RARE DISEASE WEEK ON CAPITOL HILL

Presented by

ALEXION®
AstraZeneca Rare Disease

RDLA
Rare Disease Legislative Advocates
POWERED BY THE EVERYLIFE FOUNDATION

FEBRUARY 24-26
2026

#RAREDC2026 @RAREADVOCATES

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AstraZeneca Rare Disease

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Welcome

Welcome to the EveryLife Foundation's 15th Annual Rare Disease Week on Capitol Hill 2026!

We are honored to gather once again with advocates from across the country — patients, caregivers, clinicians, researchers, and partners — united this week to ensure that the voices of the rare disease community continue to shape public policy and drive meaningful change. Whether you are joining us for the first time or a seasoned advocate, we are thrilled you're here.

Rare Disease Week is more than a conference or fly-in. Rare Disease Week reflects the power of collective advocacy. Each story shared, each meeting held, and each voice raised on Capitol Hill reinforces an essential truth: progress for rare diseases happens when our community shows up, speaks out, and works together. Over the past year, your advocacy has helped advance several important milestones. Most recently we celebrated the reauthorization of the Rare Pediatric Disease Priority Review Voucher (PRV) Program. After a two-year campaign by our rare disease community to reauthorize the PRV Program, your relentless advocacy paid off. Congress passed the Labor, HHS, and Related Agencies Appropriations bill, effectively reauthorizing the PRV Program for five years while also funding a number of other critical healthcare agencies.

Other accomplishments include continued progress in newborn screening. We saw Virginia become aligned with the Recommended Uniform Screening Panel (RUSP), meaning that more than 52% of all babies born in the US will be screened for more than 35 conditions. And we reached a long-awaited turning point with the evidence review that led to the addition of metachromatic leukodystrophy (MLD) and Duchenne muscular dystrophy (Duchenne) to the RUSP. This achievement represents years of persistence and collaboration, and it underscores what is possible when data, policy, and patient voices come together. We also took important steps forward with the launch of the EveryLife Foundation's Newborn Screening Roadmap, helping to chart a clearer, more predictable path from federal recommendation to state implementation.

This year also marked the launch of two initiatives that speak directly to long-standing gaps in access and equity: our Rural Health Initiative and the Rare Access Program. While both efforts are still in their early stages, they represent a critical commitment to reaching individuals and families who too often face additional barriers to diagnosis, care, and treatment simply because of where they live. As part of this work, we began what is shaping up to be the most comprehensive analysis to date of rare disease ICD codes. The codes are an essential foundation for improving data, visibility, and ultimately access across the health care system.

But these accomplishments are not endpoints. They are building blocks, made possible by your engagement and sustained by your continued advocacy. As we look ahead to a week with new programming and additional opportunities to connect with your fellow advocates, remember that Rare Disease Week is also an opportunity to strengthen relationships with policymakers, welcome new champions, and reinforce the urgent need for policies that support timely diagnosis, access to care, and innovation for all rare disease patients.

Thank you for being here, for lending your voice, and for the leadership you bring to this community. We wish you a productive and impactful week in Washington, D.C., and I look forward to the progress we will continue to achieve together.

Michael Pearlmutter
Chief Executive Officer
EveryLife Foundation for Rare Diseases

EVERYLIFE FOUNDATION FOR RARE DISEASES

EveryLife Foundation for Rare Diseases
Board of Directors

The EveryLife Foundation Board of Directors is comprised of a diverse group of individuals who are both personally and professionally dedicated to improving the lives of the 30 million Americans living with a rare disease. With decades of experience in the government, nonprofit, finance, science, medicine, industry, and academic sectors, EveryLife board members provide valuable guidance to the Foundation toward achieving its mission. Several of our board members are the parents of children with a rare disease or rare disease patients themselves, enabling them to offer firsthand knowledge of the challenges facing the rare disease community.

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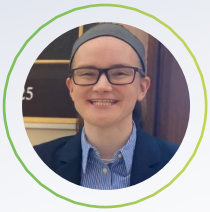
Policy, Advocacy & Patient Community Engagement

Amy Aikins
Director of
Rare Access Program

Lindsey Cundiff
Associate Director
of Policy Programs

Syed Ejaz, PhD
State Advocacy
Manager



Abbey Hauser
Associate Director of Patient
and Community Engagement

Kendly Jones
RDLA Program
Manager

Mary Michael Kelley
Vice President of
Patient Community Engagement

Annie Kennedy
Chief Mission Officer

Baillie McGowan
Director of
Policy Research

Kathryn Poe
State Policy Manager

Stephanie Riordan
Senior Director of
Patient Programs

Laura Romano
YARR Program
Manager

Dylan Simon
Senior Director
of Policy

Jamie Sullivan
Senior Vice President
of Policy & Advocacy

Shannon von Felden
Vice President
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Vice President of Operations & Events

2026 Schedule of Events

Thank you to the Presidential Sponsor of Rare Disease Week on Capitol Hill

ALEXION AstraZeneca Rare Disease

TUES 24

- **Share Your Story**
  1:00 P.M. – 2:00 P.M. EST - Registration/Check-In
  2:00 P.M. – 5:00 P.M. EST
  Ronald Reagan Building and International Trade Center
  1300 Pennsylvania Ave, NW, Concourse Level, Atrium Hall, Washington, DC 20004
  Metro Stop: Metro Center and Federal Triangle

RareVoice Awards Presented by: Takeda

- **Rare Disease Week Welcome Reception**
  5:00 P.M. – 6:00 P.M. EST
  Ronald Reagan Building and International Trade Center
  1300 Pennsylvania Ave, NW, Concourse Level, Atrium, Washington, DC 20004
  Metro Stop: Metro Center and Federal Triangle

- **Community Meetups**
  5:45 P.M. – 6:30 P.M. EST
  Ronald Reagan Building and International Trade Center
  1300 Pennsylvania Ave, NW, Concourse Level, Washington DC, 20004
  Metro Stop: Metro Center and Federal Triangle

Presented by: AMGEN

  - **Young Adult Rare Representatives (YARR)***
    Concourse Level, Ballroom B
  - **RDLA Advisory Committee**
    Concourse Level, Atrium Hall
  - **Community Scholarships****
    Concourse Level, Ballroom A

* Advocates 16-30 years old only

** #RAREis and Segalman Scholarship Recipients only

Energy Guide Key

Physical

Low: Little movement, ample seating available.

Medium: Prolonged standing, some walking, and some seating.

High: Ample walking and standing, seating not guaranteed.

Mental

Low: Optional or little to no participation and low noise level

Medium: Might require participation, note taking or cognitive effort. Low to moderate noise level.

High: Requires participation, note taking, and/or cognitive effort. Moderate to high noise level.



WEDS 25

- **Legislative Conference**
  8:00 A.M. – 9:00 A.M. EST - Registration/Check-In & Breakfast
  9:00 A.M. – 5:00 P.M. EST
  Ronald Reagan Building and International Trade Center
  1300 Pennsylvania Ave, NW, Concourse Level, Washington, DC 20004
  Metro Stop: Metro Center and Federal Triangle

Presented by: sanofi

THU 26

- **Meetings with Members of Congress**
  9:00 A.M. – 5:00 P.M. EST
  Capitol Hill, Washington D.C 20004
  Metro Stop: Union Station (Senate) or Capitol South (House)

- **Advocacy Day Launch Pad**
  8:30 A.M. – 9:30 A.M. EST - Breakfast
  9:30 A.M. – 11:30 A.M. EST - Senate Aging Committee Hearing Livestream
  Dirksen Senate Office Building, Room G-11
  50 Constitution Ave NE, Washington, DC 20002
  Metro Stop: Union Station

Launch Pad Presented by: WORLDWIDE CLINICAL TRIALS

- **Senate Aging Committee Hearing - In person**
  9:30 A.M. – 11:30 A.M. EST
  120 Constitution Ave NE, Hart Senate Office Building, SH-216, Washington, DC 20510
  Metro Stop: Union Station

- **Rare Disease Congressional Caucus Briefing**
  12:00 P.M. – 12:30 P.M. EST - Registration/Check-In & Lunch
  12:30 P.M. – 2:00 P.M. EST
  Cannon House Office Building, Room 390, 27 Independence Ave SE, Washington, DC 20003
  Metro Stop: Capitol South

Presented by: MERCK

- **Group Photo on Capitol Hill Steps**
  4:30 P.M. EST
  Capitol Hill, Washington, DC 20004 - East Steps
  Metro Stop: Union Station (Senate) or Capitol South (House)

- **Closing Reception**
  5:00 p.m. – 7:00 P.M. EST
  Top of the Hill Banquet & Conference Center
  1 Constitution Ave NE, 5th Floor Ballroom, Washington, DC 20002
  Metro Stop: Union Station (Senate) or Capitol South (House)

Share Your Story Day
Agenda

2026

- **Tuesday, February 24**
  Ronald Reagan Building and International Trade Center
  1300 Pennsylvania Ave, NW, Concourse Level
  Washington DC, 20004

1:00 P.M. – 2:00 P.M. — Registration

2:00 P.M. – 2:15 P.M. — Welcome
Lisa Langenderfer, Alexion
Amy Gaviglio, Board Chair, EveryLife Foundation for Rare Diseases

2:15 P.M. – 3:00 P.M. — RareVoice Success Panel

RareVoice Awards Presented by: Takeda

Introduction: 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 P.M. – 3:40 P.M. — Rare Artist: Arts & Health Panel

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

Family Space

Ronald Reagan Building, Oculus, Ground Level. The Family Space will be available for families all day except from 2:55 P.M. - 4:25 P.M., 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.
Thank you to our Family Space sponsor, Biogen.

Biogen

Share Your Story Day
Agenda

TUES
24

3:50 P.M. – 4:20 P.M.

Breakouts

Track 1: The Intersection of Identity & Advocacy: A Pride in Rare Conversation
Atrium Hall
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 P.M. – 5:00 P.M.

Breakouts

Track 1: Share Your Story 201: Connecting Data and Your Story
Atrium Hall
Baillie McGowan, EveryLife Foundation for Rare Diseases
Annie Kennedy, EveryLife Foundation for Rare Diseases
Jamie Sullivan, EveryLife Foundation for Rare Diseases

Track 2: Youth & Teen Advocacy
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 A
Stephanie Riordan, EveryLife Foundation for Rare Diseases
RDLA Advisory Committee coaches:
- **Marlene Riero**
- **Michelle O'Dell**
- **Mike Lane**
- **Misha Mehta**

5:00 P.M. – 6:00 P.M.

Welcome Reception – Atrium

5:45 P.M. – 6:30 P.M.

Community Meetups

Presented by: AMGEN

Young Adult Rare Representatives (YARR)
Ballroom B

RDLA Advisory Committee
Atrium Hall

Community Scholarships
Ballroom A

**Sessions and speakers are subject to change.*

Legislative Conference Agenda

2026

Wednesday, February 25

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

Presented by: sanofi

8:00 A.M. – 9:00 A.M. Registration and Breakfast
Atrium

Registration Presented by: GSK

Breakfast Presented by: Pfizer

9:00 A.M. – 9:45 A.M. Welcome
Atrium Hall and via Livestream
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 Pearlmutter, EveryLife Foundation for Rare Diseases

Logistics Overview
Shannon von Felden, EveryLife Foundation for Rare Diseases

9:45 A.M. – 10:15 A.M. Legislative Outlook
Atrium Hall and via Livestream
Hear from experts on the 119th Congress and how Congress will impact healthcare policy in 2026.
Moderator: : **Jamie Sullivan, EveryLife Foundation for Rare Diseases**
Jenn Bernstein, Monument Advocacy
Nick Manetto, Faegre Drinker
Caitlin Van Sant, Mehlman Consulting
Shayne Woods, Alpine Group

10:15 A.M. – 10:35 A.M. Break & Artist Meet-and-Greet
Atrium Hall

Reagan Wi-Fi Access

Network Name: RareDC2026
Password: Travere1
Thanks to our Wi-Fi sponsor Travere Therapeutics

TRAVERE THERAPEUTICS

Photo Booth

Thank you to our Photo Booth sponsor UCB.

ucb Inspired by patients. Driven by science.

Legislative Conference
Agenda

WEDS
25

10:35 A.M. – 11:25 A.M. **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 A.M. – 12:15 P.M. **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 P.M. – 12:25 P.M. **Group Photo**
Atrium Stairs

12:35 P.M. – 1:35 P.M. **Networking Lunch**
Atrium

Presented by:
CSL

1:35 P.M. – 2:05 P.M. **Deep Dive Policy Ask #3:** Credit for Caring Act

Moderator: Sky Collins, Oklahoma Rare
Rhonda Richards, AARP
Sarah Skirmont, Office of Representative Linda Sanchez
Wayne Galasek, HDSA Illinois Chapter

2:05 P.M. –2:35 P.M. **Deep Dive Policy Ask #4:** Genomic Answers for Children's Health Act

Moderator: Dylan Simon, EveryLife Foundation for Rare Diseases
Victoria Gemme, Leavitt Partners
LeighAnn Fairley, Office of Representative Bilirakis
Tatiana Lopez, RDLA Advisory Committee

2:35 P.M. –2:55 P.M. **Snack Break**
Atrium

Nap Nook Sponsor

Thank you to our Nap Nook sponsor Harmony Biosciences.

HARMONY BIOSCIENCES

**Sessions and speakers are subject to change.*

Legislative Conference
Agenda

WEDS
25

2:55 P.M. – 4:25 P.M. — **Preparing for Successful Meetings***

**Mandatory for advocates participating in Hill Day (Our Family Space will be closed at this time).* 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 P.M. – 4:50 P.M. — **Question and Answer Panel with the EveryLife Foundation Team**

4:50 P.M. – 5:00 P.M. — **Closing Remarks**

Medical Station

Thank you to our Medical Station sponsor Beam Therapeutics.

All Day Beverage Station

Thank you to our Beverage Station sponsor Alnylam Pharmaceuticals.

*Sessions and speakers are subject to change.

Rare Disease
Congressional Caucus Briefing

- ## Thursday, February 26

Registration and Lunch
12:00 P.M. – 12:30 P.M.

Rare Disease Congressional Caucus Briefing
12:30 P.M. – 2:00 P.M.

Cannon House Office Building, Room 390
27 Independence Ave SE, Washington, DC 20003

RARE DISEASE CONGRESSIONAL CAUCUS

Presented by: MERCK

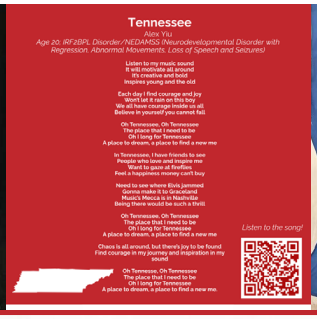
Rare Disease: The Time is Now

Rare Disease Legislative Advocates and the Rare Disease Congressional Caucus invite you to a rare disease briefing. The briefing is focused on time-sensitive opportunities to optimize outcomes for this generation of rare disease patients and will highlight current policy solutions that support timely diagnosis and newborn screening, advance biomedical research, and accelerate therapy development.

Welcome
Janelle Gillings, Merck

Guest Panel
Moderator: **James Valentine, Hyman Phelps & McNamara**
Michael Beacham, Rare Disease Advocate
Ron Bartek, Friedrich's Ataxia Research Alliance
Brittany Clayborne, Rare Disease Advocate
Jamie Sullivan, EveryLife Foundation for Rare Diseases





RAREARTIST

2025 Awardees

The Atrium Gallery features work by:

Music

- Alex Yiu, IRF2BPL Disorder/NEDAMSS, "Tennessee"
- Sophie Seaver, MED13L (Sibling), "Another You"
- Zanny Nicholas, Complex Regional Pain Syndrome, "Alive Again"

Poetry

- Maria Fernanda Llave, Spinal Muscular Atrophy Type 2, "No Borders for My Voice"

Visual Art

- Beatriz Fraga, Neurosarcoidosis, "Digested"
- DaNice Marshall, Granulomatosis with Polyangiitis, "In Someone Else's Shoes"
- Eva Agus, Nasopharyngeal Carcinoma, "Soaring Unbroken"
- Krista Webb, Usher Syndrome, "Imperfect Pathway"
- Solana Acuna, Severe Combined Immunodeficiency (SCID), "PrismofLove"
- Waiyee Hui, Antisynthetase Syndrome, "Staying Afloat with a Rare Disease"

Hear the stories behind the art

Meet the Artists & Grab a Postcard

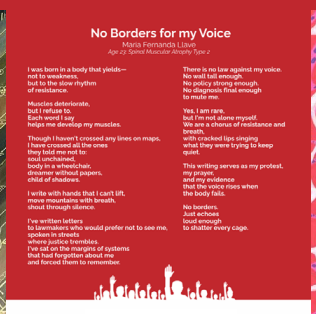
Wednesday, February 25 | 10:15 - 10:35 am (Morning Break) | Atrium Gallery

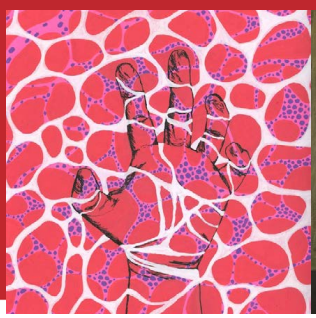
Connect with Rare Artist awardees, pick up postcard reproductions of artwork, and have them signed by the artists. Postcards can be taken to your Capitol Hill meetings as visual advocacy tools to support conversations with legislators. Postcards are available all day.

Save the date! Rare Artist 2026 opens June 8 through July 20

Award categories include: 2D Visual Art, 3D Material Art, Digital Art & Photography, Poetry (300 words max), Music (4 minutes max), and NEW! Short-Form Video (5 minutes max). One Rising Artist Award is given to an artist under the age of 18, chosen from any category.

Beginning in 2026, Rare Artist no longer has age-based categories.
Scan QR Code to the right for Submission Guidelines




Congress passed policies to improve the lives of kids with rare diseases. If your Member of Congress was a co-sponsor, don't forget to pick up a special handout to thank them in your Hill meetings.

In February 2026, Congress passed legislation that included important wins for the rare disease community. Two parts of this package were the Give Kids a Chance Act and the Accelerating Access to Kids Act. Together, these policies strengthen rare disease research, expand access to care for children, and accelerate the development of lifesaving treatments.

- **The Give Kids a Chance Act** reauthorized the Rare Pediatric Disease Priority Review Voucher (PRV) program, a proven FDA program that has helped advance treatments for more than 40 rare pediatric conditions over the past decade. Many of these treatments would not exist without the PRV program. At no cost to taxpayers, the Program has improved health outcomes, saved lives, and fueled innovation. After more than two years of advocacy, its renewal means research, clinical trials, and new treatments for rare pediatric diseases can continue to move forward.

- **The Accelerating Kids Access to Care Act** addresses one of the most persistent barriers facing rare disease families: access to specialized care. By streamlining the process for physicians to enroll in Medicaid programs across state lines, the law enables children to receive expert care more quickly. Shortening the time it takes for a child to access the diagnosis, care, and treatment they need eases the burden on families and improves health outcomes.

When you pick up your leave-behind materials during the Legislative Conference, please sign your handouts and thank the Members of Congress who made this progress possible.
To see the list of co-sponsors for both pieces of legislation, scan the QR code below.

Legislative Ask #1
Rare Disease Innovation Hub Appropriations Request

Talking Points

- ✓ The Rare Disease Innovation Hub was established in late 2024 to enhance collaboration across the FDA to address common scientific, clinical, and policy issues related to rare disease product development.
- ✓ A sustainable and appropriately resourced Rare Disease Innovation Hub is needed because:
    - Only 5% of the more than 10,000 rare diseases have FDA-approved treatments
    - Developing treatments for small patient populations involves regulatory science challenges that require broad FDA expertise to address in a predictable and consistent approach.
    - Rare disease expertise is unevenly dispersed across the FDA, limiting opportunities to share best practices and advance rare disease regulatory science.
- ✓ The broad rare disease community supports the work of the Rare Disease Innovation Hub.
- ✓ The Rare Disease Innovation Hub is a strategic and efficient approach to improve the FDA's Rare Disease actions and the impact it has on the 30 million Americans living with rare diseases.
- ✓ In 2025, the Hub built cross-center collaborations, hosted two RISE Workshops tackling specific regulatory science issues, and led the development of new evidence principles for rare disease therapy development.
- ✓ The Hub's 2026 Strategic Plan lays out an ambitious agenda to improve the dissemination and uptake of rare disease best practices across the Agency, host three additional RISE Workshops on timely topics to advance therapy development, create opportunities for rare disease patient organizations and experts to inform the therapy development and evaluation process, and streamline the navigation of FDA's rare disease resources.

Scan for Legislative Asks One Pagers

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

Talking Points

- ✓ Since 1983, Congress has created development incentives and policies that recognize the inherent complexities in developing treatments for rare diseases.
- ✓ Congress has explicitly given the FDA authority to uphold the highest standards of regulatory safety and rigor, while applying a tailored approach (i.e. "Regulatory flexibility"). Such approaches have included:
  - Establishment of Accelerated Approval Pathway
  - Consideration of the totality of evidence in the regulatory review
  - Inclusion of Patient Experience Data (PED) in clinical trial design & regulatory processes
  - Utilization of innovative clinical trial designs and real-world evidence (RWE)
- ✓ Nearly 1,400 orphan-designated therapies are changing the lives of patients and families.
- ✓ A series of FDA actions on rare disease product applications appear to contradict public pledges to expand the use of regulatory flexibility in the evaluation of rare disease therapies.
- ✓ At least 23 Complete Response Letters declining to approve new rare disease therapies have been issued since the start of 2025, many of which were being considered under the accelerated approval pathway.
- ✓ In 2025, the FDA held 65% fewer advisory committee meetings for prescription drugs, biologics, and related topics than in 2024, reducing opportunities for external experts and patient insights to inform FDA decisions. In some cases, meetings expected to discuss rare disease products that later received a negative regulatory decision were cancelled.
- ✓ The establishment of the Rare Disease and Condition Advisory Committee would enable the FDA to harness outside expertise to inform challenging rare disease regulatory science policy. It would not replace the need for the FDA to resume the use of formal advisory committee meetings that provide input on product-specific applications.

More information on this ask will be provided during the Legislative Conference

Scan for Legislative Asks One Pagers

Legislative Ask #3
Credit for Caring Act (H.R. 2036/S. 925)

Talking Points

- ✓ Family caregivers help parents, spouses, and other loved ones live independently in their homes, providing about $600 billion annually in unpaid labor and saving taxpayers billions. One in five adults are family caregivers.
- ✓ Nearly eight in ten family caregivers (78%) incur out-of-pocket caregiving costs – on average, over $7,200 annually on care-related expenses, or about 25% of their income.
- ✓ Nearly half of family caregivers face financial strain, including depleted savings, increased debt, unpaid bills, borrowing money, or difficulty affording basic needs like food.
- ✓ Too often, employed caregivers leave the workforce or reduce their hours due to caregiving, resulting in a loss of income, retirement savings, benefits, and career mobility. Hispanic/Latino and African American caregivers report greater financial strain.
- ✓ The Credit for Caring Act would help working family caregivers offset the cost of some caregiving expenses such as a home care aide, adult day services, home modifications, assistive technology, respite care, transportation, or other supports that help them and their loved ones.
- ✓ Eligible family caregivers could receive the credit if the care recipient meets certain functional or cognitive limitations or other requirements certified by a licensed healthcare practitioner.
- ✓ The credit would cover 30% of qualified caregiving expenses over $2,000, up to $5,000. Higher-income individuals would be ineligible, and safeguards prevent double-dipping with existing tax credits.

Scan for Legislative Asks One Pagers

Legislative Ask #4
Genomic Answers for Children's Health Act (H.R. 7118)

Talking Points

- ✓ More than two-thirds of the 10,000 identified rare diseases start in childhood and have a genetic origin.
- ✓ Children with rare diseases can face years of delays getting the correct diagnosis.
- ✓ It takes an average of 6 years and 17 different medical encounters for an individual with a rare disease to obtain an accurate diagnosis.
- ✓ Not all state Medicaid programs cover needed genomic tests for children, or they delay approval until all other, less effective options are exhausted.
- ✓ This 'diagnostic odyssey' or the years between symptom onset and a correct diagnosis, leads to delays in treatment and irreversible disease progression.
- ✓ Genomic sequencing analyzes a person's whole DNA. It has a higher diagnosis rate than other tests that only look at one gene or a set of genes.
- ✓ Research shows that genomic testing is cost-effective and even cost-saving in some inpatient settings.
- ✓ Genomic sequencing can shorten the time to diagnose pediatric patients by identifying the cause of an undiagnosed condition and allowing targeted care and treatment.

The Genomic Answers for Children's Health Act (H.R. 7118)

Clarifies Medicaid genomic testing coverage requirements and ensures children with rare diseases can get care under Medicaid.

The bill:

- Makes clear that whole genome sequencing and whole exome sequencing are covered by Medicaid under the required early and periodic screening, diagnostic, and treatment services for children within certain clinical criteria, and adds a DRG add-on payment for inpatient sequencing services.
- Requires CMS to convene national stakeholders and educate them on new policy adopted in the bill.
- Directs GAO to publish a report to Congress within 24-months that examines state reimbursement rates and health outcomes for children receiving genomic sequencing under Medicaid, as well as assess implementation challenges, barriers to care, and recommendations for improvement.

Scan for Legislative Asks One Pagers

Hill Day
Issue Information

Ask Your Members of Congress to Join the Rare Disease Congressional Caucus in the 119th Congress

Talking Points

- ✓ The Rare Disease Congressional Caucus is a bipartisan, bicameral caucus that works to raise awareness of rare diseases.
- ✓ Rare diseases affect more than 30 million Americans and their families.
- ✓ More than 95% of the estimated 10,000 rare diseases do not have an FDA approved treatment.
- ✓ Rare or orphan diseases are defined as diseases affecting fewer than 200,000 people in the U.S.
- ✓ Rare diseases include rare cancers, tropical or neglected diseases, genetic diseases, and many pediatric diseases. Many of these diseases are life-threatening and have no treatment options.
- ✓ The Rare Disease Congressional Caucus helps bring public and Congressional awareness to the unique needs of the rare disease community (including patients, physicians, scientists, and industry), and creates opportunities to address barriers to the development of and access to life-altering treatments.
- ✓ The Caucus gives a permanent voice to the rare disease community.

RARE DISEASE CONGRESSIONAL CAUCUS

Co-Chairs

Sen. Amy Klobuchar (MN)

Sen. Roger Wicker (MS)

Rep. Gus Bilirakis (FL)

Rep. Doris Matsui (CA)

Scan for Legislative Asks One Pagers

Rare Disease Congressional Caucus
Members List

Scan for Caucus Member List

Caucus: 168 Members
House: 136 Members **Senate:** 32 Members
Democrats: 108 **Independent:** 1 **Republicans:** 59
***Caucus Co-Chairs:** *Sen. Amy Klobuchar (MN), Sen. Roger Wicker (MS), Rep. Gus Bilirakis (FL), and Rep. Doris Matsui (CA)*

RARE DISEASE CONGRESSIONAL CAUCUS

House

- Mark Amodei R-NV
- Jake Auchincloss D-MA
- Don Bacon, D-NE
- Becca Baint, D-VT
- Andy Barr R-KY
- Joyce Beatty D-OH
- Ami Bera D-CA
- Donald Beyer, Jr. D-VA
- Stephanie Bice, R-OK
- ***Gus Bilirakis* R-FL***
- Sanford Bishop Jr. D-GA
- Suzanne Bonamici D-OR
- Julia Brownley D-CA
- Vern Buchanan R-FL
- Janelle Bynum D-OR
- Ken Calvert R-CA
- Salud Carbajal D-CA
- Andre Carson D-IN
- John Carter R-TX
- Sean Casten D-IL
- Kathy Castor D-FL
- Judy Chu D-CA
- Emanuel Cleaver D-MO
- Ben Cline R-VA
- Steve Cohen D-TN
- James Comer R-KY
- Gerald Connolly D-VA
- Jason Crow D-CO
- Sharice Davids D-KS
- Donald Davis D-NC
- Diana DeGette D-CO
- Rosa DeLauro D-CT
- Suzan DelBene D-WA
- Mark DeSaulnier D-CA
- Debbie Dingell D-MI
- Lloyd Doggett D-TX
- Tom Emmer R-MN
- Brian Fitzpatrick R-PA
- Lizzie Fletcher D-TX
- Mike Flood R-NE
- Bill Foster D-IL
- John Garamendi D-CA
- Josh Gottheimer D-NJ
- Glenn Grothman R-WI
- Brett Guthrie R-KY
- Kevin Hern R-OK
- Jim Himes D-CT
- Richard Hudson R-NC
- Jared Huffman D-CA
- Dusty Johnson R-SD
- Hank Johnson D-GA
- Julie Johnson D-TX
- David P. Joyce R-OH
- Marcy Kaptur D-OH
- Tom Kean R-NJ
- Bill Keating D-MA
- Ro Khanna D-CA
- Raja Krishnamoorthi D-IL
- Darin LaHood R-IL
- Greg Landsman D-OH
- John Larson D-CT
- John Lattimer D-NY
- Bob Latta R-OH
- Susie Lee D-NV
- Teresa Leger Fernandez D-NM
- Mike Levin D-CA
- Ted Lieu D-CA
- Zoe Lofgren D-CA
- Stephen Lynch D-MA
- Nancy Mace R-SC
- Seth Magaziner D-RI
- Nicole Malliotakis R-NY
- Brian Mast R-FL
- ***Doris Matsui* D-CA***
- Sarah McBride D-DE
- Michael McCaul R-TX
- Rich McCormick R-GA
- Morgan McGarvey D-KY
- Jim McGovern D-MA
- Grace Meng D-NY
- Mariannette Miller-Meeks R-IA
- Carol Miller R-WV
- Barry Moore R-AL
- Seth Moulton D-MA
- Kevin Mullin D-CA
- Jarold Nadler D-NY
- Richard Neal D-MA
- Joe Neguse D-CO
- Donald Norcross D-NJ
- Ralph Norman R-SC
- Eleanor Holmes Norton D-DC
- Frank Pallone D-NJ
- Jimmy Panetta D-CA
- Chris Pappas D-NH
- Scott Peters D-CA
- Brittany Pettersen D-CO
- Chellie Pingree D-ME
- Mark Pocan D-WI
- Mike Quigley D-IL
- Jamie Raskin D-MD
- Mike Rogers R-AL
- Deborah Ross D-NC
- David Rouzer R-NC
- John Rutherford R-FL
- Maria Elvira Salazar R-FL
- Andrea Salinas D-OR
- Mary Gay Scanlon D-PA
- Jan Schakowsky D-IL
- Brad Schneider D-IL
- David Scott D-GA
- Lateefah Simon D-CA
- Mike Simpson R-ID
- Adam Smith D-WA
- Chris Smith R-NJ
- Jason Smith R-MO
- Lloyd Smucker R-PA
- Darren Soto D-FL
- Melanie Stansbury D-NM
- Bryan Steil R-WI
- Haley Stevens D-MI
- Marilyn Strickland D-WA
- Suhas Subramanyam D-VA
- Eric Swalwell D-CA
- Glenn Thompson R-PA
- Mike Thompson D-CA
- Rashida Tlaib D-MI
- Paul Tonko D-NY
- Lori Trahan D-MA
- Jeff Van Drew R-NJ
- Juan Vargas D-CA
- Nydia Velazquez D-NY
- Ann Wagner R-MO
- Debbie Wasserman-Schultz D-FL
- Bonnie Watson Coleman D-NJ
- Bruce Westerman R-AR
- Joe Wilson R-SC
- Robert Wittman R-VA

Senate

- John Barrasso R-WY
- Richard Blumenthal D-CT
- Lisa Blunt Rochester D-DE
- John Boozman R-AR
- Maria Cantwell D-WA
- Shelley Moore Capito R-WV
- Christopher Coons D-DE
- Tom Cotton R-AR
- Steve Daines R-MT
- Ruben Gallego D-AZ
- Charles Grassley R-IA
- John Hoeven R-ND
- Cindy Hyde-Smith R-MS
- John Kennedy R-LA
- Andy Kim D-NJ
- Angus King I-ME
- ***Amy Klobuchar* D-MN***
- James Lankford R-OK
- Edward Markey D-MA
- Jeff Merkley D-OR
- Jerry Moran R-KS
- Markwayne Mullin R-OK
- Alex Padilla D-CA
- Gary Peters D-MI
- Jack Reed D-RI
- James Risch R-ID
- Jeanne Shaheen D-NH
- Elissa Slotkin D-MI
- Tina Smith D-MN
- Chris Van Hollen D-MD
- Raphael Warnock R-GA
- ***Roger Wicker* R-MS***

EVERYLIFE FOUNDATION FOR RARE DISEASES

Our Mission

The EveryLife Foundation for Rare Diseases is powered by the rare disease community to improve health outcomes by driving change through evidence-based policy, leading science-driven policy and regulatory research, activating the community to advocate for their rights and needs, and strengthening the rare disease community.

We Must Act Now

More than **30 million** Americans live with one or more rare diseases.

The economic impact of **379 rare diseases reached nearly $1 trillion** in the U.S. in 2019.

Rare disease patients wait an average of **6.3 years and 17 healthcare encounters** before receiving a rare disease diagnosis.

95% of the more than 10,000 known rare diseases have no FDA-approved treatment.

It takes an average of **15 years** for a drug to be developed and approved by the FDA.

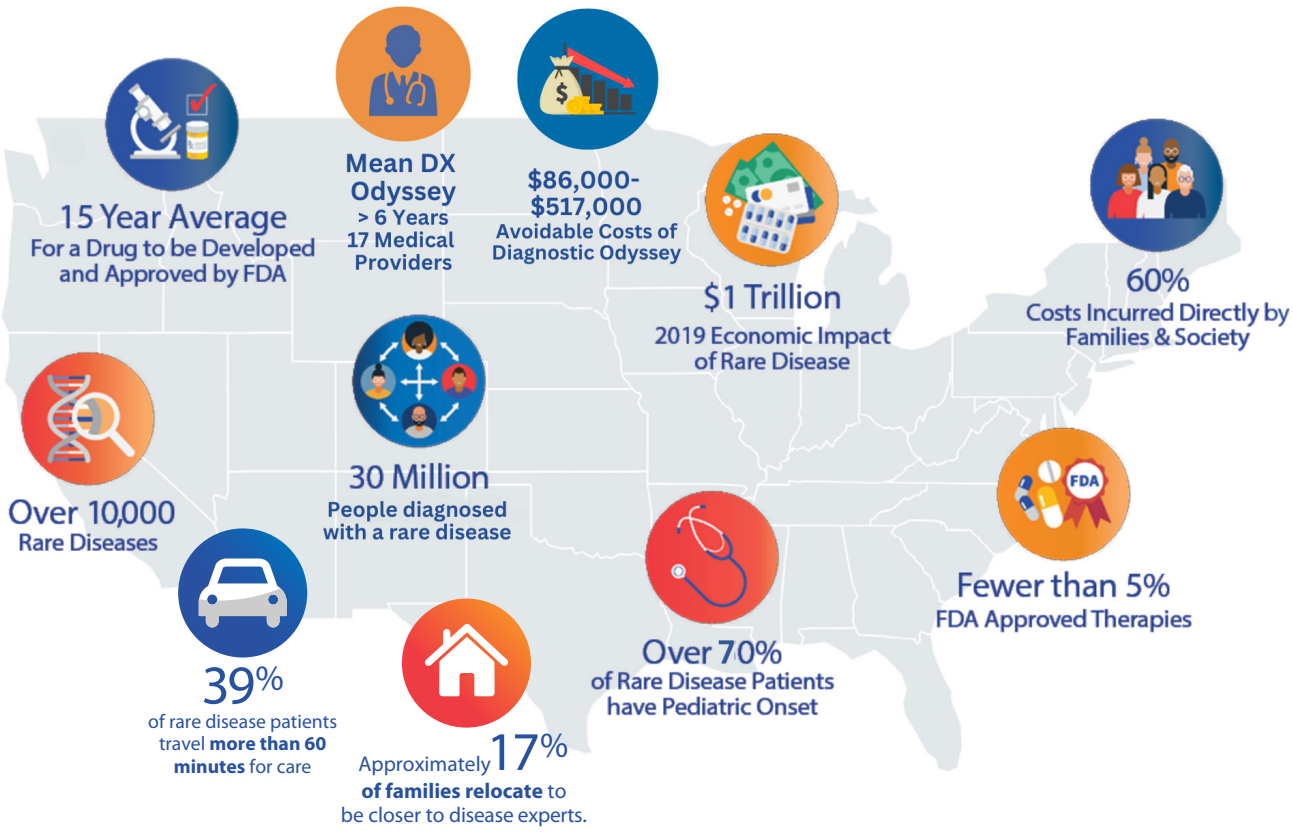
Delays in receiving a diagnosis result in an average of **$220,000** of avoidable costs per person.

EveryLife Foundation for Rare Diseases is committed to producing studies and evidence that informs policymakers and advances our mission.

everylifefoundation.org @EveryLifeOrg

Rare in Numbers

EVERYLIFE FOUNDATION FOR RARE DISEASES



Newborn Screening Facts

Newborn screening facilitates timely delivery of life-saving treatments, and other therapies that improve quality of life.

4 million
Newborns in the U.S. reached by screening every year.

~1 in 300
Newborns have a condition that can be detected through screening.

Screening tests every newborn for genetic, metabolic, hormonal, and functional conditions that are not otherwise apparent at birth.

EveryLifeFoundation.org

To learn more about the EveryLife Foundation's published articles, papers and letters scan here:

Congressional Meeting Tips

- Start each meeting by thanking the Member/staffer for meeting with you.
- Share your personal story and explain why a specific issue is important to you. Explain the problem and how your "ask" can improve or solve it.
- Make a specific "ask." Give Congress the solution.
- You don't have to be an expert on legislation.
- If you are asked a question that you are not sure how to answer, write it down and be sure to follow up.
- Respect the time of the Member, staffer, and fellow advocates by limiting your story to no more than one to two minutes.
- Typical meetings will last 15 minutes in total.
- Email the Congressional staffer with a one-pager on your asks as well as your contact information.
- Remember rare disease issues are nonpartisan. Don't talk about partisan politics in your meetings.
- Report back to RDLA on how the meeting went by completing the Online Meeting Feedback Form.
- Follow-up with a thank you note or email reinforcing your asks.

RDLA Congressional Scorecard

Encourage your legislator to join the Rare Disease Caucus and cosponsor rare disease legislation to improve their score.

Scan to view your state specific scorecard. ➡

Tips from the Rare Disease Week Chairs

Paloma Juarez
Advocacy Chair,
Rare Disease Week
on Capitol Hill

Kyle Underwood
Advocacy Vice Chair,
Rare Disease
Week on Capitol Hill

- ✓ Lead with your personal experience, then connect it to the policy issue. Stories are remembered long after statistics.
- ✓ Be mindful of time. Meetings often run short, so prioritize your top two points.
- ✓ Do not be discouraged if you meet with staff instead of the legislator. Staff play a critical role in shaping policy.
- ✓ Take notes during or immediately after each meeting to track follow-ups and commitments.
- ✓ Ask for a specific next step, such as co-sponsoring a bill or attending a briefing.
- ✓ Follow up with a thank-you email within 24 to 48 hours to reinforce your message and build the relationship.
- ✓ Bring a one-page leave-behind with key facts, your story, and clear asks so staff can reference it later.
- ✓ Take care of yourself throughout the day. Hydrate, pace yourself, and rest when needed. Advocacy is a marathon, not a sprint.

Social Media
Advocacy Tips

Social Media Correspondents Presented by: argenx

- **How does a hashtag "#" work?**
  On Facebook, Instagram, LinkedIn, and X the pound sign is a hashtag (#) and turns any word or group of words that directly follow it into a searchable link. This allows you to organize content and track discussion topics based on those keywords. For instance, if you want to post about Rare Disease Week on Capitol Hill, you would include **#RareDC2026** to join the conversation. You could then click the hashtag to see other posts on Rare Disease Week on Capitol Hill.
- **How do I 'mention' someone on X, Facebook or Instagram? "@"**
  Many Congressional offices have Social Media accounts to keep in touch with constituents. If you know your legislator's handle, you can mention them in your post about **#RareDC2026** using the "@" symbol before the name. If you don't know your legislator's Social Media handle, check his or her official website.

Tip: Look for a blue checkmark on their Instagram or X account to make sure the account identity has been verified.

- **Before your meeting:**
  Create a post tagging the Member's office and the issue you will be talking about. This is a good way to introduce yourself and your issue to the staff. This will add a face to the upcoming meeting and will help them remember you.
- **During the meeting:**
  Ask to take a photo, preferably towards the end of the meeting. Write down any notes that might make for good tweets or quotes for your social post.
- **After the meeting:**
  Post your picture with a thank you note on Facebook, Instagram, LinkedIn, or X to re-emphasize the ask or any key points you discussed during the meeting.

Thank you @RepGusBilirakis for joining the Rare Disease Congressional Caucus and supporting #RareDisease legislation! #RareDC2026

Official Rare Disease Week Social Media Correspondents

Flynn Shaw
EveryLife Foundation for Rare Diseases

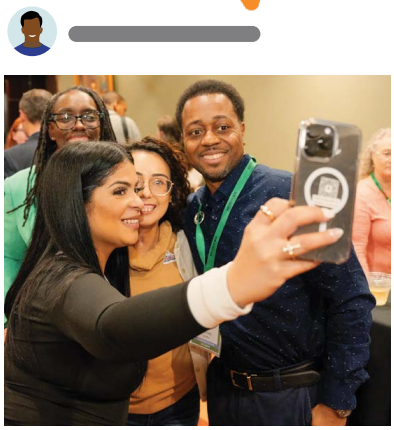
Katie Wagman
EveryLife Foundation for Rare Diseases

Follow the Rare Disease Legislative Advocates (RDLA) on Instagram @Rare_Advocates for behind-the-scenes content from our #RareDC2026 social media correspondents.

Share Your #RareDC2026 Experience

Follow us and share your Rare Disease Week experience for a chance to win a $100 Gift Card of your choice.

Tip: Have fun and BE CREATIVE! **@RareAdvocates #RareDC2026**



Glossary

Glossary Section Presented by: VERTEX

Congressional Terms

- **Act:** A bill that has passed both house of congress and has been enacted into a law.
- **Appropriation:** The allocation of funds for a specific purpose within government. Allows for funds to be spent but is not an actual expenditure.
- **Bill Sponsor:** A Representative or Senator who introduces a bill.
- **Bill Co-Sponsor:** A Representative or Senator who formally signs on to support a bill. Only the first-named Member is the sponsor. All others are cosponsors, even those whose names appeared on the measure at the time it was submitted.
- **Bicameral Bill:** A bill that has been introduced in both the House and Senate.
- **Bipartisan Bill:** A bill that has at least one cosponsor from both parties.
- **Congressional Budget Office (CBO):** Agency within the legislative branch that produces independent analyses of budgetary and economic issues to support the Congressional process. Often calculates the cost or savings from enacting a specific bill. This is referred to as a "score."
- **Committee:** A panel with members from the House or Senate tasked with conducting hearings, examining and developing legislation, and conducting oversight. *The Senate and House have separate versions of each committee, but occasionally a joint committee is made of members from both chambers.*
- **Subcommittee:** A subpanel of a committee with a more specific jurisdiction. For example, the House Energy and Commerce Committee has a Health Subcommittee.
- **Chair:** The member of the majority party on a committee or subcommittee who has formal responsibility over the panel's agenda and resources, presides at its meetings, and can, in some circumstances, act on the committee's behalf.
- **Caucus:** An informal meeting of members of a body of government (typically belonging to the same political party and/or another common interest such as the Rare Disease Congressional Caucus).
- **Enacted:** When a bill is passed by both chambers and signed into law by the President.
- **Legislator:** An elected official of a legislative body.
- **Lobbyist:** A person who attempts to influence legislation on behalf of a specific interest group.
- **Markup:** Meeting by a committee or subcommittee during which committee members offer, debate, and vote on amendments to a bill or other measure.
- **Nonpartisan:** Not associated with a single political party or caucus.
- **Partisan:** Associated with a single political party or caucus.

Scan to Access Full Glossary

Glossary

Government Agencies

- **Centers for Disease Control and Prevention (CDC)**
  Tasked with protecting the nation from health, safety and security threats, both foreign and in the U.S. Monitors reported disease and maintains information databases on prevalence, region, etc.

- **Centers for Medicare and Medicaid Services (CMS)**
  Administers healthcare/ reimbursement programs including Medicare, Medicaid, and the Children's Health Insurance Program (CHIP).

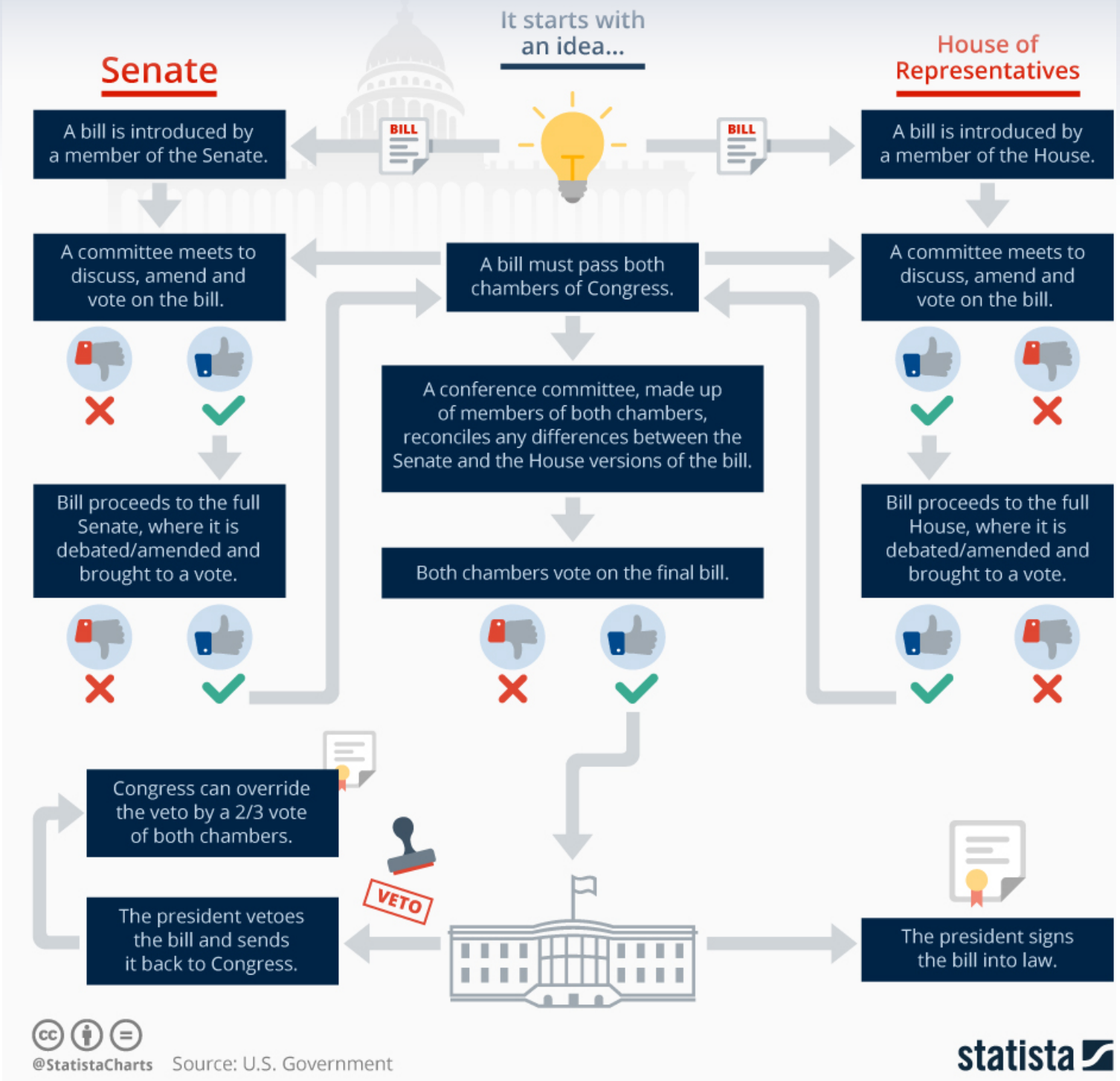
- **Department of Health and Human Services (HHS)**
  A cabinet-level department of the U.S. federal government with the goal of protecting the health of all Americans and providing essential human services.

- **Food and Drug Administration (FDA)**
  Responsible for protecting the public health by ensuring the safety, efficacy, and security of human and veterinary drugs, biological products, and medical devices; and ensuring the safety of our nation's food supply, cosmetics, and products that emit radiation.

- **Health Resources and Services Administration (HRSA)**
  The primary federal agency for improving access to health care services for people who are uninsured, isolated, or medically vulnerable. This agency administers several newborn screening programs.

- **National Institutes of Health (NIH)**
  The nation's medical research agency tasked with making discoveries that improve health and save lives. Comprised of 27 institutes and centers.

U.S. Legislative Process



@StatistaCharts Source: U.S. Government

statista

Accessibility Resources

General Travel Links

- **Visit the Capitol**
  visitthecapitol.gov/plan-visit/visitors-disabilities
- **Wheelchair Travel**
  wheelchairtravel.org/washington-dc/
- **Washington.org**
  washington.org/DC-guide-to/how-do-i-get-around-washington-dc

Transportation Options in DC

- **Capitol Shuttle**
  For your convenience, the Capitol Visitor Center provides an on-demand shuttle for those with mobility issues or in manual wheelchairs. The shuttles run from the southwest corner of Capitol Square at Independence Ave. and First Street, SW, to the Capitol Visitor Center entrance at the center of the Capitol's East Plaza. Please ask the Office of Congressional Accessibility Services at **(202) 224-4048**, Capitol Visitor Center staff in red shirts or vests, or at either of the kiosks located at the southwest corner of Capitol Square or on the east side of the Capitol near the corner of First St. NE/SE and East Capitol Street. Please provide as much advance notice as possible to help facilitate your request.
- **Metro (Subway)**
  wmata.com/service/accessibility/#main-content
  A list of out-of-service elevators are available at the information booth of every metro station. Check the WMATA website or call **(202) 637-7000** for outages before leaving.
- **Lyft Access**
  https://help.lyft.com/hc/en-us/articles/115013081668-Accessible-vehicle-dispatch
- **UberWAV**
  uber.com/us/en/ride/uberwav/

Medications

- **Cannabis on Federal Property**
  mpdc.dc.gov/marijuana
  acludc.org/en/know-your-rights/know-your-rights-marijuana-laws-district-columbia

Wheelchair Accessible Van Rentals and Sales

- **Mobility Works** – Service (877) 275-4912
  Rentals (877) 275-4915
- **Accessible Vehicles** – (301) 838-9700
  119 Taft Street, Rockville, MD

Rare Disease Week Event Buildings, Entrances, and Services on Capitol Hill

To enter the Capitol and the office buildings, all visitors are screened by a magnetometer and all personal items are screened by x-ray. Some items are prohibited from entering the Capitol such as liquid, including water. Capitol Police can make exceptions if a prohibited item is determined to be necessary for childcare, medical, or other special needs.

- For more information, go to:
  visitthecapitol.gov/visit/know-before-you-go/prohibited-items
- For questions on accessibility contact the Office of Congressional Accessibility Services (OCAS) on Capitol Hill – **(202) 224-4048**
  aoc.gov/accessibility-services

House Office Buildings Accessible Entrances:

- **Cannon House Office Building:** Entrance on New Jersey Avenue, SE, south of the terrace at the intersection with Independence Avenue.
- **Rayburn House Office Building:** Main entrance, horseshoe drive off South Capitol Street.
- **Longworth House Office Building:** Main entrance, Independence, and New Jersey Avenues.

Senate Office Buildings Accessible Entrances

- **Dirksen Senate Office Building:** First Street and C Street entrance.
- **Russell Senate Office Building:** Delaware entrance on ground level closest to Constitution Avenue.
- **Hart Senate Office Building:** Second Street entrance.

Scooters and Wheelchair Rentals

- **Scootaround – (888) 441-7575**
  Scooter and wheelchair rentals are available daily, weekly, or for longer periods of time. Take a tour of DC and the National Mall on a mobility scooter.
- **Bike and Roll – (202) 842-BIKE**
  Electric scooters and manual wheelchairs available. Two-hour, half-day, daily, and multi-day rentals.
- **Lenox Medical – (202) 387-1960**
  Provides short-term scooter, wheelchair, and knee walker rentals to tourists and residents.

Scooters and Wheelchair Repairs

- **WSR – (888)584-3095**
  wsrsolutions.com
- **Mobility City – (571) 339-5218**
  alexandriava.mobilitycity.com

Scan for easy access to resource links

Capitol Hill Resources

Food Service Options on Capitol Hill buildings

- **Dirksen Cafe** — Dirksen Building, SDB-R7
- **Inside Scoop** — Dirksen Building, SDG-21A
- **Refectory** — U.S. Capitol, S-112A
- **Senate Carry-Out** — U.S. Capitol, SB-10A
- **Senate Dining Room** — U.S. Capitol, S-110
- **The Coffee Shop** — Dirksen Building, SDB-R7

Understanding Room Numbers in the House and Senate Office

- **Rooms with three-digits:**
  The first digit in the number indicates the floor level of the room.

  Example: 231 Cannon House Office Building. The room is located on the 2nd floor

  Example: 104 Hart Senate Office Building. The room is located on the 1st floor

- **Rooms with four-digits:**
  The first digit indicates the building. Rayburn and Longworth are the only building with four-digit room numbers.

  1 is the first number for all Longworth rooms.
  Example: 1365 Longworth House Office Building

  2 is the first number for all Rayburn rooms.
  Example: 2145 Rayburn House Office Building

  The second digit in these room numbers indicates the appropriate floor level.

  Example: 1365 Longworth House Office Room is located on the 3rd floor

  Example: 2145 Rayburn House Office Room is located on the 1st floor

Public Wi-Fi Network Access

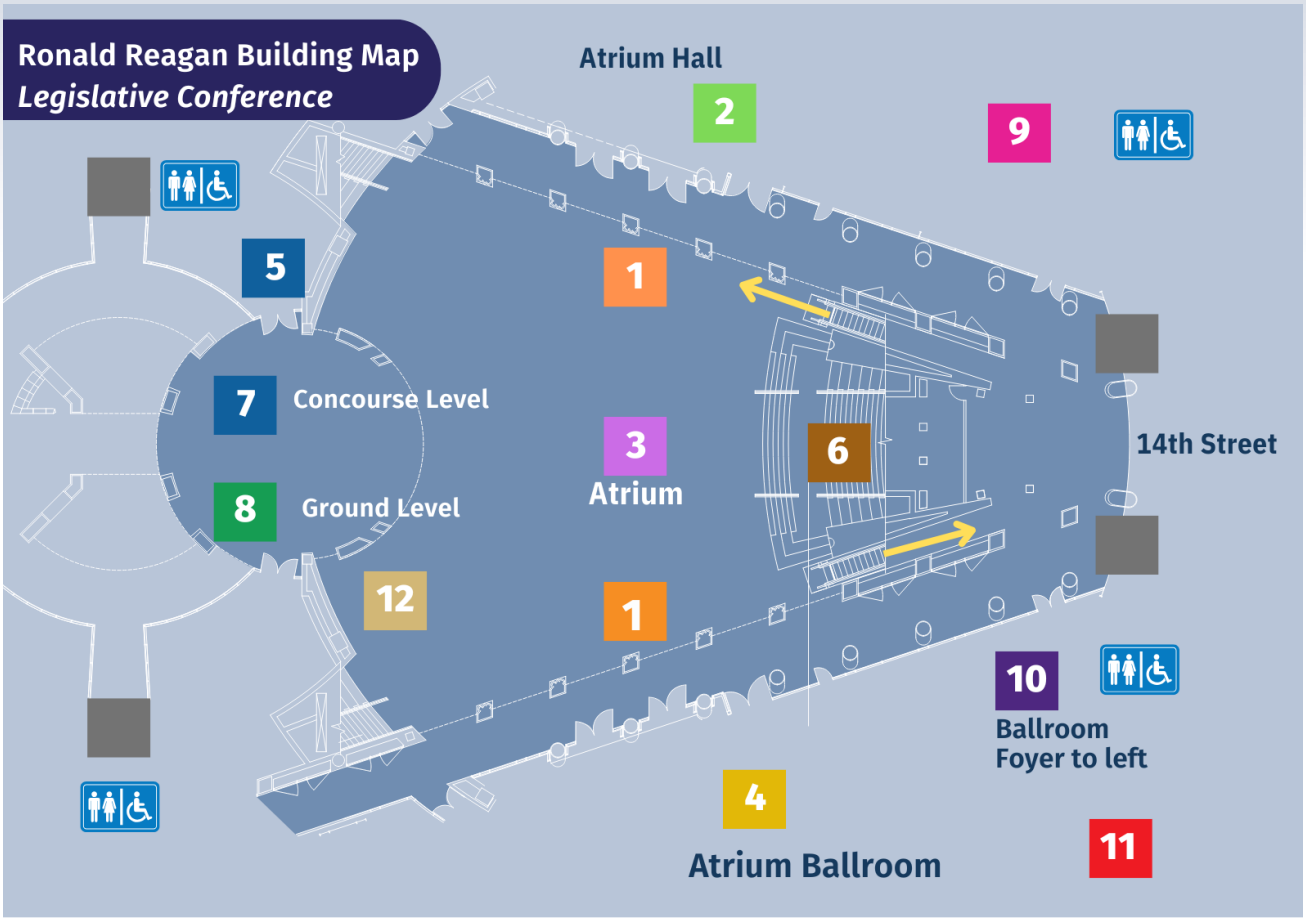
House of Representatives Office Buildings
Network Name: HousePublic
Password: HousePublic

Senate Office Buildings:
Network Name: Senate_Guest
Password: wethepeople

U.S. Capitol Map

Metro System Map

Ronald Reagan Building Map



1 Registration GSK

2 Main Sessions

3 Breakfast Pfizer

3 Lunch CSL

4 Auxiliary Room

5 Rare Artist Gallery

6 Group Photo

7 Charging Station Lounge

8 Family Space Biogen

9 Medical Station Beam Therapeutics

10 Nap Nook Harmony Biosciences

11 Nursing/Lactation Room

12 Photo Booth UCB Inspired by patients. Driven by science.

Accesible Restrooms

Escalators

Elevators

Congratulations to the 2025 RareVoice Awards Recipients!

Takeda

Federal Advocacy Patient Advocate or Organization

Foundation for Sarcoidosis Research

State Advocacy Patient Advocate or Organization

Tiffany House

Federal or State Advocacy Youth or Teen

Emily Brubaker

DEIA Empowerment Patient Advocate or Organization

Rare Disease Diversity Coalition

Federal Advocacy Congressional Staff

Ruth McDonald
Office of Senator Klobuchar

Federal Advocacy Congressional Staff

Jacquelyn Gulshen
Office of Senator Mullin

State Advocacy State Legislator

Representative Karen Karls (ND)

Thank you to the RareVoice Nominations Committee!

Stephen Groft
Sharon King
Neena Nizar
Caitlin Van Sant
Shayne Woods

Congratulations to the 2025 RareVoice Awards Nominees

Amanda Chang
Stephen Cullen
Joyce Fitz
Elisa Glass
Elena Hung
Rochelle (Shelly) Johnson
Aiden Yejoon Kim
Holly Martinez
Melissa Meyer
Nathanael Milam II
Isabella Park
Gloria Rodriguez
John Weber

The RareVoice Lifetime Achievement Award

Frank J. Sasinowski, M.S., M.P.H., J.D., is a leading expert in drug regulation whose work has significantly advanced therapies for rare and serious diseases. He has helped secure FDA approval for hundreds of drugs, including more than 100 new molecular entities, and has been involved in over half of all non-oncology drugs approved through the FDA's accelerated approval pathway. Frank played a key role in implementing the Orphan Drug Act at the FDA and has been instrumental in advancing cell and gene therapies, including the first approved systemic gene therapy, Zolgensma.

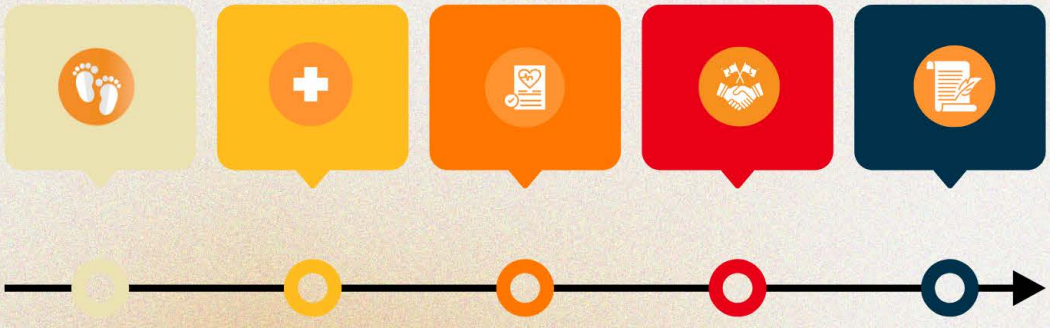
A longtime advocate for regulatory flexibility and patient-centered drug development, he most recently served as Interim Board Chair at the EveryLife Foundation, concluding his term at the end of 2025. Lifetime Achievement Award recipients receive an "Abbey" statuette, commissioned especially for the RareVoice Awards.

NEWBORN SCREENING

Introducing the
Newborn Screening Resource Roadmap

Scan to start your journey

This NBS Resource Roadmap is designed to orient people new to newborn screening to key topics and resources to help them prepare to advocate effectively for NBS for one (or more) rare diseases in one (or more) states in the U.S.



Thanks to support from

Orchard therapeutics
A Kyowa Kirin Company

sanofi

RDLA
Rare Disease Legislative Advocates
Youth & Teen Advocacy Day
POWERED BY THE EVERYLIFE FOUNDATION

Save the Date 2026!

RARE ACROSS AMERICA
EVERY VOICE, IN EVERY DISTRICT, MATTERS

Youth and Teen Advocacy Day

Rare Across America

Registration Opens **May 11**

Join us from **August 10-21**

Are you ready to be the next young adult leader?

Open to Advocates Between 18 and 30 Years of Age

- Meet other young adults passionate about rare disease.
- Learn about roles and opportunities for patient representation in drug development, policy making, and the regulatory process.
- Engage with guest speakers in a small cohort.
- Become a more effective and powerful advocate.

Classes meet Thursdays 6:00 -8:00 p.m. ET from April 23 - June 4, 2026

Apply Today!

YARR Leadership Academy

Interested in YARR year-round? Learn more and apply today!
HearUsYARR.org

Community Scholarships

POWERED BY THE EVERYLIFE FOUNDATION

#RAREis Scholarship Fund

Eligibility: U.S. residents age 17+ with a rare disease (diagnosed or verified undiagnosed) enrolling part-time or full-time in college, trade school, or other accredited course for Fall 2026

Award: Up to 58 recipients will be awarded $5,000, thanks to the support of Amgen. Optional mentorship program for selected recipients.

Apply: March 17 - April 28, 2026

Paula Kovarick Segalman Family Scholarship for ALS

Eligibility: U.S. residents affected by an ALS diagnosis (self or immediate family member) enrolling full-time in an undergraduate program for Fall 2026.

Award: One new $5,000 scholarship will be awarded, renewable up to 4 years, thanks to the support of the Segalman family and donors. Optional mentorship program.

Apply: May 12 - June 16, 2026

Ready to pursue your dreams? Scan the QR code to learn more.

Rare Advocacy Learning

EMPOWERING EVERY VOICE

POWERED BY THE EVERYLIFE FOUNDATION

ARE YOU READY TO TAKE YOUR ADVOCACY JOURNEY TO THE NEXT LEVEL?

A six-week seminar series for advocates with prior advocacy experience hosted by the Rare Disease Legislative Advocates (RDLA)

When? April 13 – June 5, 2026

Applications Open February 25 2026

EVERYLIFE FOUNDATION FOR RARE DISEASES

RARE DISEASE WEEK ON CAPITOL HILL

Thank you for participating in Rare Disease Week on Capitol Hill 2026!

Our collective efforts are driving real policy progress, expanding equitable access to lifesaving diagnoses and treatments, and elevating the voices of millions of people living with rare diseases.

By making a gift to the EveryLife Foundation for Rare Diseases, your generosity will support:

- **Rare Disease Week:** Contributions enable individuals to participate at no cost.
- **Year-Round Advocacy Efforts:** Funding sustains ongoing advocacy initiatives like Rare Across America.
- **Advancing Policy Change:** Resources help advance equitable access to lifesaving advancements.
- **Education and Engagement:** Donations help provide tools and educational opportunities for advocates.
- **Emboldening of Advocates:** Support helps train and embolden individuals and families affected by rare diseases to share their stories.

You help turn advocacy into outcomes. Every voice, every action, and every donation expands access and accelerates progress for people living with rare diseases.

Make Your Gift

ALEXION®
AstraZeneca Rare Disease

Pioneering new possibilities for the rare disease community

Amgen is proud to support the EveryLife Foundation during Rare Disease Week on Capitol Hill

Inspired by purpose that extends beyond our medicines, Amgen stands firmly in support of the rare disease community across the globe – partnering with patients, communities and clinicians to deepen understanding, accelerate recognition and expand access to care across every stage of the rare disease journey.

AMGEN

Focused on patients. Driven by science.

Breakthroughs only matter when they reach the people they're made for.

Their needs shape our science, our decisions, and our solutions. From global programs to local partnerships, we're breaking down barriers and expanding access to the patients who need it most.

Explore how we're expanding access to lifesaving medicines at merck.com

MERCK

Better Health, Brighter Future

Takeda is a global, R&D-driven biopharmaceutical company committed to discovering and delivering life-transforming treatments and vaccines that have a lasting impact on society.

Since our founding in 1781 in a market stall in Osaka, Japan, our values endure by putting patient needs first, building trust with society, strengthening our reputation, and developing the business - in that order.

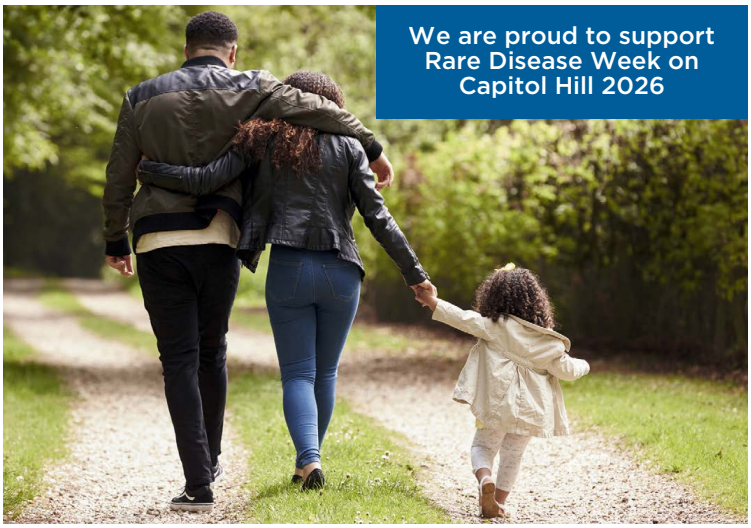
www.takeda.com

Takeda

Together
We Discover

argenx

argenx.com



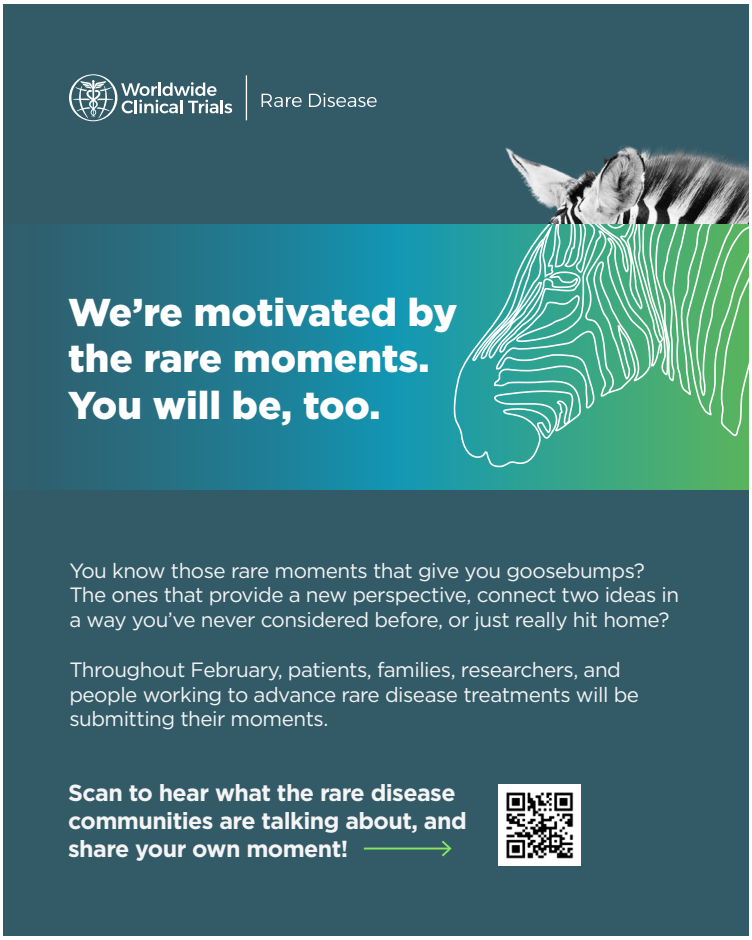
We are proud to support Rare Disease Week on Capitol Hill 2026

At Travere Therapeutics, we are in rare for life.

We come together every day to help patients, families, and caregivers of all backgrounds as they navigate life with a rare disease. On this path, we know the need for treatment options is urgent - that is why our global team works with the rare disease community to identify, develop, and deliver life-changing therapies.

travere.com I @TravereRare I #InRareForlife

TRAVERE THERAPEUTICS


Worldwide Clinical Trials
Rare Disease
We're motivated by the rare moments. You will be, too.
You know those rare moments that give you goosebumps? The ones that provide a new perspective, connect two ideas in a way you've never considered before, or just really hit home?
Throughout February, patients, families, researchers, and people working to advance rare disease treatments will be submitting their moments.
Scan to hear what the rare disease communities are talking about, and share your own moment!


Follow Us and Share Your #RareDC2026 Experience
Tag us and share your Rare Disease Week experience for a chance to win a $100 Gift Card of your choice.
Tip: Have fun and BE CREATIVE! @RareAdvocates #RareDC2026
#RAREDC2026

Notes

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EVERYLIFE
FOUNDATION
FOR RARE DISEASES

The EveryLife Foundation for Rare Diseases is powered by the rare disease community to improve health outcomes by driving change through evidence-based policy, leading science-driven policy and regulatory research, activating the community to advocate for their rights and needs, and strengthening the rare disease community.

everylifefoundation.org

RDLA
Rare Disease Legislative Advocates

POWERED BY THE EVERYLIFE FOUNDATION

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@EveryLifeOrg

#RAREDC2026 @RAREADVOCATES