



Advisory Panel on Rare Disease Fall 2019 Meeting Agenda

September 16, 2019 | 9:00 – 4:00 PM ET

Dial-In: 1-877-309-2071 | Access Code: 506-392-048 (**muted**)

Time	Agenda Item	Discussion Leader
9:00 AM	Welcome and Setting the Stage	M. Cheung, C. Luxhoj
9:20 AM	Introduction of New RDAP Members	C. Luxhoj
9:30 AM	Recap of Previous Meetings	M. Cheung
9:50 AM	Experience with the Patient & Caregiver Journey: From Diagnosis to Treatment and Beyond	J. Gortze, C. Luxhoj
10:50 AM	BREAK (10 minutes)	
11:00 AM	PCORI's Rare Disease Portfolio Synthesis (Update)	G. Moscou-Jackson A. Ruesch
12:00 PM	LUNCH (60 minutes)	
1:00 PM	PCORnet Rapid Cycle Research Opportunities	M. Zirkle
2:10 PM	BREAK (10 minutes)	
2:20 PM	Spotlight: Panelist Work Outside the RDAP	M. Cheung, C. Luxhoj
3:10 PM	Future Planning for the RDAP	M. Cheung, C. Luxhoj
3:30 PM	Recognition of Departing Panel Members	C. Luxhoj
3:40 PM	Closing and Next Steps	M. Cheung, C. Luxhoj
4:00 PM	Adjourn	