



# EMPOWERING THE RARE DISEASE COMMUNITY

A PROGRAM OF THE EVERYLIFE FOUNDATION FOR RARE DISEASES

## RDLA July 2019 Newsletter

### Capitol Hill Updates

**House Passes Health-Related Appropriations Bills for FY 2020:** The House passed a package of four appropriations bills, H.R. 2740, which included the Labor, Health and Human Services, and Education Appropriations bill on June 19, 2019. This package included \$41.1 billion for the National Institutes of Health, a \$2 billion increase from this year's funding level. Included in NIH's funding for FY 2020 is \$500 million for the All of Us precision medicine research initiative and \$195 million for the Cancer Moonshot research initiative. In addition, H.R. 2740 includes \$8.3 billion for the Centers for Disease Control and Prevention (\$938 million increase) and \$7.6 billion for the Health Resources and Services Administration (\$485 million increase).

On June 25<sup>th</sup>, the House passed another mini-bus of five appropriations bills, H.R. 3055, which provides \$3.26 billion in discretionary funding for the Food and Drug Administration. This would be a \$184 million increase from this year's funding level. The total funding for FDA in FY2020, including user fees, would be \$5.86 billion. This includes \$75 million to accelerate medical product development as authorized in the 21<sup>st</sup> Century Cures Act.

The U.S. House of Representatives has completed 9 of the 12 appropriations bills for FY 2020. The passed appropriations bills now await action by the Senate before the end of the fiscal year on September 30, 2019.

**House Energy and Commerce Health Subcommittee Hearing on Newborn Screening Saves Lives Act Reauthorization:** On June 25, 2019, the House Energy and Commerce Health Subcommittee held a hearing on several reauthorizations of health care programs including the Newborn Screening Saves Lives Reauthorization Act, H.R. 2507. Dr. Joseph Bocchini, MD, Louisiana State University Health Sciences Center, and former Chairman of the Advisory Committee on the Heritable Disorders in Newborns and Children provided testimony in support of H.R. 2507 at the hearing. Dr. Bocchini testified that H.R. 2507 supports the activities of one of the most successful public health disease prevention programs in the United States. Read more of his testimony [here](#).

## **Community Action Alerts & Policy Resources**

**EveryLife Foundation for Rare Diseases:** The EveryLife Foundation for Rare Diseases is asking advocates to contact their Members of Congress in support of the Newborn Screening Saves Lives Reauthorization Act. H.R. 2507 has 35 cosponsors so far. To contact your Representatives to cosponsor H.R. 2507, click [here](#).

**National Foundation for Ectodermal Dysplasias:** The National Federation of Ectodermal Dysplasias is asking patient advocacy organizations to sign a letter in support of the Ensuring Lasting Smiles Act. To sign on, visit the website [here](#). NFED is also asking advocates to send emails to their legislators to ask them to co-sponsor the Ensuring Lasting Smiles Act. Please visit [here](#).

**National PKU Alliance:** The National PKU Alliance is asking advocates to contact their Members of Congress in support of the Medical Nutrition Equity Act, H.R. 2105. H.R. 2105 would provide coverage of medically necessary foods and vitamins for digestive and inherited metabolic disorders under federal health programs and private health insurance. To contact your Representatives to cosponsor H.R. 2105, click [here](#).

**National Society of Genetic Counselors:** The National Society of Genetic Counselors is asking advocates to contact their Members of Congress in support of the Access to Genetic Counselors Act, H.R. 3235. H.R. 3235 would expand coverage of services provided by genetic counselors under the Medicare program. To contact your Representatives to cosponsor H.R. 3235, click [here](#).

**Friends of PCORI Reauthorization:** The Friends of PCORI Reauthorization is asking advocates to contact their Members of Congress in support of the Patient Centered Outcomes Research Institute (PCORI) reauthorization. PCORI supports research to help patients and providers make evidence-based healthcare decisions. To find sample letters, 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](#).*

**Rare Across America:** Rare Across America registration closes on July 3<sup>rd</sup>. Register before then at [www.RareAcrossAmerica.org](http://www.RareAcrossAmerica.org).

Under the Rare Across America program, RDLA staff organizes meetings for rare disease advocates with their Members of Congress and/or the Member's staff. The meetings take place in the Member's district offices during the month of August, while Congress is in recess from July 29th to September 8th, 2019. The RDLA team prepares advocates for their meetings, provides legislative resource materials, and hosts pre-meeting training webinars. No prior advocacy experience is necessary. The first training webinar for registered advocates, entitled "What to Expect at Your Meetings," will be hosted on July 25th.

**Newborn Screening Lunch Briefing on Capitol Hill:** The Muscular Dystrophy Association and March of Dimes are hosting an informational lunch briefing on Wednesday, July 10<sup>th</sup> at 12:30 pm at the US Capitol Visitors Center (SVC 209) about the United States' newborn screening program and the pressing need for the program's reauthorization, which expires this year. RSVP by July 8th to [advocacy@mdausa.org](mailto:advocacy@mdausa.org).

**Webinar: Value Assessments—The Impact on People with Rare Diseases:** The Partnership to Improve Patient Care (PIPC) and Everylife Foundation for Rare Diseases invites people with rare diseases, as well as their families and providers to join a webinar on July 17 from 1:30-3 PM EST to learn about value assessments, their potential to limit access and innovation, and related public policy threats at the federal and state level. Please RSVP to [dgleason@pipcpatients.org](mailto:dgleason@pipcpatients.org).

**RDLA Monthly Webinar and In-Person Meeting, July 18, 2019:** The next RDLA Monthly Webinar and In-Person Meeting will take place on Thursday, July 18th. 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](mailto:svonfelden@everylifefoundation.org).

**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 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. The last RARE on the Road workshop will be held in Sioux Falls, SD on July 13<sup>th</sup>. Find out more and register at [www.raretour.org](http://www.raretour.org).

**Rally for Medical Research Hill Day:** The 7<sup>th</sup> annual Rally for Medical Research Hill Day will take place on Thursday, September 19, 2019. The Rally for Medical Research's goal is to ensure policymakers make medical research a priority and to ensure funding for the National Institutes of Health. For more information and to register, visit [here](#).

**2019 BIO Patient and Health Advocacy Summit:** The 2019 BIO Patient and Health Advocacy Summit will take place in Washington, DC at the Park Hyatt on October 30-31, 2019. Learn more [here](#).

**RareVoice Awards:** Please save the date for the RareVoice Awards on December 4, 2019. The RareVoice Awards is an event to educate Congress on rare disease issues and celebrate advocates who give rare disease patients a voice on Capitol Hill.

### **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).