Rare Disease Legislative Advocates in coordination with Rare Disease Congressional Caucus Co-Chairs
Representative Leonard Lance (R-NJ), Representative Joe Crowley (D-NY),
Senator Orrin Hatch (R-UT), and Senator Amy Klobuchar (D-MN) welcome you to:

The Rare Disease Ecosystem: Fostering Patient Engagement & Driving Biomedical Innovation

Congressional Co-Chair Statements - 12:00pm – 12:30pm:
Representative Leonard Lance (R-NJ)
Representative Joe Crowley (D-NY)
Senator Orrin Hatch (R-UT)
Senator Amy Klobuchar (D-MN)

Lunch Briefing: 12:30pm – 1:30pm
Moderator: Julie Anne Smith, CEO, Raptor Pharmaceuticals
- Janet Woodcock, M.D., Director, Center for Drug Evaluation (CDER), at the Food and Drug Administration (FDA) – “The Role of the FDA and CDER in the Drug Development Process”
- Emil Kakkis, M.D. PhD, President, EveryLife Foundation for Rare Diseases & CEO, Ultragenyx Inc. – “Developing Medicines for Rare & Ultra Rare Diseases”
- Rakesh Marwah, M.D., Investment Professional, Palo Alto Investors, Clinical Faculty, Stanford University – “Incentives Driving Biomedical Investment & Innovation”
- David Fajgenbaum, M.D., M.B.A., M.Sc., Executive Director, Castleman Disease Collaborative Network, Assistant Professor of Medicine & Associate Director, Orphan Disease Center, University of Pennsylvania – “Patient/Physician/Researcher Perspective: Driving Research & Innovation for Castleman Disease”
- Brett Felter, J.D., Assistant Attorney General, Maryland Office of the Attorney General & Becker Muscular Dystrophy Patient – “Patient Perspective: How Policy Impacts Development of Rare Disease Therapies”

(Boxed Lunches will be available after the briefing in compliance with CVC rules)