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RDLA July 2020 Newsletter



CAPITOL HILL UPDATES

Research Investment to Secure the Economy (RISE) Act: On June 24, 2020 Representative Diana DeGette introduced a bipartisan bill to support the U.S research community during pandemics. If passed, this bill would provide emergency funding for federal science agencies to award to research universities, independent institutions, and national laboratories to continue working on federally funded research projects. You can read more about this bill [here](#).

Creating Hope Reauthorization Act: In June, Senators Bob Casey (PA) and Susan Collins (ME) introduced the Senate companion bill for the Creating Hope Reauthorization Act, S. 4010/H.R. 4439. The Creating Hope Reauthorization Act would permanently reauthorize the Food and Drug Administration's authorization to issue priority review vouchers in order to encourage the development of treatments for rare pediatric diseases. A priority review voucher is awarded to a drug company if the company develops a drug for a rare pediatric disease and the drug is approved. The voucher allows the company to expedite the FDA review of a future drug. The company may sell the voucher to other companies that want to expedite drug reviews.

Promising Pathway Act: On June 3, 2020, Senator Mike Braun introduced the Promising Pathway Act, S. 3872, in the Senate to amend the Federal Food, Drug, and Cosmetic Act to establish a time-limited provisional approval pathway for certain drugs and biological products. This bill is currently in the Senate Committee on Health, Education, Labor, and Pensions. You can read the bill text [here](#).

Bioeconomy Research and Development Act: On May 14, 2020, Senator Kirsten Gillibrand (NY) introduced the Bioeconomy Research and Development Act, S. 3734, to provide a coordinated federal research initiative by establishing a committee to coordinate research in engineering biology across all federal agencies. You can read the bill text [here](#).

FY21 Appropriations: The House is planning to begin marking up all 12 appropriations bills next week, with the expectation to pass them out of the full Committee within the first few weeks of July. Scheduling for Senate subcommittee markups are currently held up due to a debate on whether Senators may introduce amendments during the markup process that involve COVID-related spending. In addition, conversations remain in both chambers on which programs are exempt from the appropriations cap. However, the most likely outcome is still a continuing resolution at the end of the summer which pushes back the appropriations decisions until after the election.



COMMUNITY ACTION ALERTS & POLICY RESOURCES

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

National Burden of Rare Disease Survey – We Need YOU: What’s the cost of living with a rare disease to YOU? If you or a member of your household is living with a rare disease, we want you to take the National Burden of Rare Disease Survey. Deadline to participate is Monday, July 20, 2020. Learn more about the [survey](#).

NIH-funded Rare Diseases Clinical Research Network is conducting an online survey on how COVID is affecting rare disease patients. Fill out the survey [here](#).

The Food and Drug Administration is **seeking information and comment on rare disease clinical trial networks** and how to practically and successfully approach start-up, implementation and sustainment of global clinical trial networks. Comments close on July 31, 2020. To add a comment, 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**. H.R. 5485 is a national level bill that 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 H.R. 5485, 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](#).

Reminders for Rare Across America: The meetings for [Rare Across America](#) will take place in the Member's district offices, while Congress is in recess from August 3rd to September 7th, 2020. (Virtual meetings may take place if in-person meetings are not possible in August.) If you are registered for Rare Across America, please also register to attend one, two, or all three webinars in July.

- Register for the Rare Across America Training Webinar on July 9th at 2 pm EST [here](#).
- Register for the Social Media Training Webinar will take place on July 14th at 1:00 pm EST [here](#).
- Register for the Practice Your Pitch with the Fast Forward for RARE Webinar on July 21st at 3:00 pm EST [here](#).

Participants can find materials and resources for their meetings like the one pagers on the RDLA Legislative Asks, printable state Congressional Scorecards, and RDLA Tip Sheets to help you prepare for your meetings at www.RareAcrossAmerica.org.

RDLA Monthly Webinar and In-Person Meeting, July 16th, 2020: The next RDLA Monthly Webinar will take place on Thursday, June 16th. The RDLA 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 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.

The Rare Disease Congressional Caucus will be holding a virtual briefing on Thursday, July 23rd at 12:00pm EST. A panel of industry professionals will be discussing the impact on COVID-19 on the rare disease community, as well as proposed policy solutions for the future. You can register to attend the briefing [here](#).

The FDA will be holding a virtual public meeting on the reauthorization of the **Prescription Drug User Fee Act (PDUFA)** on Thursday, July 23rd from 9:00am-2:00pm EST. To register for this meeting, click [here](#).

Rally for Medical Research Hill Day: Save the date for the Rally for Medical Research Hill day on Thursday, September 17, 2020. This event will be virtual, allowing constituents to participate in teleconference calls with their Members. To learn more about the Rally for Medical Research, [click here](#).

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.