



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, *Eugene Washington PCORI Engagement Award Program*

Jacqueline Gannon
National Urban Fellow, *Engagement*
- 10:00 AM Guidance for Merit Reviewers**
Danielle Whicher, PhD, MHS
Program Officer, *Clinical Effectiveness and Decision Science*
- 10:30 AM Break**
- 10:45 AM Rare Disease Methodology Paper Update**
Danielle Whicher, PhD, MHS
Program Officer, *Clinical Effectiveness and Decision Science*

Naomi Aronson, PhD
Executive Director, *Clinical Evaluation, Innovation and Policy, Blue Cross and Blue Shield Association*
- 11:00 AM Core Outcome Sets for Rare Diseases**
Danielle Whicher, PhD, MHS
Program Officer, *Clinical Effectiveness and Decision Science*
- 12:00 PM Lunch**
- 12:45 PM NCATS Rare Disease Activities**
Rashmi Gopal-Srivastava, M.Sc, PhD
Director, *Extramural Research Program, Office of Rare Disease Research NIH/NCATS*

Anne Pariser, MD
Deputy Director, *Office of Rare Disease Research NIH/NCATS*
- 1:30 PM Leveraging PCORnet**
Claudia Grossmann, PhD
Program Officer, *Research Infrastructure*

Maryan Zirkle, MD, MS, MA
Program Officer, *Research Infrastructure*
- 2:15 PM Break**

2:30 PM Other Areas of Interest

Parag Aggarwal, PhD

Senior Program Officer, *Healthcare Delivery and Disparities Research*

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