



Rare Disease Day Recap & More!

This year, Rare Disease Day fell on the rare day of February 29, 2024 and the energy around it was palpable!

From the halls of Congress to the White House to the NIH & FDA, government officials joined thousands of rare disease patients to mark the day by lighting up national landmarks, sharing lived experiences, and raising awareness of the incredible unmet medical need in the rare disease community.

With over 10,000 diseases, 95% with no treatments, a resounding collective voice called for robust funding for research and additional legislation to expedite treatments to patients.

FARA Ambassadors Darla Sparacino (Arkansas) and Kelly Barendt (Ohio) joined FARA President Ron Bartek and FARA Director of Advocacy Brigid Brennan for the action-packed week in DC. The event details and links to recordings are below. But, for a wonderful recap, please this slideshow created by Kelly.



RARE DISEASE DAY®

[Check Out Kelly's Recap](#)

A special shout out to FARA Ambassador Mary Nadon Scott who demonstrated that each of us holds the power to advocate and effect change! Mary could not make it to DC but that did not stop her from advocating! She scheduled meetings with the local offices for her US Senators and US House Representative. She also met with Governor Phil Scott which resulted in a state proclamation recognizing February 29 as Rare Disease Day.

Rare Disease Day/Week



This year was the 15th Anniversary of the EveryLife Foundation for Rare Diseases and the 13th annual Rare Disease Week on Capitol Hill which was marked by a powerhouse assembly of more than 800 advocates from all 50 states including Puerto Rico, Washington, DC, and the sovereign Cherokee Nation. Advocates joined together on Capitol Hill for over 330 meetings with elected officials to address rare disease policy solutions.



FARA was proud to be a part of the Rare Disease Week on Capitol Hill, including having FARA's Director of Advocacy Brigid Brennan speak at the Rare Disease Congressional Caucus briefing. You can watch all recorded programs [here](#).



OFFICE OF SCIENCE AND TECHNOLOGY POLICY

For the first time, the Office of Science and Technology Policy's Health Outcomes Team held a **White House Rare Disease Forum** on Wednesday, February 28. It was at this event that a \$48.3 million grant was announced by the Advanced Research Projects for Health (ARPA-H). This investment will be used to repurpose existing drugs to address rare diseases currently lacking treatment options and will be led by Dr. David Fajgenbaum of [Every Cure](#).

You can find a [readout of the event](#) and the [event livestream](#) online.



TODAY Show Plaza in New York, New York: A mighty herd of zebras joined us to brace the cold at the TODAY show plaza! Advocates showed up from far and wide in our stripes and spent the morning raising awareness for Rare Disease Day in the plaza and through the window. #ShowYourStripes signs even made appearances on air!



#LightUpForRare

Rare disease advocates from around

the world illuminated landmarks and buildings in Rare Disease Day colors as part of the global #LightUpforRare initiative. FARA arranged to light up the Tower Crown Light – Capella Tower Minneapolis!



Food and Drug Administration (FDA)
Silver Spring, Maryland



Notre Dame College of Science
St. Joseph County, Indiana



Hoan Bridge
Milwaukee, Wisconsin



Rare Disease Day at the National Institute of Health (NIH) was held on February 29, 2024 and was an extraordinary occasion dedicated to raising awareness for rare diseases and all those who are impacted. A recording of the event is [here](#).



If you missed the virtual Food and Drug Administration Rare Disease Day on March 1, 2024, you can view a recording of the event on www.fda.gov/rarediseaseday2024.



In recognition of Rare Disease Day 2024, the Oxford-Harrington Rare Disease Centre (OHC) hosted its 4th annual Rare Disease Day Webinar on February 28, titled ***Pioneering a Path to Rare Disease Therapeutics***.

[Watch the Recording](#)

Capitol Hill Updates



Rare Disease Day Houe Energy and Commerce Hearing

On February 29, 2024, *for the first time*, the House Energy and Commerce Health Subcommittee held a hearing to highlight 18 different bills aimed at addressing issues within the rare disease community. During the nearly three-hour hearing, legislators heard from speakers from Johns Hopkins, UMass General, Iowa Children's, Harvard, and USC as well as a rare mom, Khrystal Davis, who founded Texas Rare Alliance. The hearing marks an important milestone for the rare disease community's efforts to gain Congress' recognition that rare diseases require urgent action.



You can view a recording of the hearing and view the hearing materials [here](#).

Read Key Takeaway from NORD's Policy & Advocacy Experts

First Six Appropriations Bills Passed for FY 2024

On March 6, the House passed by a 339-85 vote, six fiscal year 2024 appropriation bills: Agriculture (includes FDA), Commerce-Justice-Science, Energy-Water, Interior-Environment, Military Construction-VA, and Transportation-HUD. The Senate followed suit on March 8 with a 75-22 vote. The President signed the bill that day and the first Continuing Resolution deadline was met.



The second CR deadline is March 22 and will cover the remaining six appropriations bills, including funding for research programs at the NIH and through the CDMRP.

Improving Air Travel for Passengers With Disabilities

The Department of Transportation announced [new, stringent standards](#) for airlines to ensure wheelchairs are not damaged and travelers in wheelchairs can fly with dignity. The proposal includes:



- **Penalties for mishandling wheelchairs, and other assistive devices:** The proposal would make those mishandlings an automatic violation of the Air Carrier Access Act, allowing DOT to "more easily penalize airlines and hold them accountable when a passenger's mobility device is damaged." It would also require airlines to promptly repair or replace damaged wheelchairs and provide a loaner.
- **Safe assistance:** The rule would require enhanced airline employee and airline contractor training that includes hands-on training, for those who physically assist passengers with mobility disabilities or handle passengers' wheelchairs. This includes the prompt return of a delayed wheelchair to the passenger's final destination within 24 hours.
- **Improved standards on planes:** The rule proposes improved performance standards for onboard wheelchairs on twin-aisle aircraft and small aircraft and notifications after loading and unloading a wheelchair.

The proposed rule will be seeking comments from the public for 60 days after it is published in the Federal Register. Stay tuned for your opportunity to advocate for this proposal!

Upcoming Advocacy Events

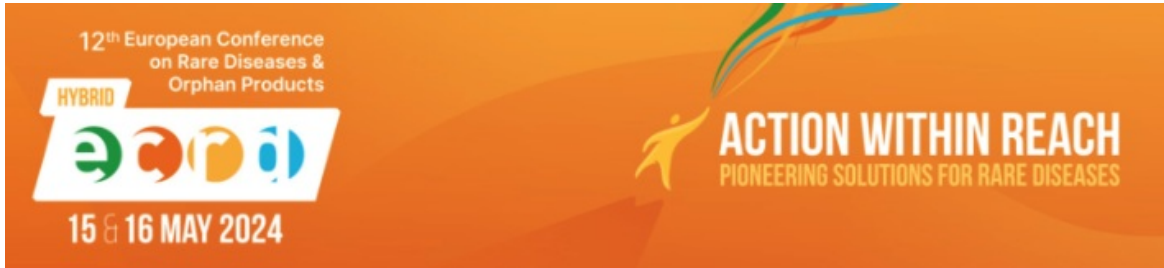


**Join us in Albany for an upcoming
Rare Disease State Advocacy Day!**

Registration is open until **Tuesday, April 2, 2024**.

To be considered for a travel reimbursement, register by **Tuesday, March 19**.

Register Now!



The ECRD is the **largest, patient-led, rare disease policy-shaping event** held in Europe.

By bringing together people with rare diseases and patient advocates, policymakers, healthcare industry representatives, clinicians, regulators, and Member State representatives, EURORDIS harnesses **the power of this extensive network** to shape goal-driven rare disease policies of the future.

With over 1000 participants, the Conference is an unrivaled opportunity to **network and exchange invaluable** insights within the rare disease community. Through collaborative efforts, these discussions culminate in **clear policy recommendations** that can influence both EU and national policies.

Get ready for the next ECRD, a fully hybrid conference taking place on **15 & 16 May 2024** online and at The Square in Brussels. Learn more [here](#).

GET YOUR PASS

PROGRAMME AT A GLANCE

Announcements

Congratulations to FA community member Alex Bode, who started a nonprofit called “Peace, Love, and Accessibility” to educate and lobby for more accessible parking options in Connecticut.

Learn More



Rare Advocacy Learning Application is Open!

**The seminar series will begin on April 23 and end on June 7.
Application closes on March 25.**

The Rare Advocacy Learning program is a free 6-week seminar series launched to provide in-dept education and advocacy training, developing a pathway toward year-round advocacy engagement. Advocates with prior advocacy experience are encouraged to apply. The Spring 2024 series is titled, "Making an Impact as a Rare Disease Patient in Patient-Focused Product Development".

[Learn More](#)



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