RDLA August 2020 Newsletter

REMINDER: If you are registered for Rare Across America, please continue to check your meeting schedule 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.

CAPITOL HILL UPDATES

COVID-19: Negotiations are now heating up in the Senate on what the next round of COVID-19 related relief legislation will contain. On July 27, Senate Republicans released an outline of their proposal, the HEALS Act, which is significantly streamlined in scope and cost from the $3.5 trillion HEROES Bill. You can read more about this package proposal here. On July 25th, Health and Human Services Secretary Alex Azar extended the COVID-19 Public Health Emergency (PHE). Many waivers and changes to public health policies are set to remain in place for the duration of the PHE. The PHE must be renewed after a 90-day period.

On July 16th, leading members of the House Congressional Telehealth Caucus -Representatives Mike Thompson (D-CA), David Schweikert (R-AZ), Bill Johnson (R-OH), Peter Welch (D-VT), and Doris Matsui (D-CA), introduced the Protecting Access to Post-COVID-19 Telehealth Act of 2020.

FY21 Appropriations: The House passed the FY 2021 Labor-HHS-Education funding bill on July 13, 2020. This bill will provide $42 million in annual appropriations for the NIH, a $500 million increase over FY2020 and an additional $5 billion in emergency appropriations focused on research institution capacity. The bill also provides an increase of $232 million for the CDC, for a total of $8 billion in annual funding, plus $9 billion in supplemental emergency funding to address public health emergency preparedness. An appropriations package including the FDA appropriations, H.R. 7608, was passed in the House on July 24. The bill will give FDA $3.21 billion in discretionary funding, $40.8 million higher than FY2020.

Trump Administration Issues Series of Executive Orders: On July 24th, the Trump Administration announced a series of four executive orders (EO) related to drug pricing. Action on one related to setting prices based on the
international pricing index was delayed at least one month to allow for negotiations with the pharmaceutical industry. The other Executive Orders were related to rebates paid by pharmaceutical companies to insurers, drug importation, and the Medicare 340B drug discount program.

On August 3rd, President Trump signed an executive order that directs the federal government to implement policies to sustain expanded access to telehealth services for Medicare beneficiaries, access made available during the public health emergency.

**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](https://everylifefoundation.salsalabs.org/augustrdlanewsletter-2/).

**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](https://www.ResearchAmerica.org/).

**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](https://www.ResearchAmerica.org/).

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**Visit [www.RareAdvocates.org/take-action](https://www.rareadvocates.org/take-action) to find more ways to take action for the rare disease community.**

Research America is asking advocates to contact their Members of Congress to reinforce the need for NIH research grant supplements to address significant funding gaps created by COVID-19. The House appropriations funding packing includes $5 billion for this purpose, but the U.S Senate leadership and the White House have agreed on a supplemental spending package that includes $15.5 billion. Click [here](https://www.RareAdvocates.org/take-action) to contact your Member of Congress to advocate for the final package including at least $15.5 billion for NIH research grants.

EveryLife Foundation for Rare Diseases has joined with Kids V. Cancer to urge for the passage of the Creating Hope Reauthorization Act, H.R 4439/ S.4010. This bill will permanently authorize the Pediatric Priority Review Voucher (PRV) program. It will allow further opportunity to spur innovation in rare and neglected diseases that disproportionately impact children. To learn more and ask your Senators and Representative to cosponsor the Creating Hope Reauthorization Act, click [here](https://www.RareAdvocates.org/take-action).

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](https://www.RareAdvocates.org/take-action) 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](https://everylifefoundation.salsalabs.org/augustrdlanewsletter-a34).

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](https://everylifefoundation.salsalabs.org/augustrdlanewsletter-a34).

### 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](https://www.rareacrossamerica.org).

**PDUFA Stakeholder Consultation:** The Food and Drug Administration (FDA) requests that public stakeholders—including patient and consumer advocacy groups, healthcare professional, and scientific and academic experts—notify FDA of their intent to participate in periodic consultation meetings on the reauthorization of PDUFA (Prescription Drug User Fee Act). More information on how to register by the August 17th deadline can be found [here](https://everylifefoundation.salsalabs.org/augustrdlanewsletter-a34).

**Newborn Screening Bootcamp:** Expecting Health at Genetic Alliance and the EveryLife Foundation for Rare Diseases are partnering to host the 2nd Newborn Screening Bootcamp 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. The Bootcamp will be held virtually in a 5-part training series starting September 30th. Registration opens August 11th, 2020.

**Reminders for Rare Across America:** Meetings for [Rare Across America](https://www.rareacrossamerica.org) with Members of Congress and their staffs take place while Congress is in recess from August 3rd to September 7th, 2020. If you are registered for Rare Across America, please continue to check your meeting schedule [here](https://everylifefoundation.salsalabs.org/augustrdlanewsletter-a34). 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](https://www.rareacrossamerica.org).

**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](https://everylifefoundation.salsalabs.org/augustrdlanewsletter-a34).

**Rare Patient Advocacy (un)Summit:** Global Genes is hosting a variety of engaging and educational online events, meet-ups, workshops and performances on September 14-25, 2020. You can register for this free event [here](https://everylifefoundation.salsalabs.org/augustrdlanewsletter-a34).
**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](https://everylifefoundation.salsalabs.org/augustrdlanewsletter-a4/).

**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](https://everylifefoundation.salsalabs.org/augustrdlanewsletter-a4/) 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.***

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Rare Disease Legislative Advocates is a program of the EveryLife Foundation for Rare Diseases designed to support the advocacy of all rare disease patients and organizations.

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