2018 Legislative Conference Agenda
February 26th, 2018

Ronald Reagan Building and International Trade Center
Atrium Ballroom
1300 Pennsylvania Ave NW, Washington, DC 20004

8:00 – 8:30am **Registration and Breakfast**
(Atrium Ballroom)

8:30 – 9:15am **Welcome: Mark Dant, Board Chair, EveryLife Foundation for Rare Diseases**
(Atrium Ballroom and via Livestream)
We are pleased introduce you to the EveryLife Foundation's new Board Chair, Mark Dant. Mark is a parent advocate and serves as Executive Director for the Ryan Foundation for MPS Kids. Mark will share his incredible story of partnering with academia and industry to save his son Ryan and will provide an overview of the EveryLife Foundation's mission to advance the development of treatment and diagnostic opportunities for rare disease patients through public policy.

9:15 – 9:45am **Back to Basics: HIV/AIDS Advocacy as a Model for Catalyzing Change**
(Atrium Ballroom and via Livestream)
Michael Manganiello, Partner, HCM Strategists
Ronnie Tepp, Principal, HCM Strategists
Hear from Michael and Ronnie, born advocates who believe in the power of the patient to impact major changes in health policy – a power that is amplified when groups unite around a common agenda. Learn the strategies of the HIV/AIDS movement that turned a death sentence into a manageable disease and see how we can apply that to the rare disease community.

9:45 – 10:45am **2018 Legislative Asks**
(Atrium Ballroom and via Livestream)
Moderator – Chris Porter, Vice President of Government Affairs and Policy, Retrophin
We encourage advocates to have one specific ask for their meetings with Members of Congress. This panel highlights some potential asks that are priorities for the rare disease patient community:

- ***Orphan Products Extension Now, Accelerating Cures and Treatments (OPEN ACT)*** **H.R.1223/S.1509**
  Lauren Fleming Paulos, Healthcare Legislative Assistant, Senator Orrin Hatch (R-UT)

95% of rare disease have no FDA approved treatments. Learn about how the OPEN ACT, bipartisan legislation supported by more than 270 patient organizations, could double the number of treatments available to rare disease patients by repurposing already approved drugs for rare diseases. If you or a loved one is on an off-label treatment, this legislation will be important to you.

- ***Advancing Access to Precision Medicine Act H.R.5062***
  Lizzy Fox, Legislative Assistant, Congressman Eric Swalwell (D-CA)
  On average, it takes 7 years for a rare disease patient to receive a diagnosis. Learn about how this new legislation will provide coverage for genetic sequencing for patients to shorten the diagnostic odyssey.
- ***The Rare Disease Congressional Caucus***
  Jordan Grossman, Deputy Legislative Director, Senator Amy Klobuchar (D-MN)
  Learn how you can help grow this bipartisan and bicameral Caucus to ensure that the rare disease community has a permanent voice on Capitol Hill.

10:45 – 11:00am **Break**

11:00 – 11:45am **Breakout Sessions**

Track A: Deep Dive Policy: Drug Regulation & the Orphan Drug Act
(Atrium Ballroom & via Livestream)
Paul Melmeyer, Director of Federal Policy, National Organization for Rare Disorders
Cartier Esham, Executive Vice President for Emerging Companies, Biotechnology Innovation Organization
Amy Comstock Rick, JD, President and Chief Executive Officer of the Food and Drug Law Institute
Learn about the legislation and regulations that affect drug development and approval. Experts will take a deep dive into the incentives in the Orphan Drug Act and will discuss the critical balance that policy plays in fostering innovation and providing affordable access to treatments.

Track B: Lobbying 101: Mock Meeting*
(Hemisphere A)
Jennifer Bernstein, Executive Vice President, Horizon Government Affairs
Cheryl Jaeger, Principal, Williams & Jensen
Ronald Bartek, Co-founder and President, Friedreich's Ataxia Research and Alliance
Darlene Shelton, Founder, Danny's Dose Alliance
Jennifer Van Houtan, Co-founder, Noah's Hope Foundation
This is a must-attend session for those new to advocacy.** Hear from professional lobbyists about how legislation is actually passed and how you can be successful in your meetings. Seasoned advocates will present some dos and don'ts in a mock Congressional meeting skit. This is a great opportunity to get your questions answered by experienced rare disease advocates.*

Track C: Advocacy for Young Adults: Your Voice Matters
(Hemisphere B)
Moderator – Lindsey Cundiff, Associate Director of Patient Engagement, EveryLife Foundation for Rare Diseases
Emily Shetty, Consultant, Stanton Park Group

Taylor Kayne, Lead Advocate, Run for ALD
Oakey Daskas, Patient Advocate for Cystic Fibrosis
Shira Strongin, Founder, Sick Chicks
First, learn a little bit about how our government works. Then, meet and hear from some rare disease young adults who have been making a mark on Capitol Hill by telling their stories.

11:45am – 12:00pm **Regroup in Atrium Ballroom**

12:00 – 1:00pm **Networking Lunch**
(Atrium Ballroom)
Grab some food, join your state, and read your fortune! Take some time to get to know your rare disease community.

1:00 – 2:15pm **Preparing for Successful Meetings***
(Atrium Ballroom & via Livestream)
Megan Holdren, Senior Manager, Congressional Relations, Soapbox Consulting
**Mandatory for advocates participating in Lobby Day (family room will be closed at this time). Receive your Lobby Day schedules and strategize with your teams to make the most of your meetings on Capitol Hill.*

Breakout Session: Partnering with Patient Organizations: Best Practices and Lessons Learned
(Hemisphere A)
Moderator – Kristina Broadbelt, Director of Patient Advocacy, Horizon Pharma
Susan Stein, MPH, Founder, Connexion Healthcare
Mary Bordoni, Director, Alliance Development, Biotechnology Innovation Organization
Eric Gascho, Vice President of Policy and Government Affairs, National Health Council
Melissa Hogan, J.D., Founder and President, Project Alive
For those not attending Lobby Day, we invite you to join us for a lively panel and discussion on how industry can work with patients and patient advocacy organizations to create successful and meaningful partnerships.

2:15 – 2:45pm **Snack Break**

2:45 – 3:30pm **Breakout Sessions**

Track A: Deep Dive Policy: Intro to Medicaid & Medicare Policy
(Atrium Ballroom & via Livestream)
Morna Murray, J.D., Senior Vice President for Health and Disabilities, First Focus
Mike Eging, Executive Director, Rare Access Project
Learn about how Medicaid and Medicare impact rare disease patients and how effective advocacy shapes policy and legislation such as the Children's Health Insurance Program (CHIP) and healthcare reform.

Track B: Lobbing 101: Practice Your Pitch
(Hemisphere A)
Chris Smith, President and Chief Executive Officer, SmithSolve
Joel White, Founder and President, Horizon Government Affairs

For new advocates who are looking for some extra practice before your Hill meetings, this session is for you. Learn how to tell your story and cohesively tie in your "ask". Refine your elevator pitch and fine-tune your legislative talking points. Gain confidence before your meetings on the Hill.

Track C: Advocacy for Young Adults: Practice Meetings with Congressional Staff
(Hemisphere B)
Moderator – Lindsey Cundiff, Associate Director of Patient Engagement, EveryLife Foundation for Rare Diseases
Rebecca Card, Press Secretary, Representative Susan Brooks (R-IN)
Saul Hernandez, Deputy Chief of Staff, Representative G.K. Butterfield (D-NC)
Taylor Hittle, Legislative Director, Representative Markwayne Mullin (R-OK)
Shayne Woods, Legislative Assistant, Representative Gus Bilirakis (R-FL)
Young adults can practice telling their stories to Congressional staffers. Attendees can get some tips and tricks for successful meetings on the Hill from those who know best.

3:30 – 3:45pm **Break**

3:45 – 4:30pm **Breakout Sessions**

Track A: Political Hot Topics: Right to Try – Is it a Solution?
(Atrium Ballroom & via Livestream)
Moderator – David Farber, FDA Life Sciences Partner, King & Spalding
Michael Becker, Biotech Entrepreneur, Author and Patient Expert
Starlee Coleman, Senior Policy Advisor, Goldwater Institute
Richard Klein, Former FDA Patient Liaison Director
Laura McLinn, Founding President, Best Day Ever Foundation
38 states across the country have passed "Right to Try" legislation, and now the federal government is considering following their lead. Hear from experts about the pros and cons of this legislation. Will this legislation bring lifesaving treatments to patients? Does it provide false hope? Does it pose potential risks? What can be done to bring experimental treatments to patients before it's too late?

Track B: Political Hot Topics: States' Rights to Medical Marijuana
(Hemisphere B)
Anneliese Clark, Parent Advocate for Medical Cannabis
Even though some states have legalized medical marijuana, federal medical marijuana regulations put access to these medications at risk. Learn more about the advocacy efforts taking shape to protect patient access to these therapies.

4:30 – 4:45pm **Closing Remarks**

The Family Room (Continental C) will be available for families all day except from 1:00 – 2:15pm when families are required to attend the "Preparing for Successful Meetings" session. We also encourage families to eat in the Atrium Ballroom with their state teams.