

RARE DISEASE WEEK ON CAPITOL HILL

Presented by

ALEXION[®]
AstraZeneca Rare Disease



FEBRUARY 24-26
2025

#RAREDC2025 @RAREADVOCATES   

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Welcome

Welcome to the 14th Annual Rare Disease Week on Capitol Hill—our biggest yet! This week, we are bringing together more advocates and more voices than ever before, all united by one goal: driving change for the rare disease community.

Rare Disease Week is our community's Super Bowl, and this year, we are honored to welcome retired NFL legends and first-time attendees Josh Andrews (Philadelphia Eagles, 2014-18) and Art Still (Kansas City Chiefs, 1978-87). As individuals living with rare diseases themselves, their presence underscores the power of advocacy and the impact we can make when we raise our voices together.

But the real MVPs this week are YOU. Your voice, your story, and your dedication are what make real change possible year after year. It is your presence here on Capitol Hill that shapes policies, educates decision-makers, and moves us closer to a world where no rare disease patient is without hope.

Our collective efforts over the last year have led to major accomplishments, including the establishment of the Rare Disease Innovation Hub (RDIH) by the FDA in 2024. This initiative has the potential to bring greater consistency and predictability to therapy development, but its success depends on strong implementation. And as federal agencies navigate their own challenges, we must ensure that RDIH delivers on its promise to address the most pressing challenges facing the rare disease community. Our nation's rare disease community deserves access to comprehensive, affordable health insurance that enables us to receive timely diagnoses, recommended clinical care, and access to prescribed therapies.

This community is at its strongest when we are facing our challenges together and head-on. This week, we have the opportunity to welcome a new Congress, reconnect with steadfast champions, and ensure that the voices of the rare disease community continue to drive meaningful change.

Thank you for being here, for your passion, for your dedication, and for being on our team. We wish you an impactful week in Washington, D.C., as you raise your voice and help drive real policy change for our rare disease community.



Michael Pearlmutter
Chief Executive Officer
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. In addition, several of our board members are the parents of children with a rare disease, enabling them to offer firsthand knowledge of the challenges facing the rare disease community.



Vicki Seyfert-Margolis, Ph.D.
Chair
Founder and CEO,
Respond Health
Family Advocate



**Frank Sasinowski, M.S.,
MPH, J.D. - Vice Chair**
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Amy Gaviglio M.S., CGC
Public Genetics &
Genomics Consultant,
Connetics Consulting



Michael Pearlmutt
Chief Executive Officer,
EveryLife Foundation for
Rare Diseases



Shandra Trantham, Ph.D.
Young Adult
Rare Disease Advocate

EveryLife Foundation for Rare Diseases Team

Policy, Advocacy & Patient Engagement



Lindsey Cundiff
Associate Director
of Policy Programs



Syed Ejaz, Ph.D.
State Advocacy
Manager



Abbey Hauser
Associate Director
of DEIA



Kelly Helm
Vice President of
Patient Engagement



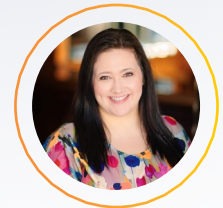
Kendly Jones
RDLA Program
Manager



Annie Kennedy
Chief of Policy, Advocacy
& Patient Engagement



Baillie McGowan
Associate Director of
Policy and Research



Stephanie Riordan
Director of
Patient Programs



Laura Romano
YARR Program
Manager



Dylan Simon
Senior Director
of Policy



Emily Stauffer
Associate Director
of State Policy



Jamie Sullivan
Vice President
of Policy



Shannon von Felden
Vice President
of Advocacy





Communications & Marketing



Brenda Colmenares
Director of
Communications



Will Nolan
Chief Marketing &
Communications Officer

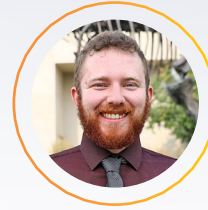
Development



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Vice President
of Alliance Development



Stephanie Siddiqi
Associate Director
of Development



Collin Sovie
Alliance Development
Manager



James Uyeda
Vice President of
Individual Giving



Liz Warren-Novick
Annual Giving
Manager

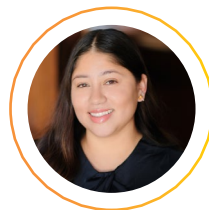
Operations



Lina Arslanian
Associate Director of
Finance & Salesforce



Hannah Rhee
Events Manager



Mariela Romero
Executive Assistant



Alyssa Terwall
Vice President of
Operations & Events

Rare Disease Week on Capitol Hill



Every Voice Matters

2025 Schedule of Events

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



MON
24

- **Pride in Rare Meetup**  
3:00 p.m. - 4:00 p.m. EST

Ronald Reagan Building and International Trade Center
1300 Pennsylvania Ave, NW, 2nd Floor, Pavilion, Washington DC, 20004
Metro Stop: Metro Center and Federal Triangle

- **Rare Reels**  
5:00 P.M. - 8:00 P.M. EST

Ronald Reagan Building and International Trade Center
1300 Pennsylvania Ave, NW, 2nd Floor, Pavilion, Washington DC, 20004
Metro Stop: Metro Center and Federal Triangle



TUES
25


- **Legislative Conference**  
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




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 participation, minimal to no participation

 **Medium:** Might require participation, note taking or cognitive effort



 **High:** Requires participation, note taking, and/or cognitive effort



TUE 25 ● **#RAREis Scholarship Recipient Meet-up**  
 2:45 p.m. - 3:15 p.m. EST
 Family Space **invite only*




● **Young Adult Rare Representatives (YARR) Meetup**  
 5:00 p.m. – 6:30 p.m. EST
**Advocates 16-30 years old only*
 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

WED 26 ● **Rare Disease Congressional Caucus Briefing**  
 8:30 a.m. - 9:00 a.m. EST - Breakfast
 9:00 a.m. - 10:00 a.m. EST
 Top of the Hill Banquet & Conference Center
 1 Constitution Ave NE, 5th Floor Ballroom, Washington DC, 20002
Metro Stop: Union Station (Senate side) or Capitol South (House side)

Presented by:
CSL Behring

● **Meetings with Members of Congress**  
 10:00 a.m. - 5:00 p.m. EST
 Capitol Hill, Washington D.C 20004
Metro Stop: Union Station (Senate side) or Capitol South (House side)

● **Group Photo on Capitol Hill Steps**   
 4:30 p.m. EST
 Capitol Hill, Washington D.C 20004 - East Steps
Metro Stop: Union Station (Senate side) or Capitol South (House side)

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

Presented by:
 **MERCK**

Rare Reels Screening & Reception



- Monday, February 24

5:00 p.m. - 8:00 p.m. EST

Ronald Reagan Building and International Trade Center
1300 Pennsylvania Ave, NW, 2nd Floor, Pavilion
Washington DC, 20004

Presented by:



Scan to Watch
Full Films

This special event celebrates the art and craft of storytelling through film. It will feature four documentaries that highlight impactful stories from the rare disease community. Attendees will watch trailers for each selected film, followed by a panel discussion.

- 5:00 p.m. - 6:30 p.m. Reception
- 6:30 p.m. - 6:45 p.m. Opening Remarks
- 6:45 p.m. - 7:00 p.m. Trailers Screening
- 7:00 p.m. - 8:00 p.m. Panel Discussion

Introduction



Michael Pearlmuter
Chief Executive Officer,
EveryLife Foundation

Discussion Panel Featuring:



Vicki Seyfert-Margolis, Ph.D.
Moderator
Founder and CEO,
Respond Health



Jill Castle, M.Ed
Featured in Film
*Carry On: Finding Hope
in the Canyon*



Levi Gershkowitz
Director
The Tenacity of Hope
Founder of Living in the Light

Sponsor Remarks



Rodney Dickson
Senior Director
Therapeutic Policy and Advocacy,
Rare Disease U.S. Public Affairs
Takeda Pharmaceuticals



Katia Mortiz, Ph.D., ABPP
Director and Undiagnosed Patient
UNDIAGNOSED



Andrea Lytle Peet
Featured in Film
Go On, Be Brave
President, Team Drea Foundation

- **Tuesday, February 25**

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

Presented by:

sanofi

8:00 - 9:00 a.m.

Registration and Breakfast
Atrium

9:00 - 10:00 a.m.

Welcome
Atrium Hall and via Livestream

Lisa Langenderfer, Alexion Pharmaceuticals
James Griffin, Rare Disease Week Advocacy Chair

Keynote
Josh Andrews, Retired NFL Player and Rare Disease Advocate

Logistics Overview
Shannon von Felden, EveryLife Foundation for Rare Diseases

10:00 - 10:30 a.m.

Legislative Outlook
Atrium Hall and via Livestream

Hear from experts on the 119th Congress and how Congress will impact healthcare policy in 2025.

Moderator: Shannon von Felden, EveryLife Foundation for Rare Diseases
Clay Alspach, Leavitt Partners
Remy Brim, BGR Group
Caitlin Van Sant, Mehlman Consulting
Shayne Woods, Alpine Group

10:30 - 10:45 am

Break



Family Space

Ronald Reagan Building, Oculus, Ground Level. The Family Space will be available for families all day except from 1:45-2:45, 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.



Legislative Conference Agenda



- **Tuesday, February 25 - Continued**

10:45 a.m. - 11:45 a.m.

Deep Dive Policy Ask #1:

Protecting the Biomedical Rare Disease Research Ecosystem
Atrium Hall and via Livestream

Introduction: Duane Clark, Sanofi

Moderator: Annie Kennedy, EveryLife Foundation for Rare Diseases

Amy Brower, Ph.D., Creighton University School of Medicine

Jennifer Bernstein, Horizon Government Affairs, EveryLife Foundation Board Member

Kevin Brennan, NCATS Alliance

E. Cartier Esham Ph.D., Alliance for a Stronger FDA

11:45 a.m. - 12:30 p.m.

Deep Dive Policy Ask #2:

Orphan Drug Incentives and Rare Pediatric Disease Priority Review
Voucher (PRV) Program
Atrium Hall and via Livestream

Moderator: Jamie Sullivan, EveryLife Foundation for Rare Diseases

Neena Nizar, Ph.D., The Jansen's Foundation

Deanna Portero, Orphan Therapeutics Accelerator

Jill Wood, Phoenix Nest Inc.

12:35 pm

Group Photo 

Atrium Stairs

12:45 - 1:45 pm

Networking Lunch

Atrium

1:45 - 2:45 pm

Preparing for Successful Meetings*

Atrium Hall, Ballroom A & B, and via Livestream

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

Kendly Jones, EveryLife Foundation for Rare Diseases

2:45 - 3:15 pm

Snack Break

Atrium



Reagan WiFi Access

Network Name: RareDC2025

Password: Travers1

Thanks to our WiFi sponsor

Traverse Therapeutics



Legislative Conference Agenda



3:15 - 4:00 p.m.

Breakout Sessions

Track 1:

Deep Dive Policy Ask #3: Accelerating Kids' Access to Care Act
Atrium Hall and via Livestream

Moderator: Dylan Simon, EveryLife Foundation for Rare Diseases
Jennifer Dexter, National Health Council
Nicholas Manetto, Faegre Drinker
Kyle Underwood, Rare Disease Advocate

Track 2:

Advocacy for Young Adults
Atrium Ballroom B

This session is for young adults (ages 16-30) to learn more about the Young Adult Rare Representatives (YARR) community legislative ask.

Moderator: Laura Romano, EveryLife Foundation for Rare Diseases
Camryn Berry, Young Adult Rare Representative
Amelia Hartley, Young Adult Rare Representative
Anneliese Williams, Young Adult Rare Representative



4:00 - 4:05 p.m.

Transition Between Rooms

4:05 – 4:50 pm

Breakout Sessions

Track 1:

Working to Achieve Broad & Equitable Access to Innovative Therapies
Atrium Hall and via Livestream

Moderator: Abbey Hauser, EveryLife Foundation for Rare Diseases
Temilola Adolabi, Sick Cells
Ron Bartek, Friedrich's Ataxia Research Advocate
Siobhain Carolan, Rare Disease Advocate
Jamie Sullivan, EveryLife Foundation for Rare Diseases

Presented by:



Track 2: Practice Your Pitch

(Atrium Ballroom B)

***This is a must-attend session for those individuals who are new to advocacy.** Learn how to develop and make your legislative ask during your meetings. The session will offer new advocates an opportunity to practice making their ask and telling their story with other advocates. This is a great opportunity to get questions answered by experienced rare disease advocates.

Moderator: Stephanie Riordan, EveryLife Foundation for Rare Diseases
RDLA Advisory Committee Members: Leah Campbell, Kelly Considine, James Griffin, Molly Maywood, Nate Milam, and Marlene Soto
James Griffin, Rare Disease Week Advocacy Chair

4:50 – 5:00 pm

Closing Remarks

Atrium Hall and Atrium Ballroom B

Rare Disease Congressional Caucus Briefing



- **Wednesday, February 26**

Check-in and Breakfast

8:30 – 9:00 am

Rare Disease Congressional Caucus Briefing

9:00 am – 10:00 am

Top of the Hill Banquet & Conference Center

1 Constitution Ave NE, Ballroom, Washington DC, 20002

The Rare Disease Community in America in 2025

Rare Disease Legislative Advocates and the Rare Disease Congressional Caucus invite you to a rare disease briefing.

Welcome

Congressman Gus Bilirakis (FL), Rare Disease Congressional Caucus Co-Chair

Emma Hatcher, CSL Behring

Frank Sasinowski, M.S., MPH, J.D., EveryLife Foundation Board of Directors

Guest Panel

Moderator: Sati Cooper-McCann, 10-year-old Rare Disease Advocate

Joshua Andrews, Retired NFL Player and Rare Disease Advocate

Nell Choi, 16-year-old Rare Disease Advocate

Jennifer Dexter, National Health Council

Matthew Ellinwood, DVM, Ph.D., National MPS Society

Annie Kennedy, EveryLife Foundation for Rare Diseases

Presented by:
CSL Behring



Hand Sanitizer

Thank you to our Rare Disease Week
hand sanitizer sponsor Genentech.

Genentech
A Member of the Roche Group



RAREARTIST Reception

Wednesday, February 26th from 5:00 PM - 7:00 PM
Top of the Hill Banquet & Conference Center
1 Constitution Ave NE, Washington, DC 20002

Remarks and the 2024 Rare Artist Awardee highlight video will kick off at 5:30 PM. Before and after the remarks, artists will be stationed by their artwork for a special meet-and-greet opportunity. Enjoy delicious hors d'oeuvres and refreshments as you connect with these incredible artists and hear their powerful rare disease stories. Plus, don't miss the chance to take home beautiful postcards of their artwork as a keepsake!

2024 Rare Artist Awardees

**Artist in attendance -- look for their nametag!*

Adults:

Dana Simmons, "Strength is Not Always Loud" *
 Eugenie Hsu, "The Art of Surviving Craniopharyngioma" *
 Gillian Sapia, "Subject ID: PJS2017" *
 Lena Regina Smith, "Hidden Clarity" *
 Niki Lake, "Moyamoya's Seasonal Tapestry"
 Therea Alo, "Upside Down" *

Teenagers:

Grey Pomeroy, "Experiment" *
 Nell Choi, "Twist of Life" *

Young Adults:

Lia Ottinot, "Crow's Armor" *

Children:

Sati Cooper-McCann, "I AM RESILIENT" *

Thank you to our Rare Artist Reception Sponsor



Scan for more artist info



Save the date! Rare Artist 2025 opens on June 2nd at RareArtist.org



Hill Day Issue Information



Legislative Ask #1 Ensuring Steady and Robust Federal Biomedical Research Funding & Public Health Agency Support

Rare Disease Community & Federal Agencies – A Critical Partnership

While many federal agencies support our rare disease ecosystem, the federal agencies housed within the Department of Health and Human Services (HHS) are essential to supporting timely diagnosis, conducting research, enabling therapy development, facilitating insurance coverage, and implementing public health programs.

The removal of key experts at Health and Human Services Agencies, including NIH, FDA, and CDC – paired with recent executive orders on federal funding and public health agencies – will have a devastating and lasting impact on programs that are vital to thousands of rare disease communities, and to our nation as a whole.

Among the federal agencies that support our community are:

National Institutes of Health (NIH)

NIH includes 27 Institutes and Centers that fund and conduct innovative rare disease research, without which rare diseases would go unstudied, and therapy development would be nearly impossible.

- The National Center for Advancing Translational Sciences (NCATS) is considered the ‘rare disease home’ at NIH.
- NCATS speeds the development of new rare disease treatments by focusing on scientific approaches that can address more than one disease at a time
- NCATS has contributed to 55 Investigational New Drugs and 14 approved therapies

Food and Drug Administration (FDA)

FDA partners with rare disease researchers, patient communities, and medical product developers to advance the science of the design, development and evaluation of safe and effective treatments.

- FDA Centers with rare emphasis include:
 - ✓ Center for Drug Evaluation and Research (CDER)
 - ✓ Center for Biologics Evaluation and Research (CBER)
 - ✓ Center for Devices & Radiological Health (CDRH)
- The newly established Rare Disease Innovation Hub works across both CDER and CBER.
- Within FDA, the Office of Orphan Products Development (OOPD) implements the Orphan Drug Act and oversees a targeted grant program whose research has led to over 80 FDA-approved therapies.

Centers for Disease Control and Prevention (CDC)

CDC works to protect public health by conducting research, providing health information, and responding to health threats.

- CDC leads national newborn screening (NBS) programs through the development of testing materials that enable states to identify several rare diseases at birth and maintain quality in state NBS laboratories through technical support and training .
- The National Center for Health Statistics (NCHS) maintains the International Classification of Diseases (ICD) codes, the coding system used to record medical conditions, symptoms, and injuries, unlocking access to treatment reimbursement and advancing research about rare disease impacts .
- The National Center for Birth Defects and Developmental Disability (NCBDDD) supports efforts to promote newborn screening and healthy outcomes for individuals with pediatric onset conditions including surveillance programs for muscular dystrophies and Spina Bifida.

Scan to view more
agencies and sources



Hill Day Issue Information



Legislative Ask #2 Reauthorize the Rare Pediatric Disease Priority Review Voucher (PRV) Program at FDA

Talking Points

- ✓ Developing drugs for rare pediatric diseases is challenging due to the small populations affected, difficulties associated with conducting clinical trials for children, delays in diagnosis, and more.
- ✓ About 70% of rare diseases are exclusively pediatric onset and overall, 95% of rare diseases have no approved treatments.
- ✓ The Creating Hope Act expanded the Priority Review Voucher (PRV) Program to include drugs that treat rare pediatric diseases in 2012.
- ✓ To be eligible for a PRV, the treatment must obtain a Rare Pediatric Designation from the FDA, be eligible for priority review, and it must be the first approval for the drug's active ingredient.
- ✓ After the FDA approves an eligible treatment, the company is issued a PRV. The opportunity to obtain a PRV is an important incentive in pediatric rare disease therapy development because:
 - Earlier Review: a company who gets a PRV can use it on a future treatment that wouldn't otherwise qualify for priority review, leading to about a 4-month reduction in review time.
 - Revenue Generation: some companies choose to sell the PRV to another company, generating revenue for the seller that is often used to continue and expand their rare disease research and development programs.
- ✓ The Rare Pediatric Disease PRV Program was last reauthorized in 2020 for a four-year period.
- ✓ Despite a five-year reauthorization passing the House in September 2024, and inclusion in the bipartisan healthcare policy package at the end of December, the Rare Pediatric PRV Program expired on December 20, 2024. As a result, companies must have received Rare Pediatric Designation by December 20, 2024, to be eligible. After September 30, 2026, FDA will no longer be able to award Rare Pediatric PRVs.

The Give Kids a Chance Act

- The Give Kids a Chance Act of 2025 (H.R. 1262) includes a five-year reauthorization of the PRV Program, similar to the legislation of the same name that passed the House in September 2024.
- The Senate is expected to introduce companion legislation to reauthorize the PRV Program soon.



Scan for Legislative
Asks One Pagers



Legislative Ask #3 Include Accelerating Kids' Access to Care Act (AKACA) in the first available legislative package

Talking Points

- ✓ Many children live in states where specialized care is not available locally. Even some states with leading medical centers lack health providers with expertise in some rare conditions.
- ✓ Children with complex medical needs like rare diseases and cancer often must travel outside their states to receive treatment.
- ✓ More than half of children in the U.S. rely on Medicaid and the Children's Health Insurance Program (CHIP) for their health insurance coverage. But bureaucratic rules in these programs often limit kids' ability to get timely treatment outside their home state.
- ✓ This process needlessly results in delays in treatment that can cause a child's condition to worsen.

Accelerating Kids' Access to Care Act (AKACA)

- Will ensure better, faster healthcare for kids who need it most by reducing the burden on the doctors who treat them.
- On September 17, 2024, the House of Representatives unanimously passed the Accelerating Kids' Access to Care Act. This legislation was also included in the bipartisan negotiated health title of the end-of-year package. Unfortunately, the healthcare policies were dropped from the end-of-year package and AKACA did not pass.



Scan for Legislative
Asks One Pagers

Hill Day Issue Information



Legislative Ask #4

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

Talking Points

- ✓ The Rare Disease 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.



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 Member List



House

- Mark Amodei R-NV
- Jake Auchincloss D-MA
- Don Bacon, D-NE
- 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
- 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
- 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
- Raul Grijalva D-AZ
- Glenn Grothman D-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
- 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
- John Larson D-CT
- 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
- Nicole Malliotakis R-NY
- Brian Mast R-FL
- **Doris Matsui* D-CA**
- Michael McCaul R-TX
- Morgan McGarvey D-KY
- Jim McGovern D-MA
- Grace Meng D-NY
- Carol Miller R-WV
- Mariannette Miller-Meeks R-IA
- 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
- Chellie Pingree D-ME
- 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
- Mary Gay Scanlon D-PA
- Jan Schakowsky D-IL
- Brad Schneider D-IL
- David Scott D-GA
- Mikie Sherrill D-NJ
- 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
- Eric Swalwell D-CA
- Glenn Thompson R-PA
- 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
- John Barrasso R-WY
- 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
- 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
- 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**

Senate



Scan for up to date
Caucus members



Caucus: 154 Members
House: 125 Members **Senate:** 29 Members
Caucus Co-Chairs*: Sen. Amy Klobuchar (MN), Sen. Roger Wicker (MS), Rep. Gus Bilirakis (FL), and Rep. Doris Matsui (CA)



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.



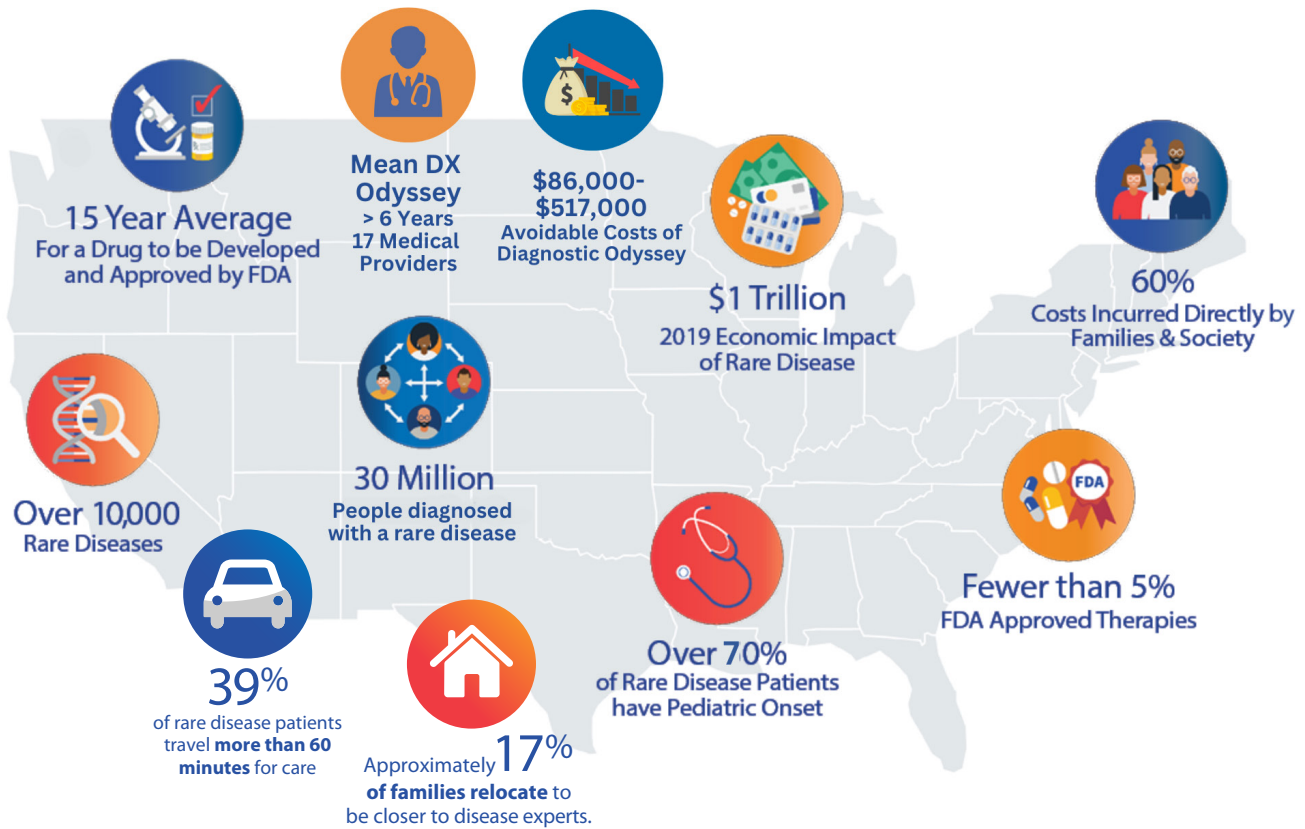
It takes an average of **15 years** for a drug to be developed and approved by the FDA.



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.

Rare in Numbers



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

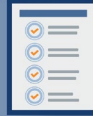
To learn more about the EveryLife Foundation's published articles, papers and letters scan here:



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 a minute or two.
- 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 filling out the Online Meeting Feedback Form.
- Follow-up with a thank you note/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

- ✓ Arrive at your meetings early to allow time for potential security lines and to accommodate individuals with mobility concerns.
- ✓ Use your map (page 29) as a resource guide - it helps you understand the layout to best navigate the space.
- ✓ Come ready to share your story, practice your pitch to ease nerves and confidently share your message with legislators.
- ✓ Most importantly... **BE YOUR AUTHENTIC SELF!**



James Griffin
Advocacy Chair,
Rare Disease Week
on Capitol Hill



Paloma Juarez
Vice Chair,
Rare Disease Week
on Capitol Hill

Social Media Advocacy Tips

- **How does a “#” work?**

On X, Facebook, Instagram and LinkedIn the pound sign (#) 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 **#RareDC2025** 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 **#RareDC2025** 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 X/Instagram account to make sure their account’s identity has been verified.

- **Before your meeting:**

Create a post tagging the Member’s office and the issue you will be talking about. Example post shown at right. ➔

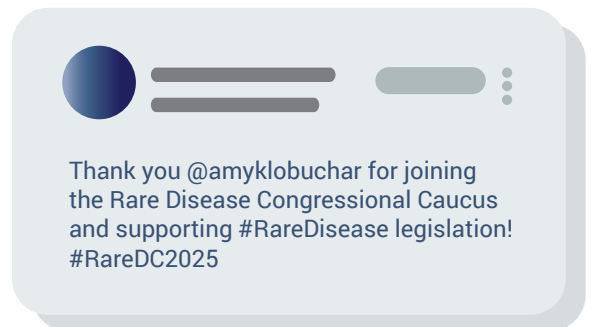
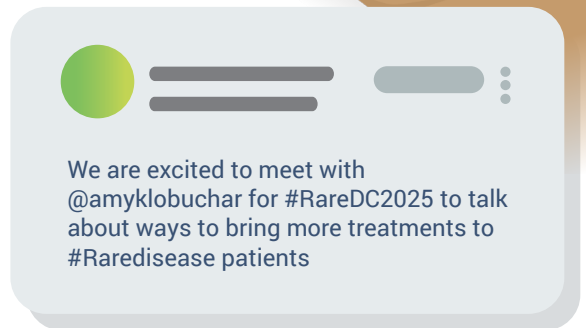
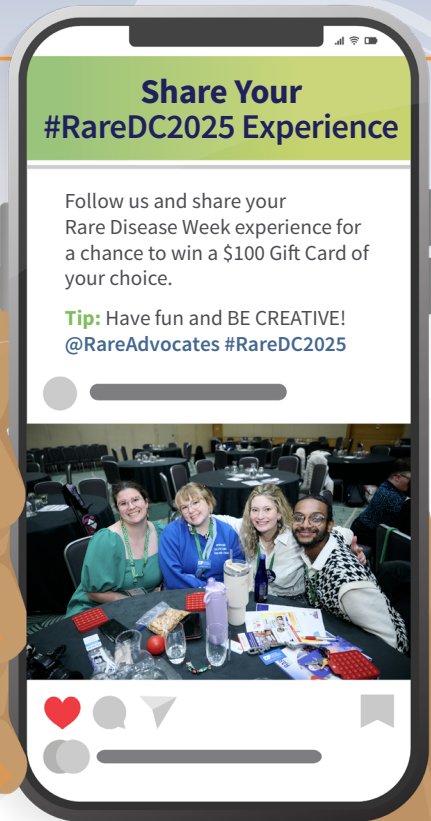
This is a good way to introduce yourself and your issue to the staff. This will add a face to the upcoming meeting and will help them remember you.

- **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. Example post shown at right. ➔



Glossary



Congressional Terms

Glossary Section
Presented by:



- **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 Cosponsor:** 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

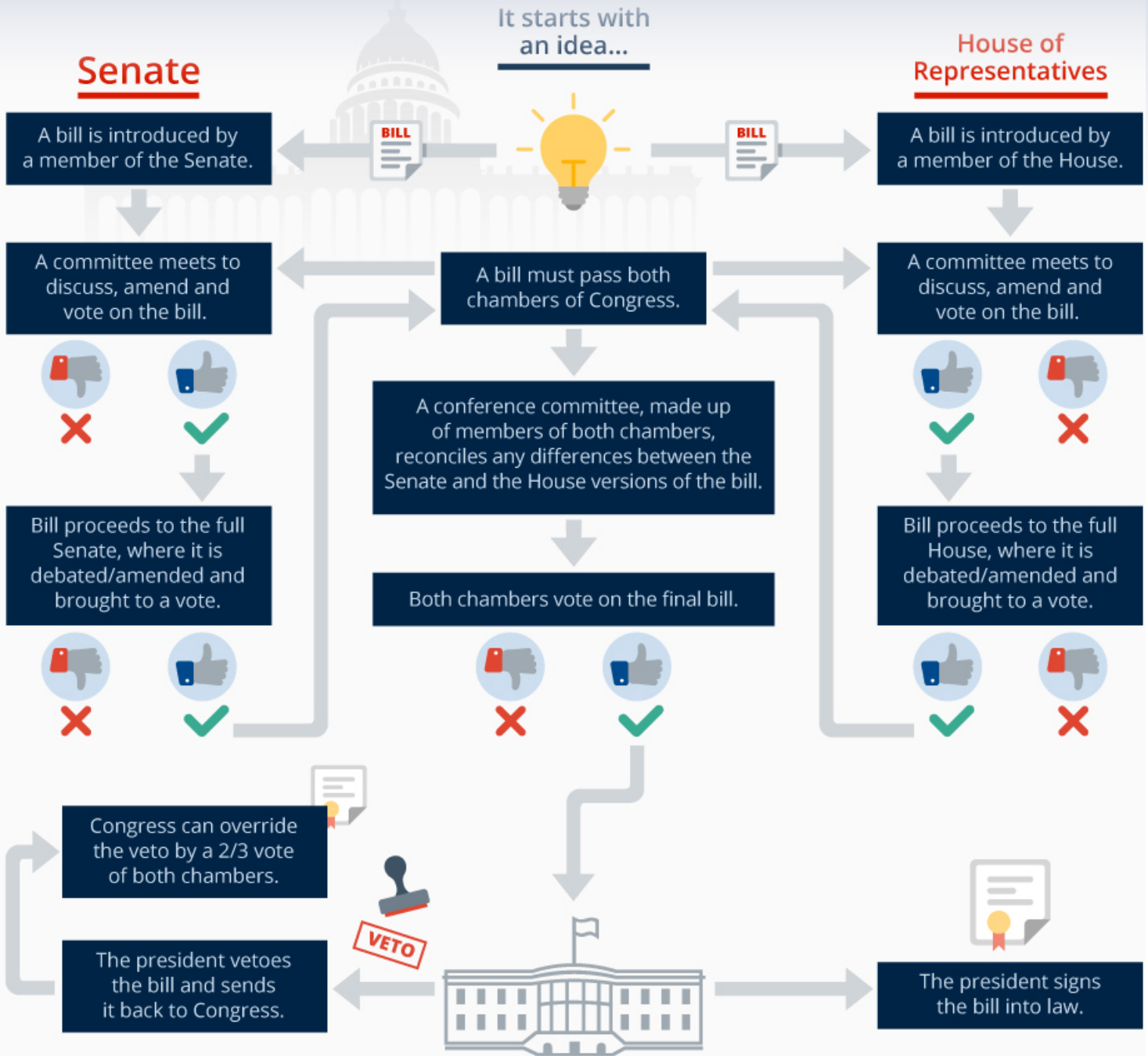


Government Agencies

- **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. This Department includes the below agencies, among others (12 total).
- **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



Accessibility Resources



General Travel Links

- **Visit the Capitol**
visiththecapitol.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 service for individuals who use wheelchairs or who need mobility assistance. The shuttles run from the bus drop-off and pick-up areas on the West side of the Capitol to the Capitol Visitor Center entrance at the center of the Capitol's East Plaza. They operate continuously, as needed, from 8:30am – 4:30pm, Monday – Saturday.
- **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:
visiththecapitol.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

Resources Section
Presented by:



Scan for easy access
to resource links



Capitol Hill Resources



Food Service Options on Capitol Hill buildings

- **Longworth Cafeteria - B223**
Basement level of Longworth House Office Bldg.
- **Rayburn Cafeteria - 2063**
Ground level of Rayburn House Office Bldg.
- **Dirksen Cafeteria - SD-G26**
Ground level of Dirksen Senate Office Bldg.
- **The Coffee Shop - SD-BR8**
Basement level of Dirksen Senate Office Bldg.
- **Southside Buffet - SD-BR8**
Basement level of Dirksen Senate Office Bldg.
- **Dirksen North Cafe - SD-BR7**
Basement level of Dirksen Senate Office Bldg.

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 WiFi Network Access

House of Representatives Office Buildings

Network Name: HousePublic
Password: HousePublic

Senate Office Buildings:

Network Name: Senate_Guest
Password: 119congress

Metro System Map



wmata.com
 Information: 202-637-7000 | TTY: 202-962-2033
 Metro Transit Police: 202-962-2121 | Text: MYMTPD (696873)

- ### Legend
- **RD** Red Line • Glenmont / Shady Grove
 - **OR** Orange Line • New Carrollton / Vienna
 - **BL** Blue Line • Franconia-Springfield / Downtown Largo
 - **GR** Green Line • Branch Ave / Greenbelt
 - **YL** Yellow Line • Huntington / Mt Vernon Sq
 - **SV** Silver Line • Ashburn / Downtown Largo

- ### Station Features
- P Parking
 - H Hospital
 - A Airport
- ### Connecting Rail Systems
- VRE
 - MARC



Metro is accessible.
WASHINGTON METROPOLITAN AREA TRANSIT AUTHORITY © 2023

N
 Map is not to scale

- No Smoking
- No Eating or Drinking
- No Animals (except service animals)
- No Audio (without earphones)
- No Littering or Spitting
- No Dangerous or Flammable Items

Ronald Reagan Building Map



- | | |
|--|---|
| 1 Registration Johnson&Johnson | 7 Charging Station Lounge gsk |
| 2 Main Sessions | 8 Family Space Biogen |
| 3 Breakfast ucb | 9 Medical Station |
| 3 Lunch Pfizer | 10 Nap Nook HARMONY BIOSCIENCES |
| 4 Auxiliary Room Mallinckrodt | 11 Nursing/Lactation Room |
| 5 Breakout Sessions | 12 Community Corner |
| 6 Group Photo | |

 Accessible Restrooms
  Escalators
  Elevators



By activating the patient advocate, we can change public policy and save lives.

BEGIN YOUR ADVOCACY JOURNEY TODAY



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.

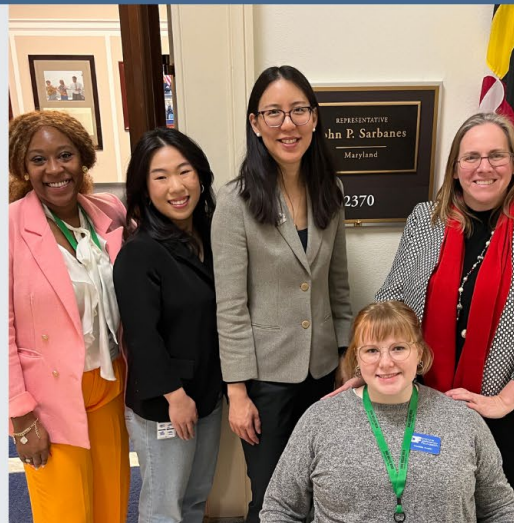
f X in @EveryLifeOrg

EVERYLIFEFOUNDATION.ORG



THE RDLA IS YOUR ADVOCACY PARTNER

We provide free resources, tools and events for patients, caregivers and organizations.



RAREADVOCATES.ORG

@RAREADVOCATES



NEWBORN SCREENING

Join the fight to protect and advance
one of America's most successful public health programs!

RARESCREENING.ORG



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 21 - June 6, 2025

Applications Open February 28, 2025



RARE
ACROSS AMERICA

EVERY VOICE, IN EVERY DISTRICT, MATTERS

ADVOCATE FROM HOME!
Coming this August
Registration Opens May 12, 2025



RAREACROSSAMERICA.ORG

June 17

V!RTU@L YOUTH & TEEN HILL ADVOCACY DAY



#RAREis Scholarship Fund

Powered by the EveryLife Foundation



Thanks to the support of Amgen, The EveryLife Foundation for Rare Diseases will provide one-time awards of \$5,000 scholarships up to 104 rare disease recipients in 2025.



APPLICATIONS OPEN MARCH 18 - APRIL 28, 2025

Scan QR code to learn more & apply



"Receiving this scholarship not only eases my financial worries, but also validates the challenges individuals living with rare diseases face. It inspires me to continue advocating for and researching ways to enhance the lives of those affected by rare diseases." - Sara Moore

Join the Young Adult Rare Representatives (YARR)!

- Meet other young adults passionate about rare disease
- Impact policy at the federal and state levels
- Develop your public speaking and leadership skills
- Become a more effective and powerful advocate

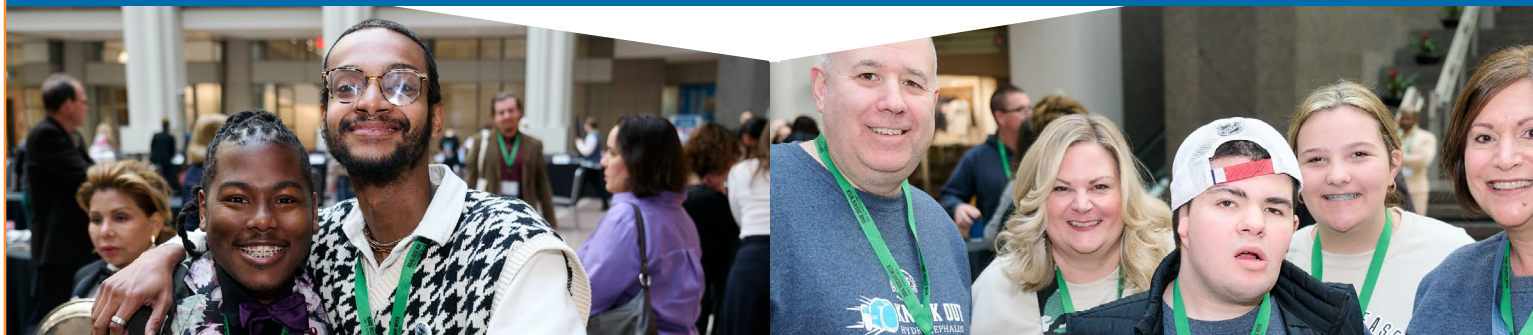


Open to
Advocates
Between 16
and 30 Years
of Age



Part of a company or
organization?
Contact us to invite a young
adult speaker for your event.

Thank you for participating in Rare Disease Week on Capitol Hill 2025!



Our collective efforts have been instrumental in advocating towards critical policy changes, enhanced access to lifesaving diagnoses and treatments, and increased awareness of the urgent needs of the 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 ignite hope, action, and resilience. Every voice, every partnership, every donation moves us closer to a world where the needs of those living with rare diseases are heard and addressed.

Make Your Gift >>>



KENDALL
LIVING WITH NFT

Transforming Lives. Every Day.

Alexion, AstraZeneca Rare Disease is focused on serving patients and families affected by rare diseases and devastating conditions through the discovery, development and delivery of life-changing medicines. [alexion.com](https://www.alexion.com)

Fighting the World's Toughest Diseases

AMGEN IS PROUD TO SUPPORT THE EVERYLIFE FOUNDATION

Amgen harnesses biology and technology to make people's lives easier, fuller, and longer. We draw upon our deep knowledge of science to push beyond what's known today. With roots in the biotech revolution, we are one of the world's leading independent biotech companies – fighting the toughest diseases and helping millions of people globally. For more information, visit www.amgen.com.



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



Driven by our promise to meet patients' needs, CSL Behring has a long history of innovation. It's what fuels us to deliver life-saving medicines and protect public health. By providing medicines to people in need around the world, we continue to deliver on our promise of global collaboration and innovation.

Learn more at [CSLBehring.com](https://www.CSLBehring.com).



CSL Behring

We are proud to support Rare Disease Week on Capitol Hill 2025



At Traveře 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 | [@TravereRare](https://twitter.com/TravereRare) | [#InRareForLife](https://www.instagram.com/InRareForLife)

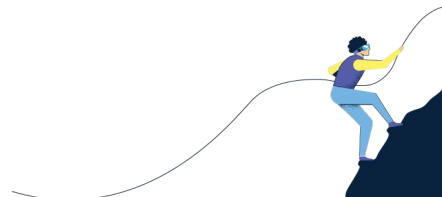


Challenge accepted.

We don't expect solutions to come easy.

We use the power of leading-edge science to save and improve lives around the world.

For more than a century, we've been at the forefront of research, bringing forward medicines, vaccines and innovative health solutions for some of the world's most challenging diseases.



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Yathish & Pawan, friends living with *Gaucher disease*, India



We are an innovative global healthcare company, driven by one purpose: we chase the miracles of science to improve people's lives.

In Specialty Care, our mission is to help people with debilitating and complex conditions in rare diseases, rare blood disorders, neurology, oncology, and immunology. These conditions are often difficult to diagnose and treat. But we aren't afraid of challenges. They just push us to work harder, to chase new potential therapies that help patients to live their lives.

sanofi

Follow Us on Social Media and Share Your #RareDC2025 Experience



#RareDC2025
@RareAdvocates



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!

RARE
DISEASE WEEK
ON CAPITOL HILL






EVERYLIFE

FOUNDATION
FOR RARE DISEASES

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everylifefoundation.org



POWERED BY THE EVERYLIFE FOUNDATION

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Office: (202) 697-RARE(7273)
rareadvocates.org

@EveryLifeOrg    

#RAREDC2025 @RAREADVOCATES   