



Agenda

**Advisory Panel on
Rare Disease
In-Person Meeting**

April 26th, 2017

PCORI Offices

9:00 AM	Welcome and Setting the Stage Matt Cheung, PhD, RPh, Chair
	Vincent Del Gaizo, Co-Chair
9:30 AM	Engagement Webinar and Updates Lia Hotchkiss, MPH Director, <i>Eugene Washington PCORI Engagement Award Program</i>
	Jacqueline Gannon National Urban Fellow, <i>Engagement</i>
10:00 AM	Guidance for Merit Reviewers Danielle Whicher, PhD, MHS Program Officer, <i>Clinical Effectiveness and Decision Science</i>
10:30 AM	Break
10:45 AM	Rare Disease Methodology Paper Update Danielle Whicher, PhD, MHS Program Officer, <i>Clinical Effectiveness and Decision Science</i>
	Naomi Aronson, PhD Executive Director, <i>Clinical Evaluation, Innovation and Policy</i> , <i>Blue Cross and Blue Shield Association</i>
11:00 AM	Core Outcome Sets for Rare Diseases Danielle Whicher, PhD, MHS Program Officer, <i>Clinical Effectiveness and Decision Science</i>
12:00 PM	Lunch
12:45 PM	NCATS Rare Disease Activities Rashmi Gopal-Srivastava, M.Sc, PhD Director, <i>Extramural Research Program, Office of Rare Disease Research</i> <i>NIH/NCATS</i>
	Anne Pariser, MD Deputy Director, <i>Office of Rare Disease Research</i> <i>NIH/NCATS</i>
1:30 PM	Leveraging PCORnet Claudia Grossmann, PhD Program Officer, <i>Research Infrastructure</i>
	Maryan Zirkle, MD, MS, MA Program Officer, <i>Research Infrastructure</i>
2:15 PM	Break

2:30 PM	Other Areas of Interest
	Parag Aggarwal, PhD
	Senior Program Officer, <i>Healthcare Delivery and Disparities Research</i>
3:30 PM	Recognition of Panelists Rolling Off
	Vincent Del Gaizo, Co-Chair
3:45 PM	Wrap Up and Next Steps
	Matt Cheung, PhD, RPh, Chair
4:00 PM	Adjourn