



RDLA April 2020 Newsletter



CAPITOL HILL UPDATES

COVID-19 Response: COVID-19, also known as the coronavirus, began in December 2019 in Wuhan City, China. The first case in the United States was confirmed on January 21, 2020. Since January 21st, thousands of individuals in the United States have tested positive for COVID-19. In response to COVID-19, Congress has taken the following actions:

- Coronavirus Preparedness and Response Supplemental Appropriations Act, H.R. 6074, was passed by the House and Senate and signed into law on March 6th and includes funding to support developing, manufacturing and procuring vaccines as well as grants for local, state, and tribal public health agencies and organizations.
- H.R. 6201 was passed by the House and Senate and signed into law on March 18th and provide paid sick leave and free corona virus testing and expanded food assistance and unemployment benefits.
- \$2 trillion Coronavirus Stimulus package was passed by the House on March 27th which will include \$1200 checks to Americans making up to \$75,000 annually, unemployment insurance for those who lose their jobs, \$500 billion Treasury fund to shore industries damaged by COVID-19 and \$300 billion in small business loans.

Cameron's Law: On March 12th, Representatives Josh Gottheimer (NJ) and Fred Upton (MI) introduced H.R. 6238, Cameron's Law, which would restore the amount of the orphan drug tax credit to the same levels as they were prior to 2017. The orphan drug tax credit incentives companies to develop treatments for rare diseases which may not make a profit due to the small patient population.

Rare Disease Caucus Update: We are pleased that the Rare Disease Caucus has 9 new members of the caucus bringing the total membership of the caucus to 170, including 146 Representatives and 24 Senators. The list of members of the caucus can be found at rareadvocates.org/rarecaucus.



COMMUNITY ACTION ALERTS & POLICY RESOURCES

EveryLife Foundation for Rare Diseases is asking advocates to contact their Members of Congress to include in their FY2021 Appropriations requests increased funding for two Food and Drug Administration (FDA) programs, the Orphan Product Clinical Trial Grants Program and the Natural History Grants Program. To contact your Members, click [here](#).

Haystack Project is asking organizations to sign on to two letters. The first is a [letter](#) to **CMS Administrator Verma** regarding a proposed rule on Medicare and Medicaid policies. The second is a [letter](#) to the Senate and House sponsors of the **Accelerating Kids' Access to Care Act** requesting that adults as well as children with rare disorders who require treatment from out-of-state specialist through Medicaid are included in the bill language. Please contact Saira Sultan at saira.sultan@connect4strategies.com to sign on to either letter.

Kids v. Cancer is asking organizations to sign on in support of the **Creating Hope Reauthorization Act**. The Creating Hope Reauthorization Act will permanently reauthorize FDA priority review vouchers (PRVs) for rare pediatric diseases. The PRV is a pediatric rare disease therapy development incentive program in which companies developing products for children with cancer and other life-threatening diseases may be eligible to receive a voucher from FDA that can be applied to the review for a future product that does not meet this same criteria. If your organization would like to officially support the Creating Hope Act, please sign on [here](#).

National Foundation for Ectodermal Dysplasias is asking patient advocacy organizations to sign a letter in support of the **Ensuring Lasting Smiles Act**. To sign on, visit the website [here](#). NFED is also asking advocates to send emails to their legislators to ask them to co-sponsor the Ensuring Lasting Smiles Act. Please visit [here](#).

National PKU Alliance is asking advocates to contact their Members of Congress in support of the **Medical Nutrition Equity Act, H.R. 2501**. H.R. 2501 would provide coverage of medically necessary foods and vitamins for digestive and inherited metabolic disorders under federal health programs and private health insurance. To contact your Representative to cosponsor H.R. 2501, click [here](#).

National Society of Genetic Counselors is asking advocates to contact their Members of Congress in support of the **Access to Genetic Counselors Act, H.R. 3235**. H.R. 3235 would

expand coverage of services provided by genetic counselors under the Medicare program. To contact your Representatives to cosponsor H.R. 3235, click [here](#).

Aidan Jack Seeger Foundation is asking organizations to sign onto a letter in support of **Aidan's Law, H.R. 534**, to make newborn screenings of MPS1, Pompe, ALD, and SMA available nationwide. To view and sign on to the letter, click [here](#).

EveryLife Foundation for Rare Diseases is asking advocates to contact their Members of Congress in support of the **Advancing Access to Precision Medicine Act**. This legislation would ensure that many children and young adults living with an undiagnosed condition will have access to DNA sequencing clinical services beyond Whole Genome Sequencing that are currently out of reach. To contact your Representatives to cosponsor H.R. 4393, click [here](#).



COMMUNITY EVENTS

Below are upcoming policy and advocacy events of interest to the rare disease community. To view more policy and advocacy events for this year and beyond, please visit the [RDLA events calendar](#).

RDLA Monthly Webinar and In-Person Meeting, April 23, 2020: The next RDLA Monthly Webinar and In-Person Meeting will take place on Thursday, April 23rd. The RDLA Monthly Meetings are an opportunity to educate patient advocates about pressing health policy topics so that they can be successful legislative advocates. The meetings are attended either through a Webinar or in person in Washington, DC. Advocates, staffers, and industry are welcome to join. Register to join on the [RDLA website](#). If you would like to present at the meeting about a current policy issue, please email Shannon von Felden at svonfelden@everylifefoundation.org.

RARE on the Road, a Rare Disease Leadership Tour: Join the EveryLife Foundation and Global Genes this spring and summer for RARE on the Road which brings critical education and insights to rare disease patients, caregivers and other advocates. This event is for those who are new to the rare disease community and “seasoned veterans”. Events in Raleigh, NC and Burlingame, CA have been postponed. Other locations include Minneapolis, MN and New Orleans, LA. For more information and to register, [click here](#).

Rare Across America: Under the Rare Across America program, RDLA staff organizes meetings for rare disease advocates with their Members of Congress and/or the Member’s staff. The meetings take place in the Member’s district offices during the month of August, while Congress is in recess from August 3rd to September 7th, 2020. The RDLA team prepares advocates for their meetings, provides legislative resource materials, and hosts pre-meeting training webinars. No prior advocacy experience is necessary.

Advocates interested in participating should register between May 4th and July 3rd at www.RareAcrossAmerica.org. The first training webinar for registered advocates, entitled “What to Expect at Your Meetings,” will be hosted in July.

Rally for Medical Research Hill Day: Save the date for the Rally for Medical Research Hill day on Thursday, September 17, 2020, with the “Rally Hill Day” reception taking place during the evening of Wednesday, September 16, 2020. To learn more about the Rally for Medical Research, [click here](#).

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***This E-Blast shares action alerts, legislative, and policy news and events from the patient advocacy community. RDLA does not take positions on the issues herein but serves as a supportive clearinghouse for the rare disease community. Send us an email if you'd like your alerts and/or events included! Email svonfelden@everylifefoundation.org.