



2017 Legislative Conference Agenda

February 28th, 2017

FHI 360 – 1825 Connecticut Ave NW, 8th Floor, Washington, DC 20009

Presented by



8:30 - 9:00am Registration and Breakfast

9:00 - 9:05am Welcome: Robert Ostrea, Co-Founder, Little Miss Hannah Foundation

9:05 – 9:15am Overview of the EveryLife Foundation for Rare Diseases: Stephanie Fischer, Senior Director of Patient Engagement and Communications

9:15 - 10:00am What to Expect from the New Congress and Administration

- How the New Congress and Administration Will Impact Rare Disease Policy
 - Democratic Perspective: Saul Hernandez, Deputy Chief of Staff, Office of Rep. G.K. Butterfield (D – NC)
 - Republican Perspective: Stuart Portman, Senior Healthcare Legislative Assistant, Office of U.S. Senator Orrin Hatch (R – UT)
- Importance of Congressional Committees: Nick Manetto, Principal, Faegre Baker Daniels Consulting

10:00 - 10:45am Top Health Policy Issues in 2017

Moderator: Marilyn Vetter, Vice President of Government and Public Affairs, Horizon Pharma

- Prescription Drug User Fee Act (PDUFA) Reauthorization: Sara Radcliffe, President and CEO, California Life Sciences Association
- Affordable Care Act (ACA)
 - Democratic Perspective: Wendell Primus, Senior Policy Advisor on Budget and Health, Office of Minority Leader Nancy Pelosi (D – CA)
 - Republican Perspective: Cheryl Jaeger, Principal, Williams & Jensen
- Keeping Medicaid and Children's Health Insurance Program Strong for Children: James Baumberger, Associate Director of the Department of Federal Affairs, American Academy of Pediatrics

10:45 - 11:00am Break

11:00 - 11:45am Rare Disease Legislation in the Queue

- Appropriations: Funding for the National Institutes of Health (NIH) and Food and Drug Administration (FDA): Sara Chang, Director of Policy and Advocacy, Research!America
- Healthcare Reform: Paul Melmeyer, Associate Director of Public Policy, National Organization for Rare Disorders
- Orphan Product Extensions Now, Accelerating Cures and Treatments (OPEN ACT): Max Bronstein, Chief Advocacy and Science Policy Officer, EveryLife Foundation for Rare Diseases
- Rebuilding and Expanding the Rare Disease Congressional Caucus: Cristina Might, Executive Director, NGLY1.org

11:45am - 12:30pm Meet and Greet Lunch

Sponsored by the Biotechnology Innovation Organization (BIO)

12:30 - 1:45pm Tricks of the Trade: Preparing for a Successful Meeting

- Becoming an Empowered Advocate - How to Make the Most Impact: Lisa Schill, Vice President, RASopathies Network USA
- Congressional Scorecards, Hill Asks and Leave Behinds: Vignesh Ganapathy, Associate Director of Advocacy and Government Relations, EveryLife Foundation for Rare Diseases
- Being an Effective Advocate: Christopher Kush, CEO and Author, Soapbox Consulting

1:45 - 2:00pm Scenes from the Hill: Your License to Advocate

Member of Congress: Jennifer Bernstein, Executive Vice President, Horizon Government Affairs
Legislative Aide: Molly McDonnell, Principal, Winning Strategies Washington
Advocate 1: Dean Suhr, Co-Founder and President, MLD Foundation
Advocate 2: Pam Mace, Executive Director, Fibromuscular Dysplasia Society of America
Advocate 3: Marc Yale, Executive Director, International Pemphigus and Pemphigoid Foundation

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 and Social Media to Build Momentum: Emily Eckland, Digital and Social Media Communications Manager, Eli Lilly & Company

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

- Centers for Disease Control and Prevention: Annie Kennedy, Senior Vice President for Legislation and Public Policy, Parent Project Muscular Dystrophy
- NIH: Charles Mohan, Jr., CEO and Executive Director, The United Mitochondrial Disease Foundation
- FDA: Ryan Hohman, Vice President of Public Affairs, Friends of Cancer Research

3:15 - 3:30pm Snack Break to Move to Breakout Sessions

Sponsored by Vertex

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

- Communications: Chris Smith, President and CEO, SmithSolve
- Policy: Joel White, Founder and President, Horizon Government Affairs
 - *How do you tell your story and cohesively tie-in your "ask" when meeting with a Member of Congress? In this session, refine your elevator pitch, fine-tune your legislative talking points and get your policy questions answered.*

Breakout Session 2: Rare Diseases Issues State by State (Academy Hall)

- Newborn Screening: Julia Jenkins, Executive Director, EveryLife Foundation for Rare Diseases
- Creating a State Rare Disease Caucus: Craig Lincoln Tucker, Vice President of Policy and Public Affairs, Life Sciences Pennsylvania
- Advocating for Rare Patient Access in Medicaid: Sue Landgraf, Executive Director, Cystic Fibrosis Research, Inc.
 - *There is so much legislative work you can do in your own backyard! Learn how the newborn screening state-by-state system can be improved, how to advocate for the creation of a rare disease caucus in your home state, and why experts should be involved in the Medicaid decision-making process.*

Breakout Session 3: Understanding the Clinical Drug Development Process (Angle Room)

Jeffrey Sherman, MD, FACP, Chief Medical Officer and Executive Vice President of Research and Development, Horizon Pharma

- *Do you have questions about the drug development process? Learn the steps of the process from bench to bedside.*

Breakout Session 4: Advocacy for Young Adults (Balcony D)

- Shira Strongin, Founder, Sick Chicks
- Emily Muller, Founder, Emily's Fight
 - *Are you a young adult new to advocacy? Hear from your peers about different ways you can get involved and how you can get your voice heard. Parents of pre-teens and teenagers are welcome to attend.*

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

4:30 - 5:00pm Closing Remarks

- Logistics for Lobby Day
- Final Q&A

Family Room sponsored by Dohmen Life Sciences (Balcony E)