

Rare Disease Week on Capitol Hill 2026

Share Your Story Day Agenda

Tuesday, February 24, 2026

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

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| 1:00-2:00pm | Early Registration |
| 2:00-2:15pm | Welcome <ul style="list-style-type: none">• Lisa Langenderfer, Alexion• Amy Gaviglio, Board Chair, EveryLife Foundation for Rare Diseases |
| 2:15-3:00pm | RareVoice Success Panel <ul style="list-style-type: none">• Introductions: Deena Andreola, Takeda• Moderator: Sarah Lloyd Stevenson, Board Member, EveryLife Foundation for Rare Diseases• Emily Brubaker, 2025 RareVoice Awardee• Andrea Faris representing the legacy of Tiffany House, 2025 RareVoice Awardee• Mary McGowan representing the Foundation for Sarcoidosis Research, 2025 RareVoice Awardee• Jenifer Waldrop representing the Rare Disease Diversity Coalition, 2025 RareVoice Awardee |
| 3:00-3:40pm | Rare Artist: Arts & Health Panel <ul style="list-style-type: none">• Introductions: Stephanie Riordan, EveryLife Foundation for Rare Diseases• Live performance: Sophie Seaver, 2025 Awardee• Moderator: Lisa Simms Booth, Smith Center for Healing and Arts• Wes Burian, 2022 Awardee• DaNice Marshall, 2025 Awardee• Krista Webb, 2025 Awardee• Nell Choi, 2022 & 2024 Awardee |
| 3:50-4:20pm | <u>Track 1:</u>
The Intersection of Identity & Advocacy: A Pride in Rare Conversation
<i>Atrium Hall</i> <ul style="list-style-type: none">• Hannah Yale, YARR• Abbey Hauser, EveryLife Foundation for Rare Diseases |

Track 2:

Advocacy For Young Adults

Ballroom A

- Moderator: Laura Romano, EveryLife Foundation for Rare Diseases
- Carol Shea Linton, YARR
- Molly Maywood, YARR
- Sarina Smith, YARR

Track 3:

New Advocates: Welcome to Rare Disease Week

Ballroom B

- Shannon von Felden, EveryLife Foundation for Rare Diseases

4:30-5:00pm

Track 1:

Share Your Story 201: Connecting Data and Your Story

Atrium Hall

- Annie Kennedy, EveryLife Foundation for Rare Diseases
- Jamie Sullivan, EveryLife Foundation for Rare Diseases
- Baillie McGowan, EveryLife Foundation for Rare Diseases

Track 2:

Advocacy for Youth & Teens

Ballroom A

- Kendly Jones, EveryLife Foundation for Rare Diseases
- Shandra Trantham, Board Member, EveryLife Foundation for Rare Diseases

Track 3:

Share Your Story 101 for New and Developing Advocates

Ballroom B

- Stephanie Riordan, EveryLife Foundation for Rare Diseases
- RDLA Advisory Committee coaches:
 - Marlene Riero
 - Michelle O'Dell
 - Mike Lane
 - Misha Mehta

5:00-6:00pm

Welcome Reception

Atrium

5:45-6:30pm

Community Meetups

- Young Adult Rare Representatives
Ballroom B
- RDLA Advisory Committee
Atrium Hall
- Community Scholarships
Ballroom A