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ACTION THROUGH ADVOCACY!



RARE DISEASE DAY®

Rare Disease Day will be recognized on February 28, 2023 and celebrations are currently underway. Below is an amazing list of events, throughout the world, that you can participate in to help raise awareness of rare disease in general, and FA specifically! Moreover, sharing your experience is the key to lawmakers understanding FA, and paves the road to legislative actions that can expedite treatments. Don't let this Rare Disease Day pass without being part of the conversation!

The FA community has witnessed the impact of their advocacy in many ways, as detailed recently in [FARA's December Advocacy Newsletter](#), but none are as demonstrative as the work done regarding the Congressionally Directed Medical Research Program (CDMRP). The CDMRP is a great example of how the FA community created action through advocacy.

Each year, during the budget cycle, the US Congress selects conditions eligible for this grant program. The process to get on the list starts when a Congressional Member receives an "appropriation request" from a constituent. Basically, someone needs to ask for it! Each Member then reviews the appropriations requests they receive and decides which ones to forward on to the appropriation committee for further consideration. FA community stakeholders throughout the US, working in collaboration

with FARA and the National Ataxia Foundation (NAF), not only made the request but also followed up through meetings, emails and calls to explain the relevance of FA to the goals of the CDMRP program as well as the potential benefits of investing in FA research.

The result: FA was added to the CDMRP in Fiscal Year (FY) 22, resulting in six FA researchers being recommended for funding totaling over \$14 million! These grants are a direct result of the amazing advocacy done by this community!

Let's keep the momentum going in 2023! There are many great Rare Disease Day events listed below. Pick one that works for you and start your year of FA advocacy!



**Erin Seifert, Thomas Jefferson University, was mistakenly listed in the December Advocacy Newsletter as a CDMRP FA grant recipient. Erin Seifert, an FA researcher, did receive a CDMRP grant, but it was under a different topic area. Congratulations are still in order!*

Rare Disease Day Events



Virtual! Everyone can participate!

FDA will host Rare Disease Day, a virtual public meeting, on February 27, 2023, 9:00 am – 4:45 pm ET, in global observance of Rare Disease Week. This year's theme is "Intersections with Rare Diseases – A patient focused event." You can find more information and register [here](#).



Virtual and in person! Everyone can participate!

The [National Center for Advancing Translational Sciences \(NCATS\)](#) and the [National Institutes of Health \(NIH\) Clinical Center, Rare Disease Day at NIH](#) will hold both in-person at the NIH main campus and virtually on Tuesday, Feb. 28, 2023, from 9 a.m. to 5 p.m. EST. The event aims to raise awareness about rare diseases, the people they affect, and NIH

collaborations that address scientific challenges and advance research for new treatments. The goals are to:

- Demonstrate the NIH commitment to helping people with rare diseases through research.
- Highlight NIH-supported rare diseases research and the development of diagnostics and treatments.
- Initiate a mutually beneficial dialogue among the rare diseases community.
- Exchange the latest rare diseases information with stakeholders to advance research and therapeutic efforts.
- Shine a spotlight on stories told by patients living with a rare disease, their families, and their communities.

Rare Disease Day at NIH seeks to bring together a broad audience including patients, patient advocates, caregivers, health care providers, researchers, trainees, students, industry representatives, and government staff. The event is free and open to the public.

Attendees are asked to register prior to attending in-person or viewing the livestream, and registration is **required** to use the event app. You can register [here](#).



*Although most events are in DC, the Legislative Conference will be livestreamed and you can contact Members directly.
Everyone can participate!*

[Rare Disease Week on Capitol Hill](#) is February 28th through March 2nd, 2023. Hosted by the Rare Disease Legislative Advocates (a program of the EveryLife Foundation for Rare Diseases), Rare Disease Week brings together rare disease advocates from all walks of life to make their voices heard by their Members of Congress. Participants are educated on policy proposals impacting the rare disease community and provided opportunities to advocate for policy changes directly to their Members of Congress. **REGISTRATION CLOSSES FEBRUARY 17TH.**



EURODIS Rare Disease Week 2023

*Mostly in person but livestreamed conference on Feb 8!
Everyone can participate!*

EURORDIS is delighted to welcome you soon at the second edition of the [Rare Disease Week \(RDW\)](#)! After a virtual edition in 2021 that brought together more than 30 patient advocates, we are excited to announce that the RDW 2023 will finally be held in-person at the heart of Europe in Brussels.

The goal of these four-days series of events is to empower rare disease patient advocates with knowledge and skills enabling them to effectively participate in advocacy activities at the EU level and, as a result, to influence the EU decisions that have a direct impact on their lives.

Through RDW, the hope is also to raise awareness of rare diseases amongst EU decision-makers and present a strong and united message to MEPs and other policy-makers in Brussels on behalf of the rare disease community.





Rare Disease Day 2023

Join Us for a Webinar

**ADVANCING NOVEL THERAPIES
FOR RARE DISEASES**

27 FEBRUARY 2023

10:00AM – 11:00AM EST | 3:00PM – 4:00PM GMT

More details to come

Together We Cure

REGISTER NOW

Part of the Harrington **DISCOVER** Webinar Series

Virtual! Everyone can participate!

The [Oxford-Harrington Rare Disease Centre \(OHC\)](#) brings together the strengths and capabilities of the University of Oxford in the UK and the [Harrington Discovery Institute](#) in Cleveland, Ohio, US. They are united in our mission to deliver cures for rare diseases.




**SHOW YOUR
STRIPES®**

**ON RARE DISEASE DAY®
FEBRUARY 28TH**




Virtual! Everyone can participate!

SHOW YOUR STRIPES®

The zebra has become the official symbol of rare diseases in the United States. In honor of our shared mascot, we wear striped clothing and accessories to show our support of those lives impacted by a rare disease.

Wearing stripes can start a conversation that helps others learn the facts about the prevalence and challenges of rare diseases. Take a picture of your striped look and share it on social media with the hashtags **#ShowYourStripes** and **#RareDiseaseDay** and let's make some noise for our herd. Check out NORD's RDD Social Media toolkit with sample posts [here](#).

NORD also has a running list of upcoming Community Rare Disease events [here](#). NORD partners with EURORDIS to provide an International Rare Disease Day site [here](#).

Join FARA in supporting NORD's Light Up for Rare Program



Empire State Building

Virtual! Everyone can participate!

NORD is leading the call to light up the country in rare disease colors (pink, green, blue, and purple) during February, to unite the rare disease community and the country as a whole. The more homes, buildings, landmarks, and monuments illuminated, the greater the impact! The goal of Light Up for Rare is to help spread the word and raise awareness for people living with rare diseases.

FARA has arranged for the Pennsylvania Capital Lt. Gov. Balcony Lights to be blue, green, and pink from Feb 23 to Mar 1, as well as facilitated lighting all four bridges in Boston on Feb 28. You can join the effort and light up a landmark in your community. Learn how to be a part of this initiative [here](#).

Announcements

Newborn Screening and RUSP Alignment Target States for 2023

The EveryLife Foundation is excited to announce that it will pursue newborn screening alignment legislation in both **Texas** and **Wisconsin** in 2023. This legislation requires states to screen newborn babies for any disorder on the RUSP panel. You can learn more about their program [here](#).



To date, ten states have adopted the Federal Recommended Uniform Screening Panel (or RUSP) thanks to rare disease advocates and stakeholders.

