



## Agenda

### Advisory Panel on Rare Disease

### Summer 2014 Webinar

August 13, 2014  
2:00 PM – 5:00 PM

### Webinar

## Wednesday, August 13, 2014

- 2:00 PM Welcome**  
Bryan Luce, PhD, MBA, Chief Science Officer, PCORI
- 2:05 PM Update on Leadership Meetings**  
Marshall L. Summar, MD, Chair, Advisory Panel on Rare Disease, PCORI  
Vincent Del Gaizo, Co-Chair, Advisory Panel on Rare Disease, PCORI
- 2:20 PM Registry Projects Updates**  
PCORnet: Sarita Wahba, MSPH, MS, Program Officer, CER Methods and Infrastructure, PCORI  
NORD: J. Russell Teagarden, DMH, MA, Advisory Panel on Rare Disease, PCORI  
GRDR: Yaffa R. Rubinstein, MS, PhD, Advisory Panel on Rare Disease, PCORI
- 2:35 PM PCORI's Topic Generation and Research Prioritization Process**  
Bryan Luce, PhD, MBA, Chief Science Officer, PCORI  
Kara Odom Walker, MD, MPH, MSHS, Deputy Chief Science Officer, PCORI
- 2:50 PM PCORI's Merit Review Process**  
Tsahai Tafari, PhD, Senior Program Officer, Merit Review, PCORI
- 3:20 PM Rare Disease Submitted Topics**  
Greg Martin, Deputy Director of Stakeholder Engagement, PCORI
- 3:30 PM Cross-Cutting Rare Disease Issues**  
Naomi Aronson, PhD, Methodology Committee, PCORI
- 3:40 PM CER Topics**  
David Hickam, MD, Program Director, Clinical Effectiveness Research, PCORI
- 3:55 PM Outreach and Other Solutions**  
Greg Martin, Deputy Director of Stakeholder Engagement, PCORI
- 4:50 PM Recap and Next Steps**  
Marshall L. Summar, MD, Chair, Advisory Panel on Rare Disease, PCORI  
Vincent Del Gaizo, Co-Chair, Advisory Panel on Rare Disease, PCORI  
Bryan Luce, PhD, MBA, Chief Science Officer, PCORI
- 5:00 PM Adjourn**