



Agenda

**Advisory Panel on
Rare Disease
In-Person Meeting**

**June 6th, 2018
PCORI Offices
1919 M St NW
2nd floor
Washington, DC**

Wednesday, June 6th, 2018

9:00 AM Welcome and Setting the Stage

Matt Cheung, PhD, RPh, Chair

Vincent Del Gaizo, Co-Chair

9:20 AM Recap of Last Meeting

Matt Cheung, PhD, RPh, Chair

9:30 AM Dissemination and Implementation: Updates, Challenges, and Opportunities

Joanna Siegel, SM ScD

Director, *Dissemination and Implementation*

10:30 AM Break

10:45 AM PCORI Case Study: Collaborative Assessment of Pediatric Transverse Myelitis

Benjamin Morris Greenberg, MD, MS

University of Texas Southwestern Medical Center/Dallas

11:45 PM Lunch

12:45 PM Update on NORD

Pam Gavin, MBA

Chief Strategy Officer, NORD

**1:30 PM Healthier Together: Networks of Patients, Clinicians, and Researchers to
Transform Chronic Illness Care**

Peter A. Margolis, MD, PhD

Co-Director, James M. Anderson Center for Health Systems Excellence

2:30 PM Break

2:45 PM UPDATE: PCORI Rare Disease Topic Page and Resources

Bill Silberg, PCORI Director of Communications

Marla Bolotsky, PCORI Associate Director of Digital Media

Santosh Rao, PCORI Web Editorial Specialist

3:00 PM Rare Disease Advisory Panel Planning Discussion

Matt Cheung, PhD, RPh, Chair

3:30 PM Closing and Next Steps

Matt Cheung, PhD, RPh, Chair

Vincent Del Gaizo, Co-Chair

4:00 PM Adjourn