



EXTERNALLY LED PATIENT-FOCUSED DRUG DEVELOPMENT MEETING

OCTOBER 31 2023

AGENDA



AGENDA

TIME (EST):	SESSION & TITLE:	SPEAKER(S):
09:15 - 09:20	Welcome & Housekeeping	Lara Bloom
09:20 - 09:35	Introduction on hEDS and HSD	Dr. Clair Francomano
09:35 - 09:50	Welcome from FDA staff	Dr. Cynthia Rothblum-Oviatt
REFRESHMENT BREAK: 09:50 - 10:05		
SESSION 1: The Diagnostic Odyssey		
10:05 - 10:20	An introduction to the Diagnostic Odyssey	Dr. Colin Halverson
10:20 - 10:30	Diagnostic Odyssey - hEDS	Emily Rubenstein
10:30 - 10:40	Diagnostic Odyssey - pOTS	Cato Frederiks
10:40 - 10:50	Diagnostic Odyssey - MCAS	Danielle Vaccaro
10:50 - 11:00	Diagnostic Odyssey - Pain	Brianna Cardenas
11:00 - 12:00	Panel Q&A	
LUNCH: 12:00 - 13:00		
SESSION 2: Living with hEDS and HSD		
13:00 - 13:15	Introduction on Living with hEDS and HSD	Dr. Alan Hakim
13:15 - 13:25	Living with hEDS and HSD - PoTS	Francie Fitzgerald
13:25 - 13:32	Living with hEDS and HSD - MCAS	Courtney Rabb
13:32 - 13:42	Living with hEDS and HSD - Pain	Maggie Buckley
13:42 - 13:57	Living with hEDS Including GI Issues	Harry Radcliffe
13:57 - 14:10	Living with hEDS and HSD as a Caregiver and Parent	Dr. Ashley Denmark
14:10 - 15:10	Panel Q&A	
BREAK: 15:10 - 15:25		
SESSION 3: Treatments for EDS and HSD		
15:25 - 15:40	Introduction on Current Treatment Landscape	Dr. Anne Maitland
15:40 - 15:50	MCAS - Treatment possibilities through research	Scarlett Eagle
15:50 - 16:02	Treatment: Pain, An Integrated Approach	Dr. Cortney Gensemer
16:02 - 16:12	Treatment: GI	Dr. Isabelle Brock
16:12 - 16:22	Treatment: Adaptive Aids & Devices to Help with Symptoms	Mars Lombardi
16:22 - 17:22	Panel Q&A	
17:22 - 17:30	Summarise & Close	Lara Bloom & Clair Francomano