



RDLA October 2020 Newsletter



CAPITOL HILL UPDATES

Continuing Resolution: The House has passed 10 and the Senate has passed 4 of the twelve FY 2021 Appropriations Bills. The FY 2021 appropriations were set to expire at the end of the fiscal year, September 30th, unless both the House and Senate passed the appropriations bills (and the President sign them into law) or pass a continuing resolution. Since all the Appropriations bills have not passed, the House passed a temporary funding bill, Continuing Resolution (CR), on September 22, the Senate passed the CR on September 30th, and the President signed it into law the same day. This action will keep federal agencies fully running and with level funding until December 11. The House and Senate must pass the remaining appropriations bills for FY 2021 before December 11th or pass another CR to avoid a government shutdown.

Pediatric Priority Review Voucher: A short term extension for the rare disease Priority Review Voucher program (PRV) through was included as part of the Continuing Resolution signed on September 30th. Under the short term extension the program can operate until December 11th while a longer term solution as proposed in the Creating Hope Act is negotiated. The House did make progress on a longer-term extension, passing an amended version of the Creating Hope Reauthorization Act on September 29th that would extend it for a 4-year period. The Senate has yet to act on a companion bill.

RISE Act: The Senate Commerce Committee passed the Research Investment to Spark the Economy (RISE) Act. This bipartisan legislation provides billions in emergency funding to U.S researchers who have been impacted by COVID-19. This funding will support the research workforce, mitigate the disruptions to federally supported research, and restart research that has

been halted or slowed due to COVID-19. Senate leadership must now decide whether to hold a vote for this bill by the full Senate.



COMMUNITY ACTION ALERTS & POLICY RESOURCES

Visit www.RareAdvocates.org/take-action to find more ways to take action for the rare disease community.

New RDLA Resources: RDLA has new advocacy resources on our website. There are three new advocacy tips sheets on *Comparing State Caucuses and Advisory Councils*, *Starting a State Based Organization*, and *Diversity and Inclusion* on the [website](#). There are also new RDLA Policy Primers on policy issues that impact the rare disease community. The topics for the Policy Primers include the *Prescription Drug User Fee Act (PDUFA)*, *21st Century Cures*, and *Value Assessment Frameworks*. You can find the Policy Primers [here](#).

2020 Election Resources: RDLA wants to ensure rare disease patients are heard in local, state and federal elections around the country. With the 2020 election season approaching, we have compiled resources to assist advocates to ensure all are prepared to vote! To access these resources, click [here](#).

The **Pennsylvania Rare Disease Advisory Council** has launched a survey to seek and compile the Pennsylvania rare community's input and identify commonalities within the community. The results will help to shape invaluable data that will provide effective advocacy for elected officials, as well as for researchers, medical professionals, and pharmaceutical companies. To learn more or to complete the survey, click [here](#).

The FCS Foundation asks advocates to contact their Members of Congress to cosponsor the **Helping Experts Accelerate Rare Treatments (HEART) Act, H.R. 7567**. This legislation is designed to change the Food and Drug Administration's process to review and approve drugs to treat rare diseases in the U.S by allowing participation from patients and clinicians. To learn more and ask your Representative to cosponsor the HEART Act, click [here](#).

CA for Cures asks Californians to join their Yes on 14 Coalition in Support of Proposition 14. Proposition 14 will authorize \$5.5 billion in state general obligation bonds to continue funding stem cell research and the development and delivery of treatments in California. To learn more, click [here](#).

The ALD Alliance is asking advocates to contact their Representatives to sign onto a letter to support **funding for the Centers for Disease Control and Prevention (CDC) for timely**

implementation of newborn screening condition. End “death by zip code” by clicking [here](#) to contact your Member and learn more.

Ear Community Organization is asking advocates to contact their Members of Congress in support of the **Ally's Act, H.R. 5485/S. 4532**. Ally's Act would ensure private insurance coverage for osseointegrated hearing devices, including bone anchored hearing aids and cochlear implants, for both children and adults. To learn more about how you can support Ally's Act and ask your Representative to cosponsor, 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 [RDLE events calendar](#).

RDLE Monthly Webinar, October 15th, 2020: The next RDLE Monthly Webinar will take place on Thursday, October 15th at 12:00 pm ET. The RDLE Monthly Meetings are an opportunity to educate patient advocates about pressing health policy topics so that they can be successful legislative advocates. Advocates, staffers, and industry are welcome to join. Register to join [here](#). If you would like to present on a webinar about a current policy issue, please email Shannon von Felden at svonfelden@everylifefoundation.org

New Dates for 2021 RDLE Events: We are excited to share that we have moved our dates for Rare Disease Week and Rare Across America. Rare Disease Week on Capitol Hill will be held July 19th – 22nd to ensure we can all be together again in person in 2021. Rare Across America will be held virtually February 22nd – March 5th. While we will not be in person for this event, we look forward to educating the new Members of Congress virtually. Be sure to add both to your calendars!

Newborn Screening Bootcamp: Expecting Health at Genetic Alliance and the EveryLife Foundation for Rare Diseases are currently hosting the 2nd Newborn Screening Bootcamp throughout the month of October to provide resources to rare disease community stakeholders about the newborn screening system, facilitating pilot studies, building coalitions, navigating the RUSP nomination process, and preparing infrastructure to address challenges beyond the RUSP. To register for this event or view past week's presentations, click [here](#).

Advanced Advocacy Academy: The Global Liver Institute is hosting this virtual event October 26th-30th. This program offers liver patients, caregivers, and professional the opportunity to learn from experts in the fields through a series of keynote speakers and live discussions. To learn more and register for this event, click [here](#).

BIO Patient and Health Advocacy Summit: BIO is holding a virtual event October 28-29 to bring together patient advocacy organizations, academia, regulators, biotechnology industry, and other stakeholders to discuss policy issues and best practices. You can find more information [here](#).

Rare Access Action Project will be hosting a Virtual Access Workshop and Awards for the rare disease community on November 17, 2020. Attendance is not limited, but registration is required. Registration is free for Patient and RAAP Member Organizations, \$50 per attendee for Non-Member life sciences companies. To learn more or to register, click [here](#).

Save the Date for the RareVoice Awards: RDLA will be hosting the 9th Annual RareVoice Awards on Thursday, December 10th, 2020 at 7:00pm ET. Join us from home as we celebrate advocates who give rare disease patients a voice on Capitol Hill and in state government. This event is free and open to the public. Click [here](#) to register to attend.

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.