



Advisory Panel on Rare Disease Spring 2022 Virtual Meeting

May 18, 2022

12:30 PM – 5:00 PM ET

TIME	AGENDA ITEM	PRESENTERS & DISCUSSION FACILITATORS
12:30 PM 20 minutes	Welcome, Introductions, and Setting the Stage	<u>Facilitators:</u> Mat Edick, Doug Lindsay
12:50 PM 10 minutes	RDAP Program Staff Updates, Upcoming Activities	<u>Presenters:</u> Fatou Ceesay, Meghan Berman, Nora McGhee
1:00 PM 30 minutes	Update from the Intellectual and Developmental Disabilities workgroup	<u>Presenter:</u> Carly Khan <u>Facilitator:</u> Doug Lindsay
1:30 PM 30 minutes	Uptake of Rare Disease Study Results	<u>Presenter:</u> Heather Edwards <u>Facilitator:</u> Mat Edick
2:00 PM	BREAK (15 MINUTES)	
2:15 PM 45 minutes	Building Capacity for Cross-Cutting Rare Disease Research	<u>Presenter:</u> Mat Edick <u>Facilitator:</u> Doug Lindsay
3:00 PM 45 minutes	Healthcare Cost and Value – Addressing the Full Range of Outcomes	<u>Presenters:</u> Greg Martin, Kristen Giombi <u>Facilitator:</u> Mat Edick
3:45 pm	BREAK (15 minutes)	
4:00 PM 30 minutes	Update on Strategic Planning: PCORI's Strategic Plan	<u>Presenter:</u> Laura Lyman Rodriguez <u>Facilitator:</u> Doug Lindsay
4:30 PM 15 minutes	Acknowledgments and Recap	<u>Facilitators:</u> Mat Edick, Doug Lindsay
4:45 PM 15 minutes	Farewell to Departing Members	<u>Facilitator:</u> Mat Edick
5:00 PM	Adjourn	