



## Agenda

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

June 6<sup>th</sup>, 2018  
PCORI Offices  
1919 M St NW  
2<sup>nd</sup> floor  
Washington, DC

Wednesday, June 6<sup>th</sup>, 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**