



## 2015 Legislative Conference & Lobby Day

Presented by **abbvie**

FHI 360, 1825 Connecticut Avenue Northwest #2, Washington DC

Tuesday, February 24, 2015

### Agenda

- 8:15 - 9:00 am      *Breakfast & Registration (45 Minutes)*
- 9:00 - 9:15 am      **Welcome - Overview of the Week (15 Minutes)**  
Conference Moderator: Dean Suhr
- 9:15 - 10:45 am      **Overview of the 114<sup>th</sup> Congress (30 minutes)**  
Key committees & Government 101 Joanne Kenen, Health Care Editor, Politico  
Key Members of Congress, Nick Mannelto, Principal, FaegreBD Consulting  
Q&A 5- minutes
- 10:45 - 11:15 am      **Know Your Lobbying Rights (30 minutes)**  
1976 Lobby Law & the 2002 Law/Court Case  
Education/Advocacy vs Lobbying – Siobhan Rausch, Partner, Hogan Lovells  
Different ways to take action (action alert blog)  
Q&A – 5 minutes
- 11:15 - 12:15 pm      **Avenues for Impact (60 minutes)**  
**Appropriations** (20) Katie Schubert, Vice President, Coalition for Health  
Funding & CRD Associates  
**Legislation** (15) Cheryl Jaeger, Principal, Williams & Jensen  
**Regulatory** (20) Joel White, Founder & President, Horizon Government Affairs  
Q&A – 5 minutes
- 12:15 pm              *Lunch Break (30 Minutes)*
- 12:45 – 1:45 pm      **21<sup>st</sup> Century Cures Initiative (60 Minutes)**

21 Century Cures - 15 minutes - Carly McWilliams, E&C Committee  
OPEN ACT – 10 - Tom Power, Office of Rep. Bilirakis (invited)  
CURES ACT (Expanded Access) – 10 - Andy Taylor, Office of Rep. McCaul  
Dormant Therapies – 10 – Eric Gascho, Assistant Vice President for Government  
Affairs, National Health Council  
Advancing Research for Neurological Diseases Act – Jennifer Sheridan Palute,  
Policy Director, Parkinson’s Action Network

1:45 – 2:15 pm      **Overview of Lobby Day Schedules - Advocacy Associates (30 Minutes)**

2:15 – 2:45 pm      *Break (20 Minutes)*  
*(trouble shooting with Advocacy Associates)*

2:45 – 3:05 pm      **Prepping for your Meeting (30 minutes) – Andy Russell**  
Giving your two minute personal story (10 minutes) – patient advocate  
Gene Ribbons (5 minutes) – Global Genes  
RDLA Speaker– Overview of the packets (10 minutes)

- Rare Disease Congressional Caucus
- Rare Disease Congressional Report Cards
- Hand Delivering Patient Stories for advocate
- Breakout sessions – Planning your asks with your team
- Q&A 5 minutes

3:05 – 3:55 pm      **Break-Out Skill Training Workshops – 3 additional rooms (50 minutes)**

Starting your own Non-profit – Carrie Ostrea, Global Genes Project (invited)

- Tips and tools for getting your rare disease organization to the next level. Learn about obtaining 501c3 status, creating a mission, vision, and a board of directors. Essential skills for any aspiring organization.

Polish & Practice your Presentation Pitch – Joe LaMontain, Vice President, Reingold Inc.

- Learn about persuasive and effective communication for maximum advocacy impact.

Introducing Legislation – Julia Jenkins, Executive Director, EveryLife Foundation

- Hear about the do’s and don’ts for introducing legislation, coalition building, and how to move a bill through the legislative process.

Social Media Advocacy – Joel Cohen, Non-Profits, Politics & Advocacy,  
Facebook

- Learn some insider tips for leveraging social media to raise awareness and build an action network for your cause.

4:05 - 4:55 pm

**State/Regional Break-Out Sessions Practice Meetings (50 minutes)**

CA, TX, West, North, South & East

10 minutes to switch break out rooms

5:00 pm

**Closing Remarks**

**5:15 pm**

**End Conference**