



2019 Legislative Conference Agenda

Monday, February 25th, 2019

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

8:00 – 8:45am

Registration and Breakfast

(Atrium)

8:45 – 9:30am

Welcome: Darlene Shelton, Founder, Danny's Dose Alliance

(Atrium Hall and via Livestream)

Meet Darlene Shelton, a grandparent advocate. Darlene serves as Founder and President for Danny's Dose Alliance. Darlene will share her incredible story of how she took legislative action to ensure the protection of her grandson, after he was diagnosed with severe Hemophilia B. Darlene will also 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.

9:30 – 10:00am

The New Congress: Health Policy Forecast

(Atrium Hall and via Livestream)

Healthcare continues to be one of the most challenging issues for Americans. Hear from Congressional and Administration staffers about how the new Congress will impact healthcare policy in 2019, and how you can help shape these trends.

10:00 – 11:00am

2019 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 including: newborn screening reauthorization, increased funding for the National Institutes of Health and the Food and Drug Administration, and the importance of joining the rare disease caucus.

11:00 – 11:15am

Break

11:15 – 12:00pm

Breakout Sessions

Track A: Deep Dive Policy - Newborn Screening (NBS) Reauthorization

(Atrium Hall and via Livestream)

Newborn Screening (NBS) helps identify babies who have certain serious medical conditions, so they may receive proper treatment. NBS programs in the U.S. have been successful, preventing thousands of premature illnesses and deaths. Learn about the current NBS federal legislation and how you can help to reauthorize this critical legislation to make sure every child has a chance at a healthy life. *Sponsored by Biogen.*

Track B: Introducing Your Own Legislation

(Atrium Ballroom A)

This session is designed for advocates who have an idea for legislation, but don't know where to start. Learn from a former congressional staffer as well as seasoned advocates about how to identify the problem and work with Congress to create a law that provides a meaningful solution.

Track C: 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.

12:00 – 12:30pm

Group Photo

(Atrium Stairs)

12:30 – 1:15pm

Networking Lunch

(Atrium)

Advocates enjoy good food, meet fellow advocates, and open their icebreaker fortunes!

1:15 – 2:15pm

Preparing for Successful Meetings*

(Atrium Hall & via Livestream)

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

Breakout Session: Building Effective Partnerships, A Case Study

(Atrium Ballroom A)

Those not attending Lobby Day are invited to this deep dive case study on developing a meaningful partnership with patient advocacy groups, industry, and the Food and Drug Administration (FDA). Hear from the Amyotrophic Lateral Sclerosis (ALS) Association and representatives from ALS patient community about how they worked with the FDA and industry stakeholders to develop a community patient survey (ALS PREFER), as well as ALS draft guidance.

2:15 – 2:45pm

Snack Break

2:45 – 3:30pm

Breakout Sessions

Track A: Deep Dive Policy - NIH/FDA Appropriations

(Atrium Hall & via Livestream)

Investment in rare disease research conducted by the National Institutes of Health (NIH) ultimately provides better treatments for patients. Investment into the U.S. Food and Drug Administration (FDA), which serves as the gateway for many rare disease products entering the market, is equally important to facilitate patient access to treatments. Learn how to support consistent and robust funding for both agencies, which will bring more life saving treatments to the 30 million Americans living with one of more than 7,000 known rare diseases.

Track B: 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.

Track C: 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.

3:30 – 3:45pm

Break

3:45 – 4:30pm

Breakout Sessions

Track A: Making the Case for a Rare Disease Burden Study

(Atrium Hall & via Livestream)

Scientific evidence is critical to addressing public health issues, because ill-informed policy-making can result in failed strategies and programs. One way to gather evidence about rare diseases is to conduct a burden study. Burden studies determine the impact of a health problem as measured by financial cost, mortality, morbidity, or other indicators. In this session, advocates will learn how a burden study could help the rare disease community by predicting future needs and setting priorities to address these needs. *Sponsored by Mallinckrodt Pharmaceuticals.*

Track B: 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.

Track C: Access to Treatment of Rare Diseases – A Spotlight on Rare Cancer

(Atrium Ballroom B)

There are many challenges of rare diseases such as late or incorrect diagnosis, lack of access to appropriate therapies, limited number of clinical trials, and lack of interest in developing new therapies, to name a few. In this session, healthcare advocates will examine the challenges of access and value as it pertains to cancer care. Participants will gain an understanding of how to make better decisions about the management of rare disease. *Sponsored by Amgen.*

4:30 – 4:45pm

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.

2019 Legislative Conference Presented by

