

Overview of the EveryLife Foundation for Rare Diseases



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EveryLife Foundation for Rare Diseases

@RarePOV of @EveryLifeOrg

The mission of the EveryLife Foundation is to accelerate biotech innovation through science-driven public policy.

We seek to achieve our goals by advocating practical and scientifically-sound policies to increase the predictability of the regulatory process through scientific analysis and dialogue, grassroots support and expert-led workshops.

We Believe:

- No disease is too rare to deserve treatment.
- All new drugs for rare diseases should be safe and effective.
- We could be doing more with the science we already have.

EveryLife Foundation for Rare Diseases

- 1) Serve and Support Rare Disease Patients
- 2) Promote Awareness about Rare Diseases
- 3) Advance Regulatory Science and Policy
- 4) Drive Public Policy and Legislative Change
- 5) Build A Grassroots Advocacy Community

Community Support



Rare Giving provides \$100,000+ in funding to the community in grants and travel scholarships to ensure Congress and FDA hear directly from patients and caregivers.

RAREARTIST

Rare Artist promotes awareness of rare diseases and highlights the talent of the rare community. The 2017 contest will begin accepting entries in June.



We provide financial support to the **North American Metabolic Academy** which trains and encourages the next generation of rare disease physicians and scientists.

Public and Scientific Policy Initiatives



We bring patient organizations, industry leaders, and other rare disease stakeholder organizations together to provide valuable insight on prioritizing future initiatives.



We convene leaders from FDA, NIH, patient advocacy organizations, and the biopharmaceutical industry to build the science to improve the clinical development process for rare diseases. The topic this year was expanded access.



We sponsored pilot legislation in California (SB 1095) that will require the state to screen for a disease once it's on the federal Recommended Uniform Screening Panel. The legislation was signed into law on September 16th.



We are the lead supporter of the OPEN ACT (Orphan Products Extensions Now, Accelerating Cures and Treatments) to encourage biopharmaceutical companies to repurpose approved therapies for rare disease.

Rare Disease Legislative Advocates



- Educates patient advocates about how public policy impacts availability and access to treatments.
- Provides resources to patients, caregivers, physicians and others so they can be successful legislative advocates.
- Provides an online advocacy center and legislative clearinghouse for all rare disease legislation at the state and federal level.
- Builds awareness on Capitol Hill and ensures Congress hears directly from patients and others in the rare community.

Advocacy



Brings 350+ patients to Washington, DC to learn how to build effective relationship with Congress and partner with federal agencies



Empowers advocates to meet with their Members of Congress during summer recess and hosts Regional Legislative Conferences help prepare advocates.



Hosts quarterly briefings to educate Members of Congress and their staff on issues of importance to the rare disease community



Recognizes advocates and Congressional aides making a difference in DC and state capitols

Action Alerts



RDLA can help promote YOUR action alerts on state and federal legislation that could impact the rare disease community.

A screenshot of the RDLA website's 'TAKE ACTION' section. The page has a dark blue header with the RDLA logo on the left and navigation links for 'ABOUT', 'TAKE ACTION', 'NEWS', 'CAUCUS', 'EVENTS', and 'RESOURCES' on the right. The main content area is light blue and features three white boxes, each representing an action alert. The first box has a pencil icon and is titled 'The EveryLife Foundation seeks your support to end the NIH/FDA hiring freeze', dated February 15, 2017. The second box has an envelope icon and is titled 'Join Research!America in calling for a standing fund to enable CDC/NIH response in public health emergencies', dated February 10, 2017. The third box also has an envelope icon and is titled 'National MPS Society urges your support in Missouri to advance life-changing newborn screening for MPS II and SMA!', dated February 6, 2017. Each box includes a 'Read more' link with a right-pointing arrow. The background of the page shows faint silhouettes of hands raised.

Monthly RDLA Webinars



- Any individual or patient advocacy organization is welcome to contribute agenda items, from pending legislation of interest to the rare disease community to new resources (such as NORD's state impact report) to new policy papers.
- Archived webinars are available online as a resource.

<http://rareadvocates.org/webinars/>

In-District Lobby Days



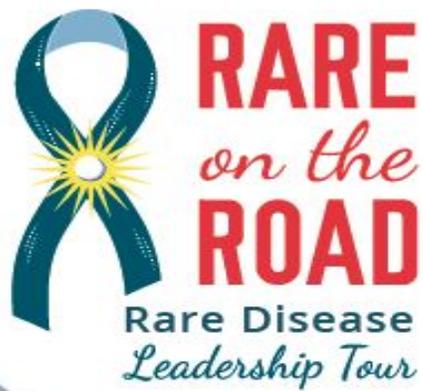
In order to help rare advocates build on their relationships with federal elected officials, we schedule meetings for them during the summer district work period in their home states.



Keep in Touch!

- Please sign-up for our email lists at EveryLifeFoundation.org/contact-us and RareAdvocates.org/contact for newsletters, action alerts and event invitations.
- Like us on Facebook as both the EveryLife Foundation for Rare Diseases and Rare Disease Legislative Advocates.
- Follow us on Twitter as [@EveryLifeOrg](https://twitter.com/EveryLifeOrg) and [@RareAdvocates](https://twitter.com/RareAdvocates).





Rare Disease Leadership Tour

Educating the next generation of advocacy leaders

This is a first of its kind collaboration harnessing the core competencies of Global Genes and EveryLife with the goal to bring increasing value, insights and knowledge to patients and advocates challenged by rare disease.

Saturday, May 13: TBD, Atlanta, GA

Monday, June 5: Kauffman Foundation Conference Center, Kansas City, MO

Saturday, July 15: Shriners Hospital for Children, Portland, OR

