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

EMPOWERING THE RARE DISEASE COMMUNITY

RDLA September 2019 Newsletter

Capitol Hill Updates

Congress to Return to DC: Representatives and Senators went home to their districts for the August recess. Both the House and Senate will return to Capitol Hill for official congressional business on September 9th. Congress is expected to continue work on drug pricing legislation and surprise billing this fall.

A Senate Appropriations Subcommittee will hold a markup on the FY 2020 Labor, Health and Human Services, and Education appropriations bill on September 10th. The Senate has not yet introduced any of the 12 appropriations bills. The U.S. House of Representatives has completed 9 of the 12 appropriations bills for FY 2020. The FY 2019 appropriations will expire at the end of the fiscal year, September 30th, unless both the House and Senate pass the appropriations bills (and the President signs them into law) or pass continuing resolutions.

Human Gene Patent Eligibility: This August Senators Tillis and Coons continued to have discussions with stakeholders on a revised proposal to rewrite patent eligibility law which may impact genetic testing and treatments.

In May 2019, Senators Thom Tillis (R-NC) and Chris Coons (D-DE) and Representatives Hank Johnson (D-GA), Steve Stivers (R-OH), and Doug Collins (R-GA) released a draft bill that would rewrite Section 101 of the Patent Act. Section 101 of the Patent Act permits issuing patents on new and useful processes, machines, manufacture, or compositions of matter or any new and useful improvement.

The draft legislation rewrites Section 101 of the Patent Act and specifically states that any judicially created exception to patent-eligibility will be abrogated, thereby overturning the decisions of *Myriad* and *Mayo*. Patient organizations are concerned that the proposal would make human genes patent-eligible and increase prices for genetic tests as well as harm innovation and research including preventing discoveries of treatments for countless diseases.

Advancing Access to Precision Medicine Act: Representative Eric Swalwell (CA) plans to reintroduce the Advancing Access to Precision Medicine Act in September. The legislation would commission a study on the use of genetic and genomic testing by the National Academy of Medicine to improve healthcare and provide a state option for improving access to DNA

sequencing for certain groups of children. After working with patient and clinician organizations, Representative Swalwell's bill will include a broader definition of DNA sequencing instead of "whole genome sequencing" as his previous bill had.

Ending the Diagnostic Odyssey Act: Representative Scott Peters (CA) introduced the Ending the Diagnostic Odyssey Act, H.R. 4144, on August 2, 2019. H.R. 4144 would provide states with better access to whole genome sequencing clinical services for certain undiagnosed children under the Medicaid program.

Community Action Alerts & Policy Resources

Aiden Jack Seeger Foundation: The Aidan Jack Seeger Foundation is asking organizations to sign onto a letter in support of Aidan's Law, H.R. 534, to make newborn screenings of MPS1, Pompe, ALD, and SMA available nationwide. To view and sign on to the letter, click here.

EveryLife Foundation for Rare Diseases: September is Newborn Screening Awareness Month and 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. To contact your Senators to cosponsor S. 2158, click here. For other ways to show your support during Newborn Screening Awareness Month, 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.

National Foundation for Ectodermal Dysplasias: The National Foundation for 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 MPS Society, CAL Rare, and EveryLife Foundation: The National MPS Society, CAL Rare and EveryLife Foundation ask patient organizations to sign onto a letter asking the Administration to ensure that migrant individuals who participate in a clinical trial or who are receiving life-saving medical treatment have a legal pathway to reside in the U.S. during the time such treatment is necessary. Deadline to sign COB Sept. 9th. To sign on email jjenkins@everylifefoundation.org.

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 Representative 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.

In addition, NSGC is asking organizations that support the bill to sign onto a letter that will be sent to Members of Congress upon their return from August recess. You can add your organization's name to the letter by clicking this link.

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 Disease Caucus Briefing: Rare Disease Legislative Advocates, in cooperation with the Rare Disease Congressional Caucus, will host a lunch briefing on Wednesday, September 11th at 12:30 pm in Russell Senate Office Building, Room 188. The briefing will be on "The Importance of the Newborn Screening Saves Lives Act". Advocates can urge their legislators to attend the briefing by sending an email here. Attendees can register to attend here.

House Subcommittee Hearing: The House Committee on Oversight and Reform's Subcommittee on Civil Rights and Civil Liberties will hold a hearing on September 11th titled "The Administration's Apparent Revocation of Medical Deferred Action for Critically Ill Children". Find more information on the Committee's website.

RDLA September Webinar and In-Person Meeting: The next RDLA Monthly Webinar and In-Person Meeting will take place on September 12, 2019. In honor of Newborn Screening Awareness Month, the RDLA Monthly Meeting will educate patient advocates about current legislation related to rare disease diagnostics. The RDLA 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.

RDLA Special Drug Pricing Legislation Webinar: RDLA will host a special webinar on the drug pricing efforts currently ongoing in Congress on Monday, September 16, 2019 at noon EST. Register to join on the RDLA website.

Rally for Medical Research Hill Day: The 7th 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.

Rare New England Annual Conference: The Rare New England is hosting an annual conference on October 26, 2019 from 8 am to 5 pm in Portland, Maine. More information and scholarship application are available 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 and state legislatures. Learn more at www.rareadvocates.org/rarevoice-awards.

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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.