



## 2015 Legislative Conference & Lobby Day

Presented by **abbvie**

FHI 360, 1825 Connecticut Avenue Northwest, Washington DC

Tuesday, February 24, 2015

### Agenda

- 8:15 - 9:00 am *Breakfast & Registration*
- 9:00 - 9:15 am **Welcome - Overview of the Week**  
Conference Moderator: Dean Suhr
- 9:15 - 10:45 am **Overview of the 114<sup>th</sup> Congress**  
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**  
1976 Lobby Law & the 2002 Law/Court Case  
Education/Advocacy vs Lobbying – Siobhan Rausch, Partner, Hogan Lovells  
Different ways to take action  
Q&A – 5 minutes
- 11:15 - 12:15 pm **Avenues for Impact**  
**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*
- 12:45 – 1:45 pm **21<sup>st</sup> Century Cures Initiative**

21 Century Cures - Carly McWilliams, E&C Committee  
OPEN ACT – Saul Hernandez, Office of Rep. Butterfield (invited)  
CURES ACT (Expanded Access) –Andy Taylor, Office of Rep. McCaul  
Dormant Therapies – 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**

Stephanie Vance, Owner & Founder, Advocacy Associates

2:15 – 2:45 pm

***Break (20 Minutes)***

***(trouble shooting with Advocacy Associates)***

2:45 – 3:05 pm

**Prepping for your Meeting**

Giving your two minute personal story – Kristine PJ Caalim, Zeqing For a Cure  
Gene Ribbons – Carrie Ostrea, Global Genes

Overview of the packets – Andy Russell, RDLA

- 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**

**Starting your own Non-profit** – Carrie Ostrea, Director of Advocacy, & Barbara  
Lavery, Vice President of Strategic Alliances, Global Genes Project

Lisa Schill, Vice President, RASopathies Network USA, Mike Illions, Vice  
President, Pediatric Hydrocephalus Organization

- 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. Get tips for making a lasting impression and laying the  
groundwork to build a first-time meeting into a lasting relationship.

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**

- Practice makes perfect! You'll be grouped by region to practice for the upcoming Hill meetings by running through your pitch and legislative "asks."

CA, TX, West, North, South & East

10 minutes to switch break out rooms

5:00 pm

**Closing Remarks**

5:15 pm

**End Conference**