

Rare Disease Week on Capitol Hill 2020
Legislative Conference Agenda
Wednesday, February 26th, 2020

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

- 8:00 – 8:45 am Registration and Breakfast (Atrium)
- 8:45 – 9:30 am **Welcome:** Brent Fisk, Director of Federal Government Affairs and Policy, Horizon
Shannon von Felden, Director of Rare Disease Legislative Advocates, EveryLife Foundation for Rare Diseases
Keynote: Mark Dant, Chair, Board of Directors, EveryLife Foundation for Rare Diseases
(Atrium Hall and via Livestream)
- 9:30 am – 4:45 pm **Fast Forward for Rare Video Suite** (closed 1:15—2:15 pm)
(Atrium Ballroom Coat Room)
- 9:30 – 10:00 am **Health Policy Forecast**
(Atrium Hall and via Livestream)
Healthcare continues to be one of the most challenging issues for Americans. Hear from former Congressional staffers about how Congress will impact healthcare policy in 2020, and how you can help shape these trends.
- Introduction: Cathy Jackson, RN, BSN, MPH, Director of Advocacy Relations, Mallinckrodt Pharmaceuticals
 - Moderator: Cheryl Jaeger, Principal, Williams and Jensen
 - Remy Brim, Ph. D., Vice President, BGR Government Relations
 - Mary-Sumpter Lapinski, Vice President, Global Government Affairs, Greenwich Biosciences
- 10:00 – 11:00 am **2020 Legislative Asks**
(Atrium Hall and via Livestream)
We encourage advocates to make one specific “ask” during their meetings with Members of Congress. This panel highlights some potential “asks” that are priorities for the rare disease patient community.
- Moderator: Nicholas Manetto, Principal, Faegre Drinker Consulting
 - Shayne Woods, Senior Policy Advisor, Office of Representative Gus Bilirakis
 - Dylan Simon, Newborn Screening Fellow, EveryLife Foundation for Rare Diseases
 - Wen-Hann Tan, BMBS, Assistant Professor of Pediatrics, Harvard Medical School

- Caitlin Van Sant, Senior Policy Advisor, G.K. Butterfield
- Ryan Fischer, Senior Vice President of Community Engagement, Parent Project Muscular Dystrophy
- Kylie Barber, Medical Foods Policy Fellow, National PKU Alliance

11:00 – 11:15 am **Break**

11:15 am – 12:00 pm **Breakout Sessions**

Track 1: Deep Dive Policy – Accelerating Treatments for Rare Diseases

(Atrium Hall and via Livestream)

Learn how a Rare Disease Center of Excellence within the FDA would elevate rare disease expertise within the agency and help to remove communication barriers across centers and divisions to accelerate and improve rare disease therapy development.

- Moderator: Annie Kennedy, Chief of Policy and Advocacy, EveryLife Foundation for Rare Diseases
- Steve Silvestri, Director of Public Policy, EveryLife Foundation for Rare Diseases
- Larry Bauer, Senior Regulatory Drug Expert, Hyman, Phelps, & McNamara
- Lisa Carlton, Ph.D., Director of Regulatory Affairs, REGENXBIO
- Nicholas Manetto, Principal, Faegre Drinker Consulting

Track 2: How to Engage in State Advocacy

(Atrium Ballroom A)

This session is designed for advocates who want to become more involved in rare disease advocacy in their state and build opportunities at the state level.

- Moderator: Julia Jenkins, Executive Director, EveryLife Foundation for Rare Diseases
- Angela Ramirez Holmes, Founder and President, CAL RARE
- Swapna Kakani, Founder and Director, Alabama Rare
- Khrystal Davis, Founder, Texas Rare Alliance
- Nikia Vaughan, Cimone and Friends
- Melissa Bowie, Senior Director, State Government Affairs, Takeda

Track 3: Lobbying 101 - Mock Meeting*

(Atrium Ballroom B)

**This is a must-attend session for those individuals who are new to advocacy.*

Hear from professional lobbyists about how legislation is passed and how to be most impactful in Congressional meetings. Seasoned advocates will present some dos and don'ts in a mock Congressional meeting skit. This is a great opportunity to get questions answered by experienced rare disease advocates.

- Jennifer Bernstein, Vice President, Horizon Government Affairs
- Ryan Fischer, Senior Vice President of Community Engagement, Parent Project Muscular Dystrophy
- Tabatha Mitchell, Emes Army
- Monica Weldon, Bridge the Gap—Syngap

12:05 pm

Group Photo

(Atrium Stairs)

12:30 – 1:15 pm

Networking Lunch

(Atrium)

We encourage families to eat in the Atrium with their state team.

1:15 – 2:15 pm

Preparing for Successful Meetings*

(Atrium Hall & via Livestream)

**Mandatory for advocates participating in Hill Day (family room will be closed at this time).* Advocates receive their Hill Day schedules and strategize with their teams to make the most of their meetings on Capitol Hill.

- Mike Gula, Co-Founder, Prime Advocacy
- Shannon von Felden, Director of Rare Disease Legislative Advocates, EveryLife Foundation for Rare Diseases

NYU Grossman School of Medicine Working Group on Pediatric Gene Therapy and Medical Ethics (PGTME) Industry Listening Session Breakout

(Atrium Ballroom A)

2:15 – 2:45 pm

Snack Break

(Atrium)

2:45 – 4:30 pm

Medical Nutrition Equity Act Breakout Session

(Continental C)

This breakout session is for those supporting the Medical Nutrition Equity Act.

2:45 – 3:30 pm

Breakout Sessions

Track 1: Deep Dive Policy – Improving Access to Treatments for Rare Diseases

(Atrium Hall & via Livestream)

As more and more treatments for rare diseases are moving into regulatory review at the FDA, there is an increasing need to ensure that patient-centered data is used to inform decision-making in the payer environment. This session will explore opportunities for innovation and outcomes-based data collection-across stakeholders- to inform decision making and facilitate favorable access environments for rare disease patients.

- Introduction: James Wu, M.Sc., MPH, Principal Health Economist, Global Health Economics, Amgen
- Moderator: Jennifer Bernstein, Vice President, Horizon Government Affairs
- Ryan Fischer, Senior Vice President of Community Engagement, Parent Project Muscular Dystrophy
- Dr. Sean Tunis, MD, MSc., Principal, Rubix Health and Senior Advisor, FDA
- Vicki Seyfert-Margolis, PhD, Founder & CEO MyOwnMed

Track 2: Advocacy for Young Adults: Young Adult Representatives of RDLA (YARR)

(Atrium Ballroom A)

This session is for young adults ages 16 – 30 years old. In this session young advocates will learn how to make a difference on Capitol Hill and how to have an effective meeting with their Member of Congress.

- Allison Herrity, YARR Representative
- Dan Pezzetta, YARR Representative

Track 3: Lobbying 101 - Practice Your Pitch

(Atrium Ballroom B)

This session is for new advocates who are looking for some extra practice before their Hill meetings. Advocates will learn how to tell their story, cohesively tie in their “ask”, refine their elevator pitch and fine-tune their legislative talking points.

- Chris Smith, President and Chief Executive Officer, SmithSolve
- Joel White, Founder and President, Horizon Government Affairs

3:30 – 3:45 pm

Break
(Atrium)

3:45 – 4:30 pm

Breakout Sessions

Track 1: Deep Dive Policy—How Federal Funding Supports Rare Disease Patients

(Atrium Hall & via Livestream)

This session will explore the appropriations process, how Congress decides to fund programs, and the different programs of importance to the rare disease community.

- Moderator: Steve Silvestri, Director of Public Policy, EveryLife Foundation for Rare Diseases
- Mark Vieth, Senior Vice President, CRD Associates
- Eric Gascho, Vice President, Policy and Government Affairs, National Health Council

- Wen-Hann Tan, BMBS, Assistant Professor of Pediatrics, Harvard Medical School

Track 2: Advocacy for Young Adults - Practice Meetings with Congressional Staff

(Atrium Ballroom A)

This session is for young adults (ages 16-30) to practice telling their stories and asks to Congressional staffers. Attendees will learn tips and tricks for successful meetings on the Hill from seasoned advocates.

- Moderator: Stefanos Koutsoukos, YARR Representative
- Juan Gomez, Legislative Aide, Office of Senator Corey Booker (NJ)
- Katherine Sears, Communications Director, Office of Rep. David Joyce (OH)
- Shannon von Felden, RDLA Program Director, EveryLife Foundation for Rare Diseases

Track 3: Hot Legislative Topics

(Atrium Ballroom B)

Learn about hot legislative topics on Capitol Hill from Hill staffers and advocates and how you can help move the needle on these issues.

- Moderator: Ritu Baral, Managing Director, Senior Biotechnology Analyst, Cowen and Company
- Adeola Adesina, Legislative Assistant, Office of Representative Eric Swalwell
- Dylan Simon, Newborn Screening Fellow, EveryLife Foundation for Rare Diseases
- Luke Hatzis, Principal, Capitol Counsel
- Jennifer Dexter, Director of Policy, National Health Council
- Annie Kennedy, Chief of Policy and Advocacy, EveryLife Foundation for Rare Diseases

4:30 – 4:45 pm

Closing Remarks

Notes: This is a draft agenda and is subject to change. The Family Room (Atrium Gallery) 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 with their state teams.