



PARTICIPATE REMOTELY

Legislative Conference Livestream

► The Legislative Conference on February 25 will be available by livestream to allow more advocates to benefit from the information. Details will be available on RareAdvocates.org/rdw.

RARE DISEASE LEGISLATIVE ADVOCATES

RDLA is a collaborative program designed to support the advocacy of all rare disease patients and organizations. By growing the patient advocacy community and working collectively, we can amplify our many voices to ensure rare disease patients are heard in state and federal government.

ABOUT THE EVERYLIFE FOUNDATION

The EveryLife Foundation for Rare Diseases is a 501(c)(3) nonprofit dedicated to accelerating biotech innovation for rare disease treatments through science-driven public policy. We can do more with the science we already have and bring life-saving treatments to millions of people suffering from rare diseases.



LEGISLATIVE ADVOCACY . POLICY NEWS . GRASSROOTS ACTION



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*RDLA is a program of the EveryLife Foundation for Rare Diseases, a 501(c)3 nonprofit, dedicated to spurring biotech innovation for rare disease treatments.
EveryLifeFoundation.org*

RARE DISEASE WEEK ON CAPITOL HILL



EMPOWERING THE PATIENT TO BE AN ADVOCATE

#RAREDC2019

FEBRUARY 24 - 28, 2019



2019



RARE DISEASE WEEK ON CAPITOL HILL

Join RDLA and more than 500 patient advocates for a full week of events dedicated to empowering patients, families and friends to become legislative advocates.

You will have an opportunity to meet with your Members of Congress, network with government leaders and learn best practices for successful advocacy. There is no cost for you to attend, and travel stipends are available.

SUNDAY, FEBRUARY 24

Rare Disease Documentary Screening and Cocktail Reception

- ▶ Ronald Reagan Building
1300 Pennsylvania Ave NW, Washington, DC
5:30 p.m. Cocktail Reception
7:00 p.m. Documentary Screening
8:30 p.m. Panel Discussion

MONDAY, FEBRUARY 25

Legislative Conference

- ▶ Ronald Reagan Building
1300 Pennsylvania Ave NW, Washington, DC
9:00 a.m. - 5:00 p.m.

TUESDAY, FEBRUARY 26

Lobby Day Breakfast

- ▶ Washington Court Hotel on Capitol Hill
525 New Jersey Ave NW, Washington, DC
7:00 - 8:30 a.m.

Lobby Day Meetings with Members of Congress

- ▶ U.S. Senate and House Office Buildings
9:00 a.m. - 5:00 p.m.

WEDNESDAY, FEBRUARY 27

Rare Disease Congressional Caucus Briefing

- ▶ Capitol Hill
12:00 - 1:30 p.m.

Rare Artist Reception

- ▶ Capitol Hill
5:00 - 7:00 p.m.

THURSDAY, FEBRUARY 28

Rare Disease Day at NIH

- ▶ National Institutes of Health
Masur Auditorium, Building 10
9000 Rockville Pike, Bethesda, Maryland
8:30 a.m. - 4:00 p.m.

REGISTRATION

▶ Registration opens January 3, 2019

RareAdvocates.org/rdw

All events are free for advocates, and all event venues are ADA compliant.

TRAVEL STIPENDS

In order to enable advocates from across the country to attend, the EveryLife Foundation will provide travel stipends ranging from \$400 to \$1000 depending on the distance to be traveled. Stipend recipients are required to attend the Legislative Conference and Lobby Day. Applications will be available online from October 8 through December 14 at RareAdvocates.org/rdw.

HOTEL ROOM BLOCK

A limited number of hotel rooms are available at a discounted rate. The hotel is centrally-located, welcomes service animals and offers complimentary Wi-Fi as well as disability access. Book your room now at 1-800-321-3010 using the group name of "EveryLife Foundation for Rare Diseases".

Washington Court Hotel

- ▶ 525 New Jersey Ave NW,
Washington, DC 20001

RAREADVOCATES.ORG/RDW
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