



## Advisory Panel on Rare Disease Spring 2021 Meeting Agenda

May 14, 2021 | 1:00 – 5:00 PM ET

TIME	AGENDA ITEM	PRESENTERS
<b>1:00 PM</b> 10 minutes	<b>Welcome, Introductions, and Setting the Stage</b>	Scott Berns, Doug Lindsay
<b>1:10 PM</b> 5 minutes	<b>Introduction of RDAP PCORI staff, RDAP Program Staff Update, Upcoming Activities</b>	Carly Khan, Nora McGhee
<b>1:15 PM</b> 55 minutes	<b>Rare Disease Research Awards: Study Highlights and Discussion</b>	Penny Mohr, Jason Gerson
	Project Title: <a href="#">Comparative Effectiveness of Palliative Surgery vs. Additional Anti-seizure medications for Lennox-Gastaut Syndrome</a> (1:25 - 1:30 pm)	Anne Berg, Sandi Lam, Tracy Dixon-Salazar
	Project Title: <a href="#">Preserving Kidney Function in Children with Chronic Kidney Disease (PRESERVE)</a> (1:30 - 1:35 pm)	Michelle Denburg, Aneta Jovanovska, Rebecca Levondosky
	Project Title: <a href="#">Utilizing PCORnet to Support Transition from Pediatric to Adult Centered Care and Reduce Gaps in Recommended Care in Patients with Congenital Heart Disease</a> (1:35 – 1:40 pm)	Tom Carton, Anitha John, Scott Leezer
	Project Title: <a href="#">Comparative Effectiveness Research for Neuroendocrine Tumors (CER-NET)</a> (1:40 – 1:45 pm)	Michael O’Rourke, Josh Mailman
	Project Title: <a href="#">Development of methods to improve identification of patients with rare or complex diseases</a> (1:45-1:50 pm)	Daniel Herman, Jinbo Chen
	Discussion (1:50 – 2:10 pm)	
<b>2:10 PM</b> 15 minutes	<b>BREAK</b>	
<b>2:25 PM</b> 45 minutes	<b>Engagement Awards and Rare Disease Organizations: An Update and Project Highlights</b>	Karen Martin Jennifer Canvasser

<b>3:10 PM</b> 30 minutes	<b>Identifying our National Priorities: Relevance for Rare Disease Populations</b>	Laura Lyman Rodriguez
<b>3:40 PM</b> 15 minutes	<b>An Update on the Cost-Data Provision</b>	Andrew Hu
<b>3:55 PM</b> 15 minutes	<b>BREAK</b>	
<b>4:10 PM</b> 30 minutes	<b>COVID Connect: PCORI's Response to the COVID-19 Pandemic</b>	Claudia Grossmann
<b>4:40 PM</b> 10 minutes	<b>Acknowledgments and Recap</b>	Scott Berns, Doug Lindsay
<b>4:50 PM</b> 10 minutes	<b>Farewell to Departing Members</b>	Doug Lindsay
<b>5:00 PM</b>	<b>Adjourn</b>	