



EMPOWERING THE RARE DISEASE COMMUNITY

A PROGRAM OF THE EVERYLIFE FOUNDATION FOR RARE DISEASES

RDLA August 2019 Newsletter

Capitol Hill Updates

House Passes Newborn Screening Saves Lives Act: H.R. 2507/S. 2158 would reauthorize existing federal programs that provide assistance to states to improve and expand their newborn screening programs, support parent and provider education, ensure laboratory quality and effective surveillance. The current authorization expires on September 30, 2019. The House passed the House version, H.R. 2507, by voice vote on July 24, 2019. The Senate will need to pass the bill next and then the House and Senate will need to conference to work out the differences in the two bills before it can be sent to the President to become law.

CCM-CARE Act: On July 27th, Representatives Lujan, Haaland, and Torres Small and Senators Udall and Heinrich introduced the Cerebral Cavernous Malformations Clinical Awareness, Research, and Education Act, S. 2010/H.R. 3573. The CCM-Care Act proposes to increase research, education, and treatment for cerebral cavernous malformations.

Surprise Billing Legislation: The House and Senate are working on different proposals to address the unexpected charges or surprise billing that patients and their families face when they receive medical treatment from out-of-network providers and hospitals. The Senate Committee on Health, Education, Labor, and Pensions passed the Lower Health Care Costs Act, S. 1895, which includes a section on surprise billing on July 8th. S. 1895 has been placed on the Senate calendar for a vote in the future. In the House, the Health Subcommittee of the Energy and Commerce Committee passed the No Surprises Act, H.R. 3630 on July 11th. H.R. 3630 will have a full Committee mark-up before it can be placed on the calendar for a House vote.

Drug Pricing Legislation: The House and Senate are continuing to work on proposals to reduce the cost of prescription drugs for consumers. Most recently, the Senate Finance Committee passed the Prescription Drug Pricing Reduction Act, introduced by Senators Grassley and Wyden, on July 25th with a vote 19-9. The Prescription Drug Pricing Reduction Act proposes changes to Medicare so the out-of-pocket costs to beneficiaries is a maximum of \$3,100 in 2022. In addition, the Senate bill includes penalties for pharmaceutical companies if prices of drugs rise faster than inflation.

Community Action Alerts & Policy Resources

Guide to the Legislative Process: Politico Pro has released the Politico Pro Essential Guide to Legislation. The guide breaks down each step of the legislative process in the House and Senate, the steps that can result in changes to the legislation before it becomes law, and how the two chambers resolve differences in legislation. You can download the guide [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 Reauthorization Act. To contact your Senators to cosponsor S. 2158, click [here](#).

National Foundation for Ectodermal Dysplasias: The National Federation 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 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](#).

Aidan 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 please visit [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](#).

RareVoice Awards: Nominations are open for the RareVoice Awards. If you know someone who has gone above and beyond in their advocacy efforts for rare diseases, please consider nominating them. Nominations are being accepted at www.rareadvocates.org/rarevoice-awards. The nominations will close on August 30th. In addition, 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.

Rare Across America: Hundreds of advocates are meeting with their Members of Congress from July 29th to September 8th, 2019. For more information on the program and materials for the meetings, please visit www.RareAcrossAmerica.org. In addition, if you would like to add your support to the advocates meetings or have your family and friends support your efforts, you can take action [here](#).

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](#).

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](#).

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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.