sitting or standing. There was excellent participation from all!

What is a 360? What is the CTRN? With June Kinoshita FSHD Society – June provided an overview of the Clinical Trial Research Network, which are centers of research excellence with the expertise to do clinical trials in FSHD and to validate new outcome measures.

Learn more <https://www.fshdsociety.org/therapeutic-accelerator/ctrn/>

FSHD 101 and overview of research at UW Leo Wang, MD PhD – Dr. Wang provided an overview of the mechanisms of FSHD and the body of research that is being worked on at the University of Washington. The Senator Paul Wellstone Muscular Dystrophy Specialized Research Center has received new funding for 2023 – 2028 through the National Institutes of Health MD Act.

Learn more <https://www.seattlemuscle.org/>

UW science mini-symposium Stephen Tapscott, MD PhD; Joel Chamberlain, PhD, & Dennis Shaw, MD –

Dr. Shaw shared the latest research being done in the area of Magnetic Resonance Imaging to track disease progression using AI analysis (with Springbok) and work to correlate findings with potential biomarkers for FSHD.

Dr. Tapscott discussed planning for a 6-month trial with the drug Clenbuterol and about the renewal of the Wellstone Grant from NIH for the next several years.

Joel Chamberlain, PhD introduced the research her lab is doing on biomarkers for FSHD to be used as an alternative to biopsies. Upcoming research will be testing targeted biomarkers in new animal models of FSHD, both mouse and pig.

Rehabilitation medicine for managing your symptoms Nassim Rad, MD, University of Washington – It takes a village to treat FSHD and Dr. Rad discussed the broad range of health care specialists that can be helpful in managing this complex disease.

Learn more <https://www.fshdsociety.org/living-with-fshd/finding-care/>

Physical therapy and exercise Cat Kieu, PT DPT, University of Washington – Ms Kieu is the PT that works with FSHD patients participating in clinical trials at UW. She provided an overview of how PTs help patients and guidelines for exercise. Some important points included stretches should be 30 seconds long, and that recovery from exercise should take no longer than 30 minutes to reduce

overexertion. She noted that generally patients wait to come see a PT when there is a problem and that early intervention from a PT may result in reduced falls/pain and improved mobility.

Clinical trial overview and trial readiness for FSHD Jamshid Arjomand, PhD, FSHD Society

- Jamshid Arjomand discussed the process of drug development, recent activity in FSHD treatment clinical trials, and how you can be prepared when opportunities for a clinical trial happen here in the PNW.

Learn more - [Hot Off the Press with Jamshid Arjomand](#)

Drug development Q&A panel Leo Wang, MD, Casey Childers, MD (Epic Bio), Amy Halseth (Avidity), Mihaela Levitchi Benea (Fulcrum)

- These three companies are either currently running clinical trials for FSHD (Fulcrum, Avidity) or starting soon (EpicBio).

Learn More [Fulcrum Therapeutics & Losmapimod](#), [Avidity & AOC-1020](#), [EpicBio & EPI-321](#)

How to enroll in current studies and trials Dani Dixon or Mike Willis, research coordinator,

University of Washington - These two are the gateway to your involvement in the natural history studies and clinical trials that are being conducted at UW.

For inquiries about FSHD Clinical Trials at UW - neustudy@uw.edu

Current Research Assistants - Mike Willis - mwillis5@uw.edu, Dani Dixon - daniedxn@uw.edu

Activating the community Anna Gilmore, Ashley Ferreira, Selina Lai - We looked at the national and local resources for education, advocacy and outreach at the FSHD Society. Patients can access multiple online resources through the [FSHD Society YouTube channel](#), monthly Zoom meetings as part of "the Gathering Place", and featured education programs of the FSHD University series. Patients can use the [calendar section of the FSHD Society](#) website to access these resources. Anna introduced a new program, the FSHD Navigator, being implemented to help patients find the answers they need.

Locally, we encourage our PNW Chapter members to provide both phone numbers and email addresses so that we can contact you to share upcoming events. We are planning our PNW Chapter winter meeting to be down in Portland, OR, date to be determined.

Also, the Friends of FSH Research will be holding their patient-focused program and fundraising auction on Feb. 3, 2024. For more information visit their website - <https://www.fshfriends.org/events/auction> or email Chris Haven - c2haven@hotmail.com.

The [PNW Chapter website](#) has past newsletters and some of our meeting recordings and handouts. Selina Lai, the chapter leader, can be reached at PNWChapter@FSHDSociety.org.