



## RDLA March 2020 Newsletter



## CAPITOL HILL UPDATES

**President's FY 2021 Budget:** The President released the Fiscal Year 2021 Budget, on February 10th with a total proposed budget of \$4.8 trillion. The budget proposed includes a cut in spending on Medicaid by approximately \$920 billion over the next 10 years. Overall the Department of Health and Human Services' budget would be cut by 9% with a decrease in funding in certain divisions. The NIH's budget would be set at \$38.7 billion, a 7% decrease from the previous year. The National Cancer Institute would see the largest reduction by 9% or \$559 million and Cancer Moonshot's funding would be \$195 million compared to the \$400 million authorized by Congress for 2020. The FDA would benefit in gaining a 4.5% or \$265.4 million budget increase with a \$6.2 billion budget request.

The Appropriations Committees in the House and Senate are currently working on the appropriations bills to fund the government and the different agencies for next year which will need to be completed and passed by September 30<sup>th</sup> to avoid any shutdowns.

**Precision Medicine Caucus:** On February 19th, the new bicameral, bipartisan Congressional Personalized Medicine Caucus was launched by co-chairs Senators Tim Scott (R-SC) and Kyrsten Sinema (D-AZ) and Representatives Eric Swalwell (D-CA) and Tom Emmer (R-MN). This new caucus seeks to expand support for, and knowledge of, personalized medicine by enhancing public awareness of the field and advocating for policies in support of its advancement.



## 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](#).

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](#).

Partnership to Fight Chronic Disease is asking organization to sign on to a [letter](#) to the Food and Drug Administration (FDA) **expressing concern regarding ICER's proposal** to partner with FDA. To sign onto the letter, organizations can email [Candace.dematteis@fightchronicdisease.org](mailto:Candace.dematteis@fightchronicdisease.org).



## 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](#).*

**Alliance for a Stronger FDA Hill Day, March 18, 2020:** Each year the Alliance for a Stronger FDA goes to Capitol Hill to discuss the importance of a fully-funded FDA. This event is open to all participants. To learn more and register, [click here](#).

**RDLA Monthly Webinar and In-Person Meeting, March 19, 2020:** The next RDLA Monthly Webinar and In-Person Meeting will take place on Thursday, March 19th. 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](mailto:svonfelden@everylifefoundation.org).

**RARE on the Road, a Rare Disease Leadership Tour:** Join the EveryLife Foundation and Global Genes in Raleigh, North Carolina on March 28<sup>th</sup> for RARE on the Road, an event that 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”. Other locations this spring include Burlingame, CA on April 17<sup>th</sup>, Minneapolis, MN on May 30<sup>th</sup>, and New Orleans, LA on June 27<sup>th</sup>. For more information and to register, [click here](#).

**Capitol Crawl Commemorative Rally:** The Pain Advocate Warriors is organizing a rally for Medical Freedom and Quality of Life on May 15, 2020 at the Capitol. For more information, visit [here](#).

**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](#).

### Stay Connected

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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](mailto:svonfelden@everylifefoundation.org).