

Vancouver | June 1, 2025

Creekside Community Centre, 1 Athletes Way, Vancouver BC
Hosted by FSHD Canada Foundation and the FSHD Society

Preliminary Agenda

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| 9:00 – 10:00 am | Doors open. Check in, social time |
| 10:00 – 10:05 am | Welcome! A new era for the FSHD community
Neil Camarta, FSHD Canada Foundation
Beth Johnston, Chief Community Engagement Officer, FSHD Society, |
| 10:05 – 10:25 am | Multidisciplinary care for people with FSHD
Cameron Cunningham, MD, Univ. of British Columbia |
| 10:25 – 10:45 am | FSHD clinical research and clinical trials
Leo Wang, MD PhD, University of Washington Seattle |
| 10:45 – 11:05 | Canadian Neuromuscular Disease Registry
Lawrence Korngut, MD, University of Calgary |
| 11:05 – 11:20 | BetterLife FSHD comes to Canada
Kayleigh Worek, FSHD Society |
| 11:20 – 11:35 pm | The Tetra Society – how it can help you
Eric Molendyk |
| 11:35 – 11:50 pm | Break |
| 11:50 – 12:45 pm | Panel: Aha moments for navigating life with FSHD |
| 12:45 – 1:15 pm | Lunch |
| 1:15 – 2:15 pm | Gathering Place Breakouts
Small group conversations on wide-ranging topics |
| 2:15 – 2:45 pm | Drug development, clinical trials and treatment readiness
Lawrence Korngut, MD |
| 2:45 – 3:15 pm | Drug development strategy for FSHD
Eva Chin, PhD, Solve FSHD |
| 3:15 – 3:25 pm | Project Mercury in Canada, Neil Camarta, FSHD Canada Foundation |
| 3:25 – 3:35 pm | Activating the local community, Vancouver chapter |

Disclaimer: This is an educational conference. The inclusion of information about therapies and products does not imply an endorsement by the FSHD Society or by any participating research or medical institutions. Always consult your personal medical provider before trying out a novel treatment.