

Rare Disease Week on Capitol Hill 2026

Legislative Conference Agenda

Wednesday, February 25, 2026

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

8:00 – 9:00 am

Registration and Breakfast (Atrium)

9:00 – 9:45 am

Welcome:

- Duane Clark, Sanofi
- Paloma Juarez, Rare Disease Week Advocacy Chair
- Annie Kennedy, EveryLife Foundation for Rare Diseases

RareVoice Lifetime Achievement Award Presentation

- Presented by Michael Pearlmuter, EveryLife Foundation for Rare Diseases

Logistics Overview: Shannon von Felden, EveryLife Foundation for Rare Diseases

9:45 – 10:15 am

Legislative Outlook

Hear from experts on the 119th Congress and how Congress will impact healthcare policy in 2026.

- Moderator: Jamie Sullivan, EveryLife Foundation for Rare Diseases
- Caitlin Van Sant, Mehlman Consulting
- Nick Manetto, Faegre Drinker
- Shayne Woods, Alpine Group
- Jenn Bernstein, Monument Advocacy

10:15 – 10:35 am

Break

10:35 am – 11:25 am

Deep Dive Policy Ask #1: Rare Disease Innovation Hub Infrastructure Appropriations Request

- Moderator: Kimberly Quaintance-Lunn, Alexion
- Eric Gascho, CRD Associates
- Amy Rick, FDA Rare Disease Innovation Hub

11:25 am—12:15 pm

Deep Dive Policy Ask #2: Support Congressional Action to Ensure Today's Patients Will Benefit from Robust Rare Disease Treatment Pipelines

- Moderator: Annie Kennedy, EveryLife Foundation for Rare Diseases
- James Valentine, Hyman Phelps & McNamara
- Ryan Fischer, Foundation for Angelman Syndrome Therapeutics
- Emily Milligan, Barth Syndrome Foundation

12:15—12:25 pm	Group Photo (Atrium Stairs)
12:35 – 1:35 pm	Networking Lunch (Atrium)
1:35—2:05 pm	Deep Dive Policy Ask #3: Credit for Caring Act • Moderator: Sky Collins, Oklahoma Rare • Sarah Skirmont, Office of Representative Linda Sanchez • Rhonda Richards, AARP • Wayne Galasek, HDSA Illinois Chapter
2:05—2:35 pm	Deep Dive Policy Ask #4: Genomic Answers for Children’s Health Act • Moderator: Dylan Simon, EveryLife Foundation for Rare Diseases • Victoria Gemme, Leavitt Partners • Leigh Ann Fairley, Office of Representative Bilirakis • Tatiana Lopez, RDLA Advisory Committee
2:35—2:55 pm	<u>Snack Break</u>
2:55 – 4:25 pm	Preparing for Successful Meetings* <u>*Mandatory for advocates participating in Hill Day (family room will be closed at this time).</u> Advocates receive information on their Hill meetings and strategize with their teams to make the most of their meetings on Capitol Hill. • Kendly Jones, EveryLife Foundation for Rare Diseases
4:25 – 4:50 pm	Question and Answer Panel • EveryLife Foundation for Rare Diseases Team
4:50 – 5:00 pm	Closing Remarks

**Sessions and speakers are subject to change.*