



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)

