



Agenda

Advisory Panel on Rare Disease In-Person Meeting

October 27th, 2016

PCORI
1919 M St. NW
Washington, DC 20036

9:00 AM	Welcome and Setting the Stage Vincent Del Gaizo, Acting Chair Danielle Whicher, PhD, MHS Program Officer, <i>Clinical Effectiveness Research</i> Parag Aggarwal, PhD Senior Program Officer, <i>Addressing Disparities</i>
9:15 AM	Rare Disease Advisory Panel: Where We Have Been and Where We Are Going Danielle Whicher, PhD, MHS Program Officer, <i>Clinical Effectiveness Research</i> Parag Aggarwal, PhD Senior Program Officer, <i>Addressing Disparities</i> Evelyn Whitlock, MD, MPH Chief Science Officer
10:00 AM	Overview of PCORI Rare Disease Research Portfolio Heather Edwards, PhD, MPH, MBA Program Officer, <i>Evaluation and Analysis</i>
11:00 AM	Break
11:15 AM	Eugene Washington Engagement Awards, Pipeline to Proposal Awards and Presentation of Results Lia Hotchkiss, MPH Director, <i>Eugene Washington PCORI Engagement Award Program</i> Eleanor Perfetto, PhD, MS Professor, <i>Pharmaceutical Health Services Research, School of Pharmacy, University of Maryland</i> , and Senior Vice President, <i>Strategic Initiatives, National Health</i>
12:15 PM	COI Forms/Lunch Jayne Jordan, Special Assistant to the General Counsel
1:00 PM	PCORnet Patient Powered Research Networks Sharon Terry, MA President and CEO, <i>Genetic Alliance</i> Co-PI of the PCORnet Coordinating Center, PI of a PPRN
1:45 PM	FDA on Rare Disease Gayatri Rao, MD, JD Director for the Office of Orphan Products Development, <i>FDA</i>
2:30 PM	Rare Disease Methodology Paper

Danielle Whicher, PhD, MHS
Program Officer, *Clinical Effectiveness Research*

Naomi Aronson, PhD
Executive Director, *Clinical Evaluation, Innovation and Policy, Blue Cross and Blue Shield Association*

3:00 PM Recognition of Panelists Rolling Off

Vincent Del Gaizo, Acting Chair

3:30 PM Wrap Up and Next Steps

3:45 PM Adjourn