



Subject to change

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