



EMPOWERING THE RARE DISEASE COMMUNITY

A PROGRAM OF THE EVERYLIFE FOUNDATION FOR RARE DISEASES

RDLA January 2019 Newsletter

Capitol Hill Updates

Remaining FY 2019 Appropriations and Partial Government Shutdown: Last year, Congress passed most of the appropriations bills for FY 2019. However, the Continuing Resolution for the remaining appropriations expired on December 21, 2018, which includes funding for the Food and Drug Administration and the Indian Health Service, resulting in a partial government shutdown.

At the Food and Drug Administration (FDA), 41% of the staff has been furloughed. Nearly half of the FDA's budget is provided by industry-paid fees and most of those activities funded by the fees can continue during the shutdown. FDA Commissioner Scott Gottlieb said in early January that the FDA can continue to communicate with drug and device developers about clinical research, and if an application was already submitted and the fees were paid, the process will continue. If fees have not been paid, then the FDA cannot accept new fees without the FY 2019 funding. The review process for some drugs could be delayed until the FDA appropriations are completed.

A deal between Congress and the President has not been reached on funding for the remaining appropriations bills. The U.S. House of Representatives voted on a bill (H.R. 21) to fund the remaining government agencies on Wednesday, January 3. In this legislation, \$11 billion would be allocated for health departments including the Food and Drug Administration (FDA), Indian Health Service, and two small divisions at the National Institutes of Health and the Centers for Disease Control and Prevention (CDC). The Agency for Toxic Substances and Disease Registry at CDC would receive the same level funding as last year at \$75 million. The FDA would receive \$5.4 billion, a \$160 million increase from last year but \$200 million less than the Administration's budget request. The Senate is not expected to vote on H.R. 21 in the near future.

The partial government shutdown, affecting a quarter of the government, will continue until both the U.S. House of Representatives and the Senate pass legislation and the President signs the bill into law.

The 116th Congress: On January 3, 2019, the 116th Congress began, and Members of Congress were sworn in. For the next two years the Senate will be comprised of 45 Democrats, 53

Republicans, and 2 Independents and the House will have 235 Democrats, 199 Republicans, and 1 congressional seat is still to be determined. The priority for the new session will be to pass the remaining spending measure to end the partial government shutdown.

Community Events

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. Register [here](#).

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 Webinar: 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?

If you answered yes to any of these questions, you should attend the Rare Disease Week on Capitol Hill Webinar on February 14th at 12 pm EST. You will learn about the different events we have lined up during Rare Disease Week on Capitol Hill, the legislative conference agenda, the Hill meeting “asks”, and our legislative priorities.

Register Now for Rare Disease Week on Capitol Hill, February 24-28, 2019: Registration is now open at rareadvocates.org/rdw. RDLA will bring over 500 patient advocates to Washington, D.C. 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.

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](#).

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***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.