



## RDLA IS YOUR ADVOCACY PARTNER!



### RDLA November 2020 Newsletter



## CAPITOL HILL UPDATES

**COVID-19 Aid Package:** The Senate adjourned on October 26<sup>th</sup> without Congress passing a new COVID-19 aid legislation before the election. Democrats and the Trump Administration attempted to negotiate a new package but did not reach agreement. Republicans did not support a deal that would cost \$2 trillion, and instead pushed for a \$519 billion aid bill. There is hope that Congress will come together after the election and renew negotiation conversations. The Senate is scheduled to be in session the week of November 9<sup>th</sup> and the House the week after.

**TREAT Act:** The Temporary Reciprocity to Ensure Access to Treatment (TREAT) Act was introduced on August 4<sup>th</sup> by Senators Roy Blunt (R-MO) and Chris Murphy (D-CT). This bill would provide temporary licensing reciprocity for health care professionals in all states for all types of services during COVID-19. Under current law, health care professionals must maintain licenses in each state they provide services. This bipartisan bill would allow health care professionals licensed in good standing to provide in-person care or telehealth visits from any state throughout COVID-19 pandemic and in future national emergencies. You can read more about the TREAT Act [here](#).



## COMMUNITY ACTION ALERTS & POLICY RESOURCES

Visit [www.RareAdvocates.org/take-action](http://www.RareAdvocates.org/take-action) to find more ways to take action for the rare disease community. Visit [www.RareAdvocates.org/advocacy-tools/](http://www.RareAdvocates.org/advocacy-tools/) to access all RDLA advocacy resources and policy primers.

The **Kaiser Family Foundation** has released a report detailing results from a **nationwide Medicaid program survey**. The report is titled **State Medicaid Programs Respond to Meet COVID-19 Challenges: Results from a 50-State Medicaid Budget Survey for State Fiscal Years 2020 and 2021**. To read the report, click [here](#).

**Clinical Trials Transformation Initiative** (CTTI) is seeking Steering Committee Patient/Caregiver Representatives to contribute ideas for projects, participate in their conduct and analysis, participate in CTTI projects and more. They are accepting applications through 11:59 p.m. ET, Sunday, November 22<sup>nd</sup>. To learn more or to apply, 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. The bill is currently in the House Committee on Energy and Commerce. To learn more and ask your Representative to cosponsor the HEART Act, 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 [RDLA events calendar](#).*

**RDLA Monthly Webinar, November 19<sup>th</sup>, 2020:** The next RDLA Monthly Webinar will take place on Thursday, November 19<sup>th</sup> at 12:00 pm ET. 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 [here](#). If you would like to present on a webinar about a current policy issue, please email Shannon von Felden at [svonfelden@everylifefoundation.org](mailto:svonfelden@everylifefoundation.org)

**Rare Disease Congressional Caucus Briefing, December 3<sup>rd</sup>, 2020:** Rare Disease Legislative Advocates, in cooperation with the Rare Disease Congressional Caucus, invites you to a Rare Disease Virtual Briefing, “Cures 2.0: What’s Next for the Rare Disease Community” on Thursday, December 3<sup>rd</sup> at 1:00 pm ET. To register, click [here](#).

**New Dates for 2021 RDLA 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 19<sup>th</sup> – 22<sup>nd</sup> to ensure we can all be together again in person in 2021. Rare Across America will be held virtually February 22<sup>nd</sup> – March 5<sup>th</sup>. While we will not be in person for this event, we look forward to educating the new Members of Congress virtually. Registration for Rare Across America will open on November 16<sup>th</sup> at [www.RareAcrossAmerica.org](http://www.RareAcrossAmerica.org).

**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](#).

**National Center for Advancing Translational Sciences:** NCATS & the Center for Biologics Evaluation and Research will be hosting a virtual two-day workshop November 30<sup>th</sup>-December 1<sup>st</sup>. This meeting will bring together scientists, therapeutic developers and patient representatives to focus on immunogenicity issues related to the systemic administration of AAV gene therapy products. Click [here](#) to learn more and register to attend.

**Save the Date for the RareVoice Awards:** RDLA will be hosting the 9<sup>th</sup> Annual RareVoice Awards on Thursday, December 10<sup>th</sup>, 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](mailto:svonfelden@everylifefoundation.org).

