



Agenda

Advisory Panel on Rare Disease Spring 2015 Meeting

May 27, 2015

Wednesday, May, 27, 2015

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| 8:30 AM | Welcome and Plans for the Day
Bryan Luce, PhD, MBA, Chief Science Officer, PCORI
Marshall L. Summar, MD, Chair, Advisory Panel on Rare Disease, PCORI
Vincent Del Gaizo, Co-Chair, Advisory Panel on Rare Disease, PCORI |
| 8:45 AM | Rare Disease Research Standards Landscape Review
Dr. Nedra Whitehead, PhD, Task Leader, RTI International, Division of
Statistics and Epidemiology |
| 10:15 PM | Break |
| 10:30 AM | PCORI's <u>DRAFT</u> Guidance on PCOR for Rare Diseases
Ayodola Anise, MHS, Program Officer, PCORI
Danielle Whicher, PhD, MHS, Program Officer, PCORI |
| 11:30 AM | Pipeline to Proposal Awards
Courtney Clyatt, MA, MPH, Senior Program Associate, Engagement,
PCORI |
| 12:00 PM | Lunch |
| 1:00 PM | CTAP Subcommittee on Recruitment, Accrual, and Retention
Margo Michaels, MPH, Founder, Education Network to Advance Cancer
Clinical Trials
Advisory Panel on Clinical Trials, Member |
| 2:00 PM | Follow Up Analysis of Letters of Intent (LOIs) on Rare
Diseases: Spring 2015 Cycle
Laura Forsythe, PhD, MPH, Senior Program Officer, PCORI
Vadim Y. Gershteyn, MPH, Program Associate, PCORI
Lauren Fayish, MPH, Program Associate, PCORI |
| 2:30 PM | Exploring the Eugene Washington PCORI Engagement
Award Program
Lia Hotchkiss, MPH, Director, Eugene Washington Engagement Awards
Program, PCORI |
| 3:00 PM | Break |
| 3:15 PM | Potential Uses for Chatter
Emma Djabali, Program Associate, Office of the Chief Science Officer,
PCORI |

3:30 PM

Recap and Next Steps

Bryan Luce, PhD, MBA, Chief Science Officer, PCORI

Marshall L. Summar, MD, Chair, Advisory Panel on Rare Disease, PCORI

Vincent Del Gaizo, Co-Chair, Advisory Panel on Rare Disease, PCORI

3:45 PM

Adjourn