

RARE DISEASE WEEK ON CAPITOL HILL

Please mark your calendar and plan to join us for Rare Disease Week on Capitol Hill from February 29th through March 3rd. During this exciting week, rare disease community members from across the country learn about federal legislative issues, meet other advocates, and share their unique stories with legislators.

SCHEDULE

The week includes a variety of events including:

· **Monday, February 29th, 7:30am – 3:30pm: Rare Disease Day at the National Institutes of Health (NIH).**

Registration is available [here](#).*

*Shuttles will be available to transport advocates from NIH to the cocktail reception and documentary screening. Wheelchairs can be accommodated.

· **Monday, February 29th, 5:30 – 9:30pm: Cocktail Reception and Rare Disease Documentary Screening** featuring [Dusty's Trail: Summit of Borneo](#) at the U.S. Naval Heritage Center

· **Tuesday, March 1st, 8:30am – 5pm: Legislative Conference** at FHI 360

· **Wednesday, March 2nd, 7:30 - 9am: Lobby Day Breakfast** at the Capitol Hill Club

· **Wednesday, March 2nd, 9am – 5pm: Scheduled Meetings with Members of the House and Senate**

· **Thursday, March 3rd, 12-1pm, Congressional Rare Disease Caucus Briefing** in the U.S. Capitol Visitor Center

· **Thursday, March 3rd, 5-7pm: Rare Artist Reception** in the Rayburn House Office Building

All of these events are free and open to the public. Registration is required and will be available at <http://rareadvocates.org/rdw/> on January 5th, with the exception of Rare Disease Day at NIH which is open and available [here](#).

TRAVEL STIPEND

In order to enable more advocates to attend, the EveryLife Foundation for Rare Diseases is providing travel stipends to offset travel costs. Our goal is to have advocates from all fifty states and Puerto Rico in attendance. The deadline to apply is December 31st and applicants will be notified in early January. Please note that there is a limit of one stipend per family. Selected advocates in Alaska, Hawaii and Puerto Rico will receive \$1000 while advocates in the continental U.S. (outside of the Washington, DC region) are eligible to receive \$600. [Apply today!](#)

HOTEL BLOCK

We have a block with a limited number of rooms at the [Fairfax at Embassy Row](#) from Sunday, February 28th, through Friday March 4th. Please mention Rare Disease Legislative Advocates when you book to get the special rate of \$219 for a king (or ADA king) and \$239 for a double. The rooms are single or double occupancy, with a charge of \$30 for each additional person. You can [book online](#) or with the toll-free registration line at [888-627-8439](tel:888-627-8439). There is a limited number of ADA rooms available at the hotel, so we advise anyone who needs one to book early.

PREPATORY WEBINARS

We will hold two webinars to help advocates prepare for the week of events. The first, to be held on January 20th at 2pm EST, will provide an introduction to Rare Disease Week on Capitol Hill with an overview of the events. The second, to be held on February 23rd at 2pm EST, will provide more detailed advice to participants such as what to wear and what to bring for each event, and where to find additional resources. You can [register now](#) for the January 20th webinar.

PATIENT STORIES

Unable to join us for Rare Disease Week on Capitol Hill? Please [submit your unique patient story](#) with us by February 15 for advocates to hand-deliver to your Member of Congress.

Thank you to the sponsors of Rare Disease Week on Capitol Hill:



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