



AGENDA

Advisory Panel on Rare Disease - Winter 2020 Meeting

December 16, 2020 | 2:00 – 5:00 PM EST | [Registration Link](#)

Time	Agenda Item	Presenters & Discussion Facilitators
2:00 PM	Welcome, Introductions, and Setting the Stage (30 minutes)	Scott Berns, Doug Lindsay
2:30 PM	Introduction of RDAP PCORI members, RDAP Program Staff Update, Upcoming Activities (10 minutes)	Carly Khan, Nora McGhee
2:40 PM	Engagement Awards and Rare Disease Organizations: Supporting Engagement in PCOR/CER (45 minutes)	Karen Martin, Scott Berns
3:25 PM	BREAK (10 minutes)	
3:35 PM	Maternal Mortality and Intellectual Disabilities: Overview and Discussion of Issues Related to Rare Diseases (40 minutes)	Els Houtsmuller, Kelly Dunham, Scott Berns
4:15 PM	BREAK (5 minutes)	

4:20 PM	Identifying our National Priorities: Relevance for Rare Disease Populations (30 minutes)	Laura Lyman Rodriguez, Jean Slutsky, Doug Lindsay
4:50 PM	Acknowledgments and Recap	Scott Berns, Doug Lindsay
5:00 PM	Adjourn	