RDLA
Rare Disease Legislative Advocates
A Program of the EveryLife Foundation for Rare Diseases

EMPOWERING THE RARE DISEASE COMMUNITY

RDLA October 2019 Newsletter

Capitol Hill Updates

FY2020 Appropriations: The U.S. House of Representatives has completed 10 of the 12 appropriations bills for FY 2020 while the Senate has passed no appropriations bills. Before the end of the fiscal year, the President signed into a law a continuing resolution on September 27th to extend government funding to November 21, 2019 to avoid a government shutdown. The continuing resolution extends the FY2019 funding through November 21st. The House and Senate will need to pass the FY 2020 appropriations bills before November 21st or another continuing resolution to avoid a government shutdown again. Under the continuing resolution, government agencies will carry out their program using the funding levels from last year. For example, this will limit FDA's ability to start new initiatives until the increased funding level for FY2020 are enacted.

Creating Hope Reauthorization Act: On September 20, 2019, Representative G.K. Butterfield (NC-1) introduced the Creating Hope Reauthorization Act, H.R. 4439, to permanently authorize priority review vouchers to encourage treatments for rare pediatric diseases. When a company develops a drug for children with cancer and other life-threatening diseases, they receive a voucher from FDA for a faster FDA review of a future FDA drug.

RARE Act: The Rare disease Advancement, surveillance Research, and Education (RARE) Act, H.R. 4228, was introduced by Representative Andre Carson (IN-7) on September 9, 2019. The RARE Act proposes to expand and improve the programs and activities of the Department of Health and Human Services for awareness, education, research, surveillance, diagnosis, and treatment concerning rare diseases.

Community Action Alerts & Policy Resources

The EveryLife Foundation, with support from the Community Congress Public Policy Working Group, has developed **Recommendations to Congress on Drug Pricing Legislation**. Please contact Julia Jenkins (jjenkins@everylifefoundation.org) if your patient organization would like to sign on before it is sent to Capitol Hill. The deadline to sign on is October 9th.

The Friends of PCORI Reauthorization is asking advocates to contact their Members of Congress in support of the **Patient Centered Outcomes Research Institute (PCORI)**

reauthorization. PCORI supports research to help patients and providers make evidence-based healthcare decisions. To find sample letters, 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 for rare pediatric diseases. When a company develops a drug for children with cancer and other life threatening diseases they receive a voucher from FDA for a faster FDA review of a future FDA drug. If your organization would like to officially support the Creating Hope Act, please sign on here.

The 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.

The National PKU Alliance is asking advocates to contact their Members of Congress in support of the **Medical Nutrition Equity Act, H.R. 2105**. H.R. 2105 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. 2105, 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.

The 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.

The EveryLife Foundation for Rare Diseases is asking advocates to contact their Members of Congress in support of the **Newborn Screening Saves Lives Reauthorization Act**. To contact your Senators to cosponsor S. 2158, click here.

Genetic Alliance is asking organizations to write letters in support of the **Ending the Diagnostic Odyssey Act, H.R. 4144**. H.R. 4144 would allow states to conduct a three-year pilot program to increase the Federal Medical Assistance Percentage (FMAP) rate to provide Whole Genome Sequencing clinical services for children on Medicaid with a disease that is suspected to have a genetic cause. If your organization would like to send a letter in support of H.R. 4144, please email Vilma Whittier at vwhittier@geneticalliance.org.

The EveryLife Foundation for Rare Diseases is circulating a sign on letter to support the **Advancing Access to Precision Medicine Act**. This legislation would ensure that many children and young adults suffering from an undiagnosed condition will have access to DNA sequencing clinical services beyond Wold Genome Sequencing that are currently out of reach. Please contact

Steve Silvestri (ssilvestri@everylifefoundation.org) if your patient organization would like to sign. The deadline to sign on is October 18th.

To learn more about the bills, please watch the recording of the September RDLA Webinar.

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 October Webinar and In-Person Meeting: The next RDLA Monthly Webinar and In-Person Meeting will take place on October 17, 2019. The RDLA 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.

WCG Fall 2019 Patient Advocacy Forum: WCG is holding the WCG Fall 2019 Patient Advocacy Forum for patient advocacy groups and drug development stakeholders in Washington, DC on October 23, 2019. There will be speakers and sessions on continuing to integrate patient voices into drug development. Learn more and register here.

Rare New England Annual Conference: The Rare New England is hosting an annual conference on October 26, 2019 from 8 am to 5 pm in Portland, Maine. More information and the scholarship application are available here.

2019 BIO Patient and Health Advocacy Summit: The 2019 BIO Patient and Health Advocacy Summit will take place in Washington, DC at the Park Hyatt on October 30-31, 2019. Learn more here.

Lunch and Learn Series: A Primer on CBD: American Brain Coalition and Bridge the Gap Syngap are inviting patients and patient organizations to attend a lunch and learn about the emerging legislative and regulatory environment for cannabidiol-derived products and the potential impact on patients, clinicians, and researchers. The lunch and learn will take place on November 14, 2019 at noon in Washington, DC. Learn more here.

RareVoice Awards: Registration is now open for the RareVoice Awards on December 4, 2019. The RareVoice Awards is an event to educate Congress on rare disease issues and celebrate advocates who give rare disease patients a voice on Capitol Hill and state legislatures. Register here.

Save the Date: Rare Disease Week on Capitol Hill, February 25-28, 2020: RDLA will bring hundreds of rare disease patient advocates to Washington, DC for a week of events dedicated to empowering patients, families, and friends to become legislative advocates. Advocates will have

an opportunity to meet with Members of Congress and learn best practices for successful advocacy.

RDLA offers travel stipends to participants to offset the cost of attending Rare Disease Week on Capitol Hill. The 2020 travel stipend application will open on October 8th and close on December 2nd, 2019. Apply for a travel stipend here. Registration for the event begins on January 3, 2020 at rareadvocates.org/rdw.

On February 28th, as part of Rare Disease Week on Capitol Hill, the NIH will host Rare Disease Day at NIH. This event aims to raise awareness about rare diseases, the people they affect and NIH research collaborations to advance new treatments.

Stay Connected
Stay up to date on breaking rare disease legislative news by following @RareAdvocates on Twitter and Facebook and rare_advocates on Instagram.

Receive this from a friend? Sign-up for our email list to make sure you don't miss monthly newsletters and action alerts!

***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.