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

EMPOWERING THE RARE DISEASE COMMUNITY

# RDLA April 2019 Newsletter

## Capitol Hill Updates

**President's FY2020 Budget:** On March 11, 2019, the President's budget for Fiscal Year 2020 was released. The President's budget included a decrease of $4.6 billion for the National Institutes of Health and an increase of $362 million for the Food and Drug Administration. The President's budget reduced funding for the Health Resources and Services Administration (HRSA) by $981 million.

The President's budget recommends zero funding for HRSA's Heritable Disorders program and recommends unspecified reductions for the Newborn Screening Quality Assurance Program at the Centers for Disease Control and Prevention.

In addition, the President's budget includes $50 million for pediatric cancer research, but it cuts the National Cancer Institute budget, reducing the National Cancer Program by $897 million.

Now that the President has released his proposed budget for FY2020, the House and Senate Appropriations Committees will write the appropriations bills for FY2020. The fiscal year ends on September 31, 2019; therefore all of the appropriations bills or a continuing resolution (temporary funding measure) need to be completed, passed, and signed into law by then to avoid any government shutdowns.

**ABLE Age Adjustment Act Reintroduced:** Representatives Cathy McMorris Rodgers and Tony Cárdenas and Senator Robert Casey reintroduced the ABLE Age Adjustment Act (S. 651). This legislation builds on the Achieving a Better Life Experience (ABLE) Act that was signed into law in 2014. ABLE created tax-free savings accounts for job training, education and disability-related expenses. The ABLE Age Adjustment Act raises the age limit for eligibility to open an ABLE account from age 26 to 46.

**Rare Disease Congressional Caucus Update:** We are pleased that the Rare Disease Caucus has 12 new members of the caucus bringing the total membership of the caucus to 112 Representatives and 17 Senators. The list of members of the caucus can be found at rareadvocates.org/rarecaucus.

## Community Action Alerts & Policy Resources

**Emergency Medical Services for Children Program:** The American Academy of Pediatrics invites organizations to sign on to a letter regarding appropriations for the Emergency Medical Services for Children (EMSC) program. The letter requests House and Senate appropriations leaders to appropriate $22,334,000 for the EMSC program within the Health Resources and Services Administration. If your organization would like to sign on, please fill out this form.

**Fibrous Dysplasia/McCune-Albright Syndrome Research:** The Fibrous Dysplasia Foundation asks you to write your Senators to sign onto a letter in support of adding FD/MAS to the Peer Reviewed Medical Research Program. Currently, fibrous dysplasia/McCune-Albright syndrome (FD/MAS) researchers are ineligible to apply for research funding from the Peer Reviewed Medical Research Program, one of the Congressionally Directed Medical Research Programs at the Department of Defense.

Senator Jeff Merkley has authored a sign-on letter in support of adding FD/MAS to the Peer Reviewed Medical Research Program. You can ask your Senators to join Senator Merkley in supporting FD/MAS research by taking action here.

**National Academy of Medicine Study on Rare Diseases Appropriations Request:** The EveryLife Foundation has submitted an appropriations request to members of the Appropriations Committee and rare disease allies in Congress for $1.5 million for the National Academy of Medicine to study the impact rare diseases have on the U.S. economy. The study would include direct medical costs, non-medical costs, loss of income, and the societal consequence of undiagnosed and untreated rare disease.

The EveryLife Foundation encourages you to share this letter with your Members of Congress, Members of the House and Senate Appropriations Committee, specifically those on the Labor, Health and Human Services, Education Subcommittee (a list of emails for the staffers is here), and with your networks so that they can make the same request. Please contact Steve Silvestri, EveryLife Foundation, at ssilvestri@everylifefoundation.org if your organization would like to sign on to the letter.

## Community Events

**National Sickle Cell Advocacy Day 2019:** The Sickle Cell Disease Association of America invites advocates to attend the National Sickle Cell Advocacy Day in Washington, DC on April 8-9, 2019 to advocate for those affected by sickle cell disease. Register here.

**RDLA Monthly Webinar and In-Person Meeting, April 11, 2019:** The next RDLA Monthly Webinar and In-Person Meeting will take place on Thursday, April 11th. 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. 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.

**FDA Meeting on Patient Perspectives on the Impact of Rare Diseases: Bridging the Commonalities:** The Food and Drug Administration announced a public meeting on April 29, 2019 at the FDA White Oak Campus and an opportunity for public comment on "Patient Perspectives on the Impact of Rare Diseases: Bridging the Commonalities." This public meeting is intended to obtain patients' and caregivers' perspectives on impacts of rare diseases on daily life and to assess commonalities that may help the Agency and medical product developers further understand and advance the development of treatments for rare diseases. The goal of this meeting is to identify common issues and symptoms in rare diseases to help advance medical product development.

Register to attend the event in-person or via webcast at Eventbrite. If you need special accommodations, please contact Eleanor Dixon-Terry at 301-796-7634 or Eleanor.Dixon-Terry@fda.hhs.gov by April 15, 2019. Comments can be submitted to the public docket by May 30, 2019. Submit electronic comments to Regulations.gov. Submit written comments to the Division of Docket's Management (HFA-305), Food and Drug Administration, 5630 Fishers Lane, Rm. 1061, Rockville, MD 20852. All comments must be identified with the docket number FDA-2019-N-0077.

**RARE on the Road, a Rare Disease Leadership Tour:** The EveryLife Foundation and Global Genes invites rare disease patients, caregivers, and other advocates to attend the RARE on the Road, a Rare Disease Leadership Tour to learn more about rare disease policy, connect with other rare disease advocates, and learn how to tell your story. RARE on the Road workshops will be held in Birmingham, AL on May 4th, Denver, CO on May 18th, and Sioux Falls, SD on July 13th. Find out more and register at www.raretour.org.

**Patients and Providers for Medical Nutrition Equity:** The Patients and Providers for Medical Nutrition Equity coalition invite advocates to participate in their advocacy day in Washington, DC on May 6th and 7th. Register by April 5th here.

**Professional Patient Advocates in Life Sciences:** Professional Patient Advocates in Life Sciences (PPALS), in conjunction with Sanford Research Institute, will host its 4th annual Patient Advocacy Certificate Training (PACT) course of study for health and life science professionals and leaders of patient advocacy organizations to enhance professional development from May 6-9th.

**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.