



RDLA June 2020 Newsletter

REMINDER: Registration for Rare Across America is open. Register to meet with your federal legislators in August in the local and state offices at www.RareAcrossAmerica.org. Registration closes on July 3rd.

Welcome to New RDLA Staff: Please join us in welcoming Katelyn Laws, RDLA Coordinator; Swapna Kakani, State Advocacy Fellow; and Adrian Palau-Tejeda, Diversity Inclusion Advocacy Fellow to the EveryLife Foundation!



CAPITOL HILL UPDATES

COVID-19 Legislative Response: Congress has now passed five bills in the last few months to respond to the growing health and economic needs resulting from COVID-19. Recently, the Paycheck Protection Program Flexibility Act, H.R. 7010, was passed by the House and Senate to extend the period the funds must be used by a business from 8 weeks to 24 weeks and provide more flexibility on the amount that must be spent on payroll expenses, from at least 70% to 60% of the loan. The bill does not include more funding for the program. To learn more about the COVID-19 response passed legislation, you can listen to the April RDLA Legislative Webinar [here](#). The EveryLife Foundation also has COVID-19 related news and resources available [here](#).

Endless Frontiers Act: On May 21st, Senators Chuck Schumer (NY) and Todd Young (IN) introduced the Endless Frontiers Act, S. 3832, to establish a new Directorate for Technology in the National Science and Technology Foundation and a regional technology hub program. A summary on this legislation can be found [here](#).

Appropriations Update: In March of 2020, the FDA requested \$6 billion from the House Committee on Appropriations to advance access to safe and effective medical products, food safety, artificial intelligence, and more. The appropriations process for FY2021 has been disrupted due to COVID-19. Fortunately, some additional funding for science and research has

been included in COVID-19 relief packages. The House and Senate Committees on Appropriations are delayed on beginning the appropriations process for FY 2021. Both Committees are resuming work on appropriations for the next fiscal year which begins on October 1, 2020.

Surprise Medical Billing: Over the last couple of years, Congress has been working to resolve issues related to surprise medical billing (when a patient receives care from an out of network provider at an in-network hospital and has higher copays or no coverage for the care). COVID-19 has put that work on pause, however work is expected to resume on the issue soon. To read more about this issue, read an op-ed [here](#).



COMMUNITY ACTION ALERTS & POLICY RESOURCES

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

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](#).

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. To add a comment, click [here](#).

EveryLife Foundation for Rare Diseases is working on a **Burden of Rare Disease Survey** that will measure the medical, indirect and non-medical costs of having a rare disease. The results will be published in a comprehensive study and will be a powerful tool for all rare disease advocates. The link for a community survey will be available mid-June, so stay tuned!

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 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](#).

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. To do so, please click [here](#).

National PKU Alliance is asking advocates to contact their Members of Congress in support of the **Medical Nutrition Equity Act, H.R. 2501/S. 3657** which 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 legislators to cosponsor H.R. 2501/S. 3657, 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](#).

Research America is asking advocates to contact their Representatives to sign onto a letter in support of **\$26 billion in COVID-19 relief to help sustain our nation's federally funded research enterprise**. To contact your Representative to 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 diagnosed 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](#).

YARR Summer Series: A series of leadership-skill building webinars will be offered for the Young Adult Representatives of RDLA (ages 16-30). The first webinar is Thursday, June 4th at 2:00pm PST/5:00pm EST. To learn more and register, click [here](#).

Register for Rare Across America: Registration is open for Rare Across America at www.RareAcrossAmerica.org until July 3rd. Under the Rare Across America program, RDLA staff organizes meetings for rare disease advocates with their Members of Congress and/or the Member's staff. The meetings take place in the Member's district offices during the month of August, 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.)

The RDLA team prepares advocates for their meetings, provides legislative resource materials, and hosts pre-meeting training webinars. No prior advocacy experience is necessary. Registered advocates can register [here](#) for the Rare Across America Training Webinar on July 9th at 2 pm EST/11am PST, [here](#) for the Social Media Training Webinar on July 14th at 1 pm EST/10 am PST, and [here](#) for the Practice Your Pitch with the Fast Forward for RARE Webinar on July 21st at 3:00 pm EST/12:00 pm PST.

RDLA Monthly Webinar and In-Person Meeting, June 18th, 2020: The next RDLA Monthly Webinar will take place on Thursday, June 18th. 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.

RARE on the Road, a Rare Disease Leadership Tour, June 23rd and 24th: Join the EveryLife Foundation and Global Genes on June 23rd and 24th for a virtual RARE on the Road. The two-part virtual experience that will empower attendees to build their skill set, enhance their knowledge, engage in advocacy, and network with their local rare disease community. These events are geared toward rare disease community members who want to tell their rare disease story, make an impact in the lives of others, and connect locally with fellow rare disease community members. Learn more about the virtual event at www.raretour.org. Register for Part I [here](#), Part II [here](#), or both.

FDA Clinical Trials Transformation Initiative, June 4th-5th: The FDA, in collaboration with the Clinical Trial Transformation Initiative, is holding a free virtual web conference June 4th and 5th from 10:00am to 1:00pm, EDT. The conference will discuss the International Council for Harmonisation (ICH) Good Clinical Practice guideline (ICH E6) and how it advances clinical trial design and conduct. To learn more or register for the web conference, click [here](#).

National Foundation for Ectodermal Dysplasias Virtual Day on the Hill, June 24th: NFED is having a Virtual Day on The Hill on June 24th to advocate for the Ensuring Lasting Smiles Act. Register to join NFED to advocate virtually on the Hill [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.