




**Monday, July 20, 2015**

Stanley Bergen Building, Rutgers University, Newark, NJ  
65 Bergen Street Building number: 7252, 3rd Floor Auditorium

- 10:30 AM Registration
- 11:30 AM **Rare New Jersey Welcome**  
**Moderator:** Michael Illions, Vice President & Director of Advocacy, Pediatric Hydrocephalus Foundation, Inc.
- 11:35 AM **Keynote Address:** Representative Frank Pallone, Ranking Member of the Energy & Commerce Committee
- 12:00 PM Lunch – Sponsored by 
- 1:00 PM **Rutgers University Welcome**  
Gwen Mahon, Dean School of Health Related Professions
- 1:15 PM **Panel: 21<sup>st</sup> Century Cures Act & the Impact on the Rare Disease Community**  
**Moderator:** Dean J. Paranicas, President and Chief Executive Officer, HealthCare Institute of New Jersey (HINJ)
- Lisa Schill, Parent Advocate, RASopathies Network USA
  - Jayne Gershkowitz, Senior Vice President, Patient and Professional Advocacy and Public Policy, Amicus Therapeutics
  - Vivien M. Hsu, MD, Associate Professor of Medicine, Robert Wood Johnson Medical Group, Rutgers
- 2:30 PM **Panel: How to Be An Effective Advocate**  
**Moderator:** Debbie Hart, MS, CAE, APR, President and Chief Executive Officer, BioNJ
- Andy Russell, Associate Director of Advocacy & Government Relations, EveryLife Foundation for Rare Diseases
  - Dina Matos, Patient Advocate, CARES Foundation
  - Molly McDonnell, Health Legislative Assistant, Office of Representative Leonard Lance

IN-DISTRICT RARE DISEASE LEGISLATIVE ADVOCATES' LOBBY DAYS NORTH-EAST CONFERENCE

- 3:15 PM Practice your Pitch – Breakout to Practice Meeting with Members of Congress
- 3:45 PM Recap of the Day, Q&A  
Moderator: Michael Illions, Vice President & Director of Advocacy, Pediatric Hydrocephalus Foundation, Inc
- 4:00 PM Keynote: Representative Leonard Lance, Co-Chair of the Rare Disease Congressional Caucus
- 4:30 – 6:00 PM Networking Cocktail Reception

Co-hosted by:



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