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

EMPOWERING THE RARE DISEASE COMMUNITY

RDLA February 2019 Newsletter

Capitol Hill Updates

Government Reopens: On December 21, 2018, part of the government was shutdown. After 5 weeks of the partial government shutdown, which included the Food and Drug Administration, funding was approved for only 3 weeks. If the President and Congress do not reach a deal on border security within this time frame, the same agencies will likely shutdown at midnight on February 15th.

During the partial government shutdown, 41% of the staff was furloughed at the Food and Drug Administration (FDA). While FDA was able to continue to communicate with drug and device developers about clinical research if an application had been submitted and paid fees, the FDA would not have been able to continue to do so indefinitely.

H.R. 534, also known as Aidan's Law. This bill, which was named for Aidan Jack Seeger whose life was taken by adrenoleukodystrophy (ALD) at age 7, will provide the necessary funding for states to screen for ALD in newborns. Unfortunately, those affected by this fatal brain disease are often left undiagnosed for years. Early diagnosis through newborn screening allows those affected to access life-saving treatment before it is too late.

Community Events

Pulmonary Fibrosis Foundation Congressional Briefing: The Pulmonary Fibrosis Foundation is hosting a Congressional briefing on "Lethal Lung Disease on the Rise: Investing in Pulmonary Fibrosis Research" on Tuesday, February 5th at noon to 1:00 pm in 485 Russell Senate Office Building. RSVP to Kelsey_Magill@coons.senate.gov.

Save the Date: In Depth Webinar on Rare Disease Week: Everyone planning to attend events during Rare Disease Week on Capitol Hill should join the webinar on February 14th at noon (EST). This webinar will provide in depth information on the events during Rare Disease Week on Capitol Hill, the agenda for the Legislative Conference, the Legislative Asks for the Lobby Day, and more! Please register for the webinar here.

Twitter Chat with NIH: The National Institutes of Health (NIH) in coordination with the National Center for Advancing Translational Sciences (NCATS) and the NIH Clinical Center

(CC) is hosting a Twitter chat on rare diseases on Friday, Feb. 22, 2019, from 1-2 p.m. ET. The chat will feature NIH Director Francis S. Collins, M.D., Ph.D., NCATS Director Christopher P. Austin, M.D., NIH Clinical Center CEO James K. Gilman, M.D., and NCATS Office of Rare Diseases Research Director Anne Pariser, M.D., as well as other representatives from the NIH and rare diseases community. Interested participants can join in the conversation using #NIHchat and follow @NIH, @NIHClinicalCntr and @ncats_nih_gov.

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.

The deadline to register for Rare Disease Week on Capitol Hill in order for Hill meetings to be scheduled for advocates on the Lobby Day is February 11th. Please register for all of the events you plan to attend 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.

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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.