RDLA
Rare Disease Legislative Advocates
A Program of the EveryLife Foundation for Rare Diseases

EMPOWERING THE RARE DISEASE COMMUNITY

RDLA December 2018 Newsletter

Capitol Hill Updates

End of Year Appropriations: Earlier this year, Congress passed most of the appropriations bills for FY 2019. However, the Continuing Resolution for the remaining appropriations expires on December 21st, which includes funding for the Food and Drug Administration and the Indian Health Service. The remaining appropriations will be included in a year-end spending package to be passed by Congress. If Congress does not pass the package by December 21st, there will be a partial government shutdown until a deal can be reached.

Advancing Care for Exceptional Kids Act: This week the House passed a bipartisan health care measure, H.R. 7217, which included the Advancing Care for Exceptional Kids Act (H.R. 3325, S. 428). The Advancing Care for Exceptional Kids Act would allow states to create "health homes" to help coordinate care for children with complex medical needs. The Senate will have to pass the bill next before it can be sent to the President to be signed into law.

The Sickle Cell Disease and Other Heritable Blood Disorder Research, Surveillance, Prevention, and Treatment Act, S. 2465: The House is expected to complete legislative action on Senate passed S. 2465 before the end of the 115th Congress. Once S. 2465 is passed by the House it will go to the President to be signed into law.

On February 26, 2018, the U.S. House of Representatives passed the Sickle Cell Disease Research, Surveillance, Prevention, and Treatment Act, HR 2410 (Rep. Danny Davis, D-IL). On February 28, 2018, Senator Cory Booker (D-NJ) and Senator Tim Scott (R-SC) introduced S. 2465, the companion bill in the Senate. The Senate bill incorporated changes to include "other heritable blood disorders" in addition to sickle cell disease and passed the Senate on October 11, 2018. Since the passed Senate bill includes changes, the House must bring the Senate passed bill to the House floor for a vote before it can be sent to the President to be signed into law.

Community Action Alerts & Policy Resources

The Ensuring Lasting Smiles Act (ELSA): The National Foundation for Ectodermal Dysplasias (NFED) asks you to write your member of Congress and ask them to cosponsor the Ensuring Lasting Smiles Act (S.3369/H.R.6689). ELSA will assure that individuals born with congenital anomalies receive health benefits for the medically necessary treatments they need.

ELSA would require all groups and individual health care plans to cover procedures to restore or repair normal body function for any missing or abnormal body part, including teeth. It closes a loophole that allows health care plans to deny such procedures as "cosmetic". Take action here.

The Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act, S. 2465: Sick Cells and the Sickle Cell Disease Association of America asks you to write your Representatives and ask them to support S. 2465 and bring it to the House floor for a vote before the end of the year. Take action here.

Community Events

Rare Disease Week on Capitol Hill Introductory Webinar, December 12, 2018: Do you want to learn how to be an advocate for rare diseases? Do you want to have your voice heard on Capitol Hill? Do you want to meet your Members of Congress? Are you interested in attending Rare Disease Week on Capitol Hill 2019?

If you answered yes to any of these questions, you should attend the Rare Disease Week on Capitol Hill Introductory Webinar. You will learn about the different events we have lined up for that week, travel stipends, the hotel room block, and more! Register to attend on the RDLA website!

BioNJ's Patient Advocacy Summit, December 13, 2018 will take place in Summit, NJ from 1:00 pm to 6:30 pm. For more information and to register, visit the website.

Deadline for Rare Disease Week Travel Stipends: RDLA offers a limited number of travel stipends to participants to offset the cost of attending Rare Disease Week on Capitol Hill. The 2019 travel stipend application is open until December 14th, 2018. Apply for a travel stipend at rareadvocates.org/rdw.

To ensure we have representation across the entire country, we are still looking for state advocates to apply for travel stipends in the following states; North Dakota, South Dakota, Alaska, New Mexico and Wyoming.

Save the Date: RDLA January Monthly Webinar and In-Person Meeting: The next RDLA Monthly Webinar and In-Person Meeting will take place on Thursday, January 17th. The RDLA Monthly Meetings are an opportunity to educate patient advocates about pressing health policy topics so that they can be successful legislative advocates.

The meetings are attended either through a Webinar or in person in Washington, DC. Advocates, staffers, and industry are welcome to join. If you would like to present at the meeting about a current policy issue, please email Shannon von Felden at svonfelden@everylifefoundation.org.

Expand Access 2.0 Summit: The Expand Access 2.0 Summit will take place on January 22-23, 2019 at the National Press Club in Washington, DC. The summit will establish best practices for pre-approval access to new medicines and is free for patients. Register to attend here.

Save the Date: Rare Disease Week on Capitol Hill, February 24-28, 2019: RDLA will bring over 500 patient advocates to Washington, DC for a week of events dedicated to empowering patients, families, and friends to become legislative advocates. Advocates will have an opportunity to meet with Members of Congress and learn best practices for successful advocacy.

Registration for the event begins on January 3, 2019 at rareadvocates.org/rdw.

On February 28th, as part of Rare Disease Week on Capitol Hill, the NIH will host Rare Disease Day at NIH. This event aims to raise awareness about rare diseases, the people they affect and NIH research collaborations to advance new treatments. Learn more and register for the NIH event on their website.

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.