



EMPOWERING THE RARE DISEASE COMMUNITY

A PROGRAM OF THE EVERYLIFE FOUNDATION FOR RARE DISEASES

RDLA May 2019 Newsletter

Capitol Hill Updates

FY 2020 Labor, Health and Human Services, and Education Appropriations: Earlier this week, the Labor, Health and Human Services, and Education Appropriations Subcommittee in the US House of Representatives released the draft text to fund the Departments of Labor, Health and Human Services, and Education for FY2020. The draft bill includes \$99 billion for the Department of Health and Human Services, \$8.5 billion more than this year's funding and \$21 billion more than the President proposed in his budget for next year.

The proposed House appropriations bill includes a \$2 billion increase for the 4th consecutive year, totaling \$41.1 billion, for the National Institutes of Health. Under this plan, each institute at NIH would receive a 5% increase over last year. In addition, the Centers for Disease Control and Prevention would receive \$8.3 billion, a \$921 million increase from this year, and the Health Resources and Services Administration's funding would increase \$475 million to \$7.6 billion.

The House Appropriations Subcommittee on Labor, Health and Human Services, and Education had a mark-up on the draft bill on April 30th where the Subcommittee debated and made amendments to the bill. The next step will be for the Full Appropriations Committee to have a mark up on the bill before it heads to the Rules Committee and the House floor for a vote later this year.

Newborn Screening Saves Lives Act: This week, Representatives Lucille Roybal-Allard (CA) and Mike Simpson (ID) introduced H.R. XXXX, the Newborn Screening Saves Lives Reauthorization Act. Through this legislation, the federal government plays a crucial role in supporting state newborn screening programs: investing in research to advance newborn screening science, providing states with funds and technical assistance to improve their newborn screening programs, facilitating the sharing of best practices among states; educating providers, patients and the public about newborn screening; and maintaining a recommended list of conditions that states should include on their newborn screening panels. This legislation's last reauthorization will expire on September 30, 2019.

Genetic Information Privacy Act: Representative Bobby Rush recently introduced the Genetic Information Privacy Act in the U.S. House of Representatives. The Genetic Information Privacy

Act proposes to restrict genetic testing services from disclosing personally identifiable information of a customer to a third party unless the service obtains consent from the consumer.

Rare Disease Congressional Caucus Update: We are pleased the Rare Disease Caucus has 6 new Members bringing the total membership of the caucus to 118 Representatives and 17 Senators. The list of members of the caucus can be found at rareadvocates.org/rarecaucus. You can ask your Members of Congress to join the Rare Disease Congressional Caucus [here](#).

Community Action Alerts & Policy Resources

Lymphedema Advocacy Group: The Lymphedema Advocacy Group is asking advocates to contact the Members of Congress the week of May 6th, during the annual Lymphedema Lobby Days, to ask Members to cosponsor the Lymphedema Treatment Act. Please contact your Senators [here](#) and Representatives [here](#).

National Foundation of 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 letters to their legislators to ask them to co-sponsor the Ensuring Lasting Smiles Act. Please visit [here](#).

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 Act. To contact your Members on H.R. XXXX, click [here](#).

Community Events

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.

Rare Across America: Rare Disease Legislative Advocates is excited to announce the rebranding of In District Lobby Days, which will now be called Rare Across America. 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.

Advocates interested in participating should register between May 8th and July 3rd at www.RareAcrossAmerica.org. The first training webinar for registered advocates, entitled "What to Expect at Your Meetings," will be hosted on July 25th.

RDLA Monthly Webinar and In-Person Meeting, May 9, 2019: The next RDLA Monthly Webinar and In-Person Meeting will take place on Thursday, May 9th. 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.

Rare Disease Congressional Caucus Briefing: Rare Disease Legislative Advocates in coordination with the Rare Disease Congressional Caucus is hosting a lunch briefing, “New Technologies and Treatments for Rare Diseases” on May 15th at 11:30 am in the Dirksen Senate Office Building, Room G-11. The briefing will be moderated by Daryl Pritchard, Senior Vice President of Science Policy at the Personalized Medicine Coalition. George Church, Professor of Genetics at Harvard Medical School; Stan Nelson, MD, Duchenne Care Center at UCLA; and Tesha Samuels, sickle cell disease advocate and participant in the NIH sickle cell gene therapy clinical trial. Register [here](#).

FDA Meeting on Patient Perspectives on the Impact of Rare Diseases: Bridging the Commonalities: The Food and Drug Administration held a public meeting on April 29, 2019 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.

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 Denver, CO on May 18th and Sioux Falls, SD on July 13th. Find out more and register at www.raretour.org.

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.