



## Advisory Panel on Rare Disease Winter 2021

### Day 1 Meeting Agenda

December 13, 2021 | 1:00 – 5:00 PM ET

TIME	AGENDA ITEM	PRESENTERS
1:00 PM 30 minutes	<b>Welcome, Introductions, and Setting the Stage</b>	Mat Edick, Doug Lindsay
1:30 PM 10 minutes	<b>Introduction of RDAP PCORI staff &amp; RDAP Program Staff Update</b>	Carly Khan
1:40 PM 45 minutes	<b>RDAP Speakers: Experience with the Patient and Caregiver Journey from Diagnosis to Treatment and Beyond</b>	Sarah Bacon, Danielle Boyce, Doug Lindsay
2:25 PM 60 minutes	<b>Discussion: PCORI-funded Rare Disease Portfolio Update</b>	Nora McGhee, Carly Khan, Rohini Mohanraj, Doug Lindsay
3:25 PM	<b>BREAK (20 minutes)</b>	
3:45 PM 30 minutes	<b>Strategic Planning: Proposed Research Agenda</b>	Marina Broitman, Mat Edick
4:15 PM 30 minutes	<b>Round Robin Brainstorming Session</b>	Mat Edick
4:45 PM 15 minutes	<b>Acknowledgments and Recap</b>	Mat Edick, Doug Lindsay
5:00 PM	<b>Adjourn</b>	



## Advisory Panel on Rare Disease Winter 2021

### Day 2 Meeting Agenda

December 14, 2021 | 1:00 – 3:00 PM ET

TIME	AGENDA ITEM	PRESENTERS
<b>1:00 PM</b> 5 minutes	<b>Welcome and Setting the Stage</b>	Mat Edick, Doug Lindsay
<b>1:05 PM</b> 50 minutes	<b>Monitoring Evidence in Rare Diseases: Health Care Horizon Scanning</b>	Gowri Raman, Doug Lindsay
<b>1:55 PM</b>	<b>BREAK (10 minutes)</b>	
<b>2:05 PM</b> 45 minutes	<b>Critical Issues in the Rare Disease Community</b>	Mat Edick
<b>2:50 PM</b> 10 minutes	<b>Acknowledgments and Recap</b>	Mat Edick, Doug Lindsay
<b>3:00 PM</b>	<b>Adjourn</b>	