8:30 - 9:00am **Registration and Breakfast**

9:00 - 9:15am **Welcome and Overview**

9:15 - 10:00am **What to Expect from the New Congress and Administration**
- How the New Congress and Administration will impact Rare Disease Policy
- Importance of Congressional Committees

10:00 - 10:45am **Top Health Policy Issues for 2017**
- Prescription Drug User Fee Act (PDUFA) Reauthorization
- Affordable Care Act (ACA)
- State Children’s Health Insurance Program (SCHIP) Reauthorization

10:45 - 11:00am **Break**

11:00 - 11:45pm **Rare Disease Legislation in the Queue**
- Appropriations: Funding for the National Institutes of Health (NIH) and Food and Drug Administration (FDA)
- Orphan Product Extensions Now, Accelerating Cures and Treatments (OPEN ACT)
- Rebuilding and Expanding the Rare Disease Congressional Caucus

11:45 - 12:45pm **Meet and Greet Lunch, Packet Pick Up**

12:45 - 1:45pm **Tricks of the Trade: Preparing for a Successful Meeting**
- Become an Empowered Advocate: Find Your Advocacy Level
- How to Make the Most Impact: 21st Century Cures Example
- Being an Effective Advocate
- Congressional Scorecards, Hill Asks and Leave Behinds

1:45 - 2:00 pm **Scenes from the Hill: Your License to Advocate**
2:00 - 2:30pm Continue the Progress Long After the Meeting: Ways to Stay Engaged
  • Follow Up, Do Not Drop Out: Best Practices for Staying in Touch
  • Social Media to Build Momentum

2:30 - 3:15pm How to Engage with Federal Agencies

3:15 - 3:30pm Snack Break to Move to Breakout Session*

3:30 - 4:15pm Breakout Session 1: Refine Your Skills for Successful Meetings on the Hill

  Breakout Session 2: Rare Diseases Issues State by State
  • Newborn Screening
  • Creating a State Rare Disease Caucus
  • Rare Action Network

  Breakout Session 3: Understanding the Clinical Drug Development Process

  Breakout Session 4: Advocacy for Young Adults

4:15 - 4:30pm Regroup in Academy Hall

4:30 - 5:00pm Closing Remarks
  • Logistics for Lobby Day
  • Final Q&A

*Sponsored by Vertex Pharmaceuticals